# REAUTHORIZING THE RYAN WHITE CARE ACT: HOW TO IMPROVE THE PROGRAM TO ENSURE ACCESS TO CARE

## HEARING

BEFORE THE

SUBCOMMITTEE ON HEALTH

OF THE

COMMITTEE ON ENERGY AND COMMERCE
HOUSE OF REPRESENTATIVES

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# REAUTHORIZING THE RYAN WHITE CARE ACT: HOW TO IMPROVE THE PROGRAM TO ENSURE ACCESS TO CARE

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**THURSDAY, APRIL 27, 2006**

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

The subcommittee met, pursuant to notice, at 9:05 a.m., in Room 2123 of the Rayburn House Office Building, Hon. Nathan Deal (chairman) presiding.

Members present: Representatives Upton, Norwood, Shimkus, Pitts, Bono, Ferguson, Burgess, Barton (ex-officio), Brown, Waxman, Towns, Pallone, Rush, Eshoo, Strickland, Capps, Baldwin and Deal.

Staff present: David Rosenfeld, Acting Chief Health Counsel; Katherine Martin, Professional Staff Member; Melissa Bartlett, Counsel; Brandon Clark, Policy Coordinator; Chad Grant, Legislative Clerk; John Ford, Minority Counsel; and Jessica McNiece, Minority Research Assistant.

MR. DEAL. I will call the subcommittee to order and recognize myself for an opening statement.

I am proud to say that once again, in the tradition of this subcommittee, we have an outstanding and distinguished expert panel of witnesses to testify today and to help us explore and examine the current implementation of the Ryan White program, and how to best improve the program as the committee considers the issue of reauthorization. While this panel consists of expert witnesses from within the Federal government, I would say to other stakeholders that we intend to have a roundtable discussion at a later time where members of the committee and other stakeholders will be invited to attend, because I believe that it is important for us to hear from as many interested parties as possible.

The Ryan White CARE Act was first authorized in 1990 and was reauthorized in 1996 and in 2000. Although the legislative authority expired on September the 30th of last year, the program continues to operate at its current funding level. The outcomes and treatments for HIV and AIDS have changed over the years, and so have the needs of those who suffer from the disease. For example, persons with HIV, of course, now live longer due to advances in drug therapies.

The President's fiscal year 2007 budget requests $2.2 billion for Ryan White activities, which is $95 million above last year's budget request. There are a number of additional Federal programs that also assist with the care and support for persons with HIV/AIDS. However, the Ryan White program is the only major Federal disease-specific comprehensive treatment program. Additionally, Ryan White providers currently use Federal funds without any limitation to provide non-treatment services for persons with HIV and AIDS. These include services not covered for Medicare or Medicaid beneficiaries, including buddy and companion services, health education, treatment adherence and counseling, and housing assistance.

During both the 2005 and 2006 State of the Union addresses, President Bush called for the reauthorization of the Ryan White CARE Act. Last summer, the President set forth a series of reauthorization principles for this program. These principles retain the basic funding structure, but called for altering the titles to reflect the overarching principle that Ryan White funds be used for prevention and to provide care and treatment to persons with HIV/AIDS. Specifically, the President's principles include: one, serve the neediest first; two, focus on lifesaving and life-extending services; three, increase prevention efforts; four, increase accountability; and five, increase flexibility. It is my sincere hope that we can improve the Ryan White program with this reauthorization opportunity, and ultimately improve outcomes for those who are suffering from this disease.

Again, I welcome our witnesses that I will introduce in a few minutes, and thank them for their participation.

[The prepared statement of Hon. Nathan Deal follows:]

## PREPARED STATEMENT OF THE HON. NATHAN DEAL, CHAIRMAN, SUBCOMMITTEE ON HEALTH

The Committee will come to order, and the Chair recognizes himself for an opening statement.

I am proud to say that we have a distinguished and expert panel of witnesses appearing before us today that will help us examine the current implementation of the Ryan White program and how to best improve the program as the Committee considers reauthorization. While this panel consists of expert witnesses from within the Federal Government, this Subcommittee intends to have a roundtable discussion at a later date where Members and stakeholders will be invited to attend because we believe it is important to hear from as many interested parties as possible.

The Ryan White CARE Act was first authorized in 1990 and was reauthorized in 1996 and 2000. Although the legislative authority expired on September 30, 2005, the program continues to operate at its current funding level. The outcomes and treatments for HIV and AIDS have changed over the years and so have the needs of those with the disease. For example, persons with HIV now live longer due to advances in drug therapies.

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- Buddy and companion services
- Health education
- Treatment adherence and counseling
- Housing assistance

During both the 2005 and 2006 State of the Union Addresses, President Bush called for the reauthorization of the Ryan White CARE Act, and last summer, the President set forth a series of reauthorization principles for this program. These principles retain the basic funding structure, but call for altering the titles to reflect the overarching principle that Ryan White funds be used for prevention and to provide care and treatment to persons with HIV/AIDS. Specifically, the President's principles include:

1. Serve the neediest first
2. Focus on life-saving and life-extending services
3. Increase prevention efforts
4. Increase accountability
5. Increase flexibility

It is my sincere hope that we can improve the Ryan White program with this reauthorization opportunity and ultimately improve outcomes for those who are suffering from this disease.

Again, I welcome our witnesses and thank them for their participation.

I now recognize the Ranking Member of the Subcommittee, Mr. Brown from Ohio, for five minutes for his opening statement.

MR. DEAL. It is now my pleasure to recognize my friend, the Ranking Member of the subcommittee, Mr. Brown from Ohio for his opening statement.

MR. BROWN. Thank you, Mr. Chairman, and thank you for holding this hearing. I would just like to offer special thanks to my friend Mr. Waxman for all he has done over the years on all kinds of issues, but especially what he has done on Ryan White.

I was a bit frustrated to hear that our guest list today does not include any individuals who actually rely on the CARE Act or any patient advocates. I am pleased that the Chairman has agreed to a follow-up roundtable where we can hear from these individuals, but their absence at this hearing, I believe, compromises its value. I urge the Chairman to convene the roundtable right away. These advocates deserve the same forum as the Administration and the same opportunity to have their voices heard as we move forward with efforts to reauthorize the CARE Act.

We made great progress in the last decade to educate the public about HIV and AIDS, to increase testing levels, to chip away at the stigma associated with infection, and to develop better treatment and standards of care, but clearly, much more needs to be done. Tens of thousands of Americans are newly infected with HIV every year. An estimated half of those infected are not receiving the treatment they need. We know there are at least 14,000 people in my State alone with HIV/AIDS. The State estimates that there are thousands more who are infected but who are unaware of their status.

In just a single year, Ohio medical providers diagnosed almost 1,000 new cases. Many of them would have no source of care were it not for the Ryan White CARE Act. More than 15 years after its enactment, Ryan White continues to be a vital tool in our Nation's arsenal to stop the spread of HIV. The Act honors Ryan White, as we know, a courageous young man who did so much to spark the fight against HIV/AIDS before it took his life.

The CARE Act provides funding and access to quality medical treatment and services without which thousands of Americans would be unable to manage this disease. The Act serves the neediest among us, over 570,000 Americans who have nowhere else to turn for the treatments that can change AIDS from a death sentence to a manageable condition.

I represent a Congressional district that is part of the only Title I eligible metropolitan area in Ohio. I have seen firsthand how indispensable the CARE Act is. We have an opportunity to reauthorize the program and renew our commitment to its future. We also have an opportunity to improve it, to figure out what is working and what is not working. We should consider whether there are inequities in the system, but we should not take needed care away from one population in order to give it to another. It is in our Nation's best interest and it is within our Nation's capabilities to help all those in need, whether they live in an urban area or rural area, or somewhere in between. Beneficiaries should continue to have access to the mutually reinforcing comprehensive set of services, both medical and support services, that they need to treat their conditions and to live long and productive lives. States should have flexibility in determining what services are needed most in their communities.

Let us make sure, Mr. Chairman, that the Act gets adequately funded and that we fix administrative loopholes that have allowed unused funds to revert back to the Treasury at the same time that States have been forced to create waiting lists for care. I am encouraged by the communication between Members on both sides of the aisle to reauthorize the CARE Act. I hope this communication continues to move us towards developing a bipartisan proposal we can all support. Our Nation has lost too many talented young men and women to this epidemic we have been battling, HIV/AIDS, for more than a quarter century. We have made progress, but this fight is far from over. Let us make the CARE Act stronger and better so that we can continue to provide opportunity and hope for thousands of Americans living with HIV/AIDS.

Mr. Chairman, thank you.

MR. DEAL. I thank the gentleman. I am pleased to recognize my colleague from Georgia, Dr. Norwood, for an opening statement.

MR. NORWOOD. Thank you very much, Mr. Chairman.

The Ryan White CARE Act probably isn't on the minds of most Americans this morning. However, this reauthorization, in my opinion, could be one of the most important pieces of legislation this committee is going to look at this year.

Not many people know what the CARE Act is, and I can probably count most of my colleagues amongst that group. But for the HIV/AIDS patients, it helps, and the cost it takes off of our State's Medicaid programs is essential.

Ryan White was a 13-year-old hemophiliac who was infected with HIV through a blood transfusion. While Ryan lost his battle many years ago, we must not forget how far we have come over the years.

Mr. Chairman, the face of AIDS has changed and the CARE Act must change with it. This change will not be easy, but we have to face the uncomfortable fact that we simply don't have unlimited funds. That means as drug therapies become even more important, we will be locked in a battle over limited resources. The CARE Act does not currently cover important medical care and where it does provide care, for example, like dental, it falls far short of where it needs to be. Personally, I do not believe in these titles, that they are holy and can't be changed, but I understand many folks want to protect those States that have succeeded. What about the States that have not succeeded under this Act? HIV infections are increasing in the South. One of the major infection strains is right up the I-95 corridor, right through the heart of my State. Congress has the opportunity to provide a better healthcare delivery system moving from a palliative care model to a blended chronic care model that recognizes HIV as an increasingly manageable disease.

We also should put the focus on HIV and AIDS cases equally. States and communities receive funding based on AIDS patients. That is wrong and creates the worst of incentives. The money needs to follow the infections. The days of defending Title I cities, protecting them in statute must end, and the money needs to go to the patients. This issue is essential in my home State of Georgia, among minorities, and in those in rural areas. No one should receive the short end of the stick because of where they live. If we really care about this population, we are going to have to focus on patients and make sure the CARE Act we create today will meet the challenges of tomorrow.

Thank you very much, Mr. Chairman, for having this hearing.

MR. DEAL. I thank the gentleman. I am now pleased to recognize the gentlelady from California, Ms. Capps, for an opening statement.

MS. CAPPS. I hesitate because Ms. Bono was here before me.

MR. DEAL. I will be pleased to recognize Ms. Bono because she was here first, but I was told to recognize you first since you had a time constraint.

MS. CAPPS. Thank you very much. Mr. Chairman, I am pleased that this subcommittee is meeting on this subject. I thank our panelists for being here today. There are a number of very important and very timely issues about which we need to make decisions very quickly, and we need your guidance and your expertise.

The reauthorization of the Ryan White CARE Act is a very critical condition and a very critical issue for this committee, the HIV/AIDS community, and indeed, our entire country. Today, I hope we can focus on how we can strengthen the CARE Act so it continues to meet the health needs of persons living with HIV disease and their families.

This issue is especially important in the State that Mr. Waxman, Ms. Eshoo, and I represent, California, which has the second largest disease burden in the United States with 14 percent of AIDS cases. I am particularly concerned that the current CARE Act law states that by October 1 of this year, all States, territories, and jurisdictions must submit names-based HIV data to the CDC. The CDC has stated that in order to accept HIV data by October 1, they need to certify that a State had a mature system by January 2006. However, the California Governor signed the HIV names-based data collection system into law just last week, and California's system will not be certified in time. The October 1 deadline does not allow our State adequate transition time. According to the February 2006 GAO report, this would penalize almost 20 jurisdictions who do not fall under CDC's definition of an accurate and reliable names-based reporting system.

I am interested to hear from the panelists today about how we can work together to ensure that the approximately 42,000 members of California's HIV community continue to receive healthcare and support services. I look forward to hearing your testimony, and I yield back the balance of my time.

MR. DEAL. I thank the gentlelady. I recognize my friend from Illinois, Mr. Shimkus, for an opening statement.

MR. SHIMKUS. Thank you, Mr. Chairman. I will just reserve my time for questions.

MR. DEAL. I recognize Mr. Upton for an opening statement.

MR. UPTON. Well, thank you. I have an opening statement and I will just insert it in the record. I support the reauthorization of this important bill and I look forward to the testimony this morning.

[The prepared statement of Hon. Fred Upton follows:]

### PREPARED STATEMENT OF THE HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. Chairman, thank you for holding today's hearing, an important step in moving forward with the reauthorization of the Ryan White CARE Act. For the estimated 16,200 people in Michigan who are HIV positive, the 11,320 people known to be living with HIV and AIDS, and the 5,774 who are known to be living with full-blown AIDS, this program is a vital source of health care, prescription assistance, and community support services.

The HIV/AIDS epidemic has changed greatly since it emerged in the early 80s. Infection was once a death sentence. Today, HIV for many has become a chronic disease, kept in check through access to quality health care, supportive services, and life-saving medications. The face and geography of the epidemic have changed as well. Today, it is rising most rapidly in our minority communities, and particularly among African-American women, and in our Southern states. We need to ensure that the Ryan White CARE Act has the flexibility to respond to the changing nature of the HIV/AIDS epidemic, and I look forward to working with you and with my colleagues on both sides of the aisle to reauthorize and update this program.

MR. DEAL. I would recognize Ms. Baldwin for an opening statement.

MS. BALDWIN. Thank you, Mr. Chairman. Thank you to the witnesses, also, who are joining us here today.

I am glad that the committee is taking up the reauthorization of the Ryan White CARE Act. This program is clearly vitally important; in fact, it is lifesaving for the estimated 1.1 million Americans who are living with HIV and AIDS.

It has been nearly 25 years since the first case of AIDS was identified, and in this past 25 years, we have seen the epidemic change. An HIV-positive diagnosis does not carry with it the expectation of rapidly deteriorating health as it once did. Advances in science and improved treatment are allowing people with HIV and AIDS to live longer than ever before. But as the HIV/AIDS epidemic changes, and as we learn more about it, we need to also ensure that we are adequately funding important parts of this program. Funding for the AIDS Drug Assistance Program, or ADAP, is inexcusably inadequate, and the waiting list that many States currently have is unacceptable.

I am heartened by the Administration's proposed budget that includes a $70 million increase for ADAP funding, and I look forward to the House eventually passing a budget that includes that significant increase. But I am concerned by some of the proposed changes to the Ryan White CARE Act, and I regret that I won't be able to stay for the full hearing today to discuss my concern with the witnesses. But I feel that the President's reauthorization principles propose some fairly drastic changes to Ryan White, and at the same time, they are strangely vague. For example, the Administration's principles include changes based on phrases like "severity of need" or "core medical services," yet there is no accompanying explanation or definition of what these terms mean, let alone how the implementation of these changes would impact people who rely on the Ryan White CARE Act funding for needed care.

Along those lines, I too have to express my disappointment that this hearing's witness list does not include any stakeholder groups, but I am heartened to hear, Mr. Chairman, that there will be a future roundtable where stakeholders will be invited, and I do look forward to that future opportunity.

Lastly, I would like to point out that we have underfunded this epidemic in a number of ways, including the underfunding of prevention efforts. And while prevention is not a significant part of the Ryan White CARE Act, I think it is a serious issue that also deserves our attention and discussion.

Thank you, Mr. Chairman.

MR. DEAL. I thank the gentlelady. I recognize Dr. Burgess from Texas for an opening statement.

MR. BURGESS. Thank you, Mr. Chairman, and thank you for holding this hearing today. I will submit my statement for the record as well, but I do want to associate myself with the remarks of Dr. Norwood. It is critically important these funds follow the patient and further just note that in my district back in Texas, we have a portion of the district where African American women are one of the largest growing demographic groups that are having to deal with this disease. It is critically important that we focus on keeping the money with the disease, keeping the money with the patient. I am anxious to hear the testimony of our witnesses today.

With that, I will yield back.

MR. DEAL. I am pleased to recognize the gentlelady from California, Ms. Eshoo, for an opening statement.

MS. ESHOO. Thank you and good morning, Mr. Chairman and members, and to our guest witnesses here today. This is an important reauthorization. It always has been, and it remains so.

As my colleague from California stated, California has the second highest AIDS incidence of any State in the Nation. Of course, we are a Nation State, the largest and most populous State in the country, and so the meaning of this statistic is not a surprise. The Ryan White CARE Act plays, therefore, an essential role in the ability of my State and localities to meet the healthcare needs of persons living with HIV/AIDS. That is why the reauthorization of this Act is critical to the HIV/AIDS community in California, and of course, across our Nation.

Last July, the White House and HHS released its recommended principles for reauthorization of the Ryan White CARE Act. Unfortunately, many of the proposals, if enacted, would do serious and substantial harm to San Francisco's HIV infrastructure and would also have a very negative impact on California's HIV funding levels. One of my friends and colleagues just said that the money needs to follow the patient. Of course it does, but there has to be an infrastructure. Wherever we go for our healthcare, there is infrastructure there in order to provide care to patients. Patients just don't show up at a tollbooth; there has to be infrastructure. And so the dollars that support that in order to care for patients is absolutely essential, and I think that is what our debate is going to be about as we reauthorize the Act. In particular, the principles called for the elimination of the hold harmless provision that protects cities from experiencing rapid declines in resources that could dismantle systems of care. This kind of change could mean a $7 million cut, for example, to San Francisco's direct HIV funding. This represents a 25 percent reduction. That has an effect on patients. People should just disabuse themselves of thinking that if you don't fund infrastructure that you really are going to be taking care of people. It doesn't work that way. So this represents a 25 percent reduction from the $28 million San Francisco currently receives.

There are other proposals that could harm California overall, including the proposal that calls for not counting AIDS cases from metropolitan areas in determining the allocation of care funds to the States. Why anyone would make that kind of proposal, I really can't figure out. It is baffling to me, unless you just want to cut out whole swaths of areas where the caseload is higher. This change could result in the reduction of nearly $20 million in HIV funding to California, where the vast majority of people living with AIDS reside in metropolitan areas. That is what it is, I mean, you are going to target a place, target metropolitan areas. You can get rid of a lot. But the Ryan White CARE Act, I think, was designed to do something else. So I think that there is a departure from some of the real core principles of the Act. And abandoning these principles, in my view, and I think in many other persons' views, would do irreparable harm, especially at a time when the

CARE Act is actually working. I think that that should be a source of pride to Members of Congress. Those that helped establish it, certainly Mr. Waxman from the beginning, the colleagues of ours whose shoulders we stand on who are not in the Congress any longer.

The OMB and the GAO found that the CARE Act has contributed to the decline of HIV/AIDS cases and deaths and reached underserved groups, including the uninsured and the poor. Lack of access to care and disparities are the results of flat funding and recessions, and not problems with the legislation.

So I look forward to hearing from the witnesses today, and also addressing, Mr. Chairman, the key areas where I think the legislation is lacking and go back to and appreciate what has worked and why it has worked. So I look forward to it and thank you for holding this important hearing. I look forward to working with all members of the committee on this. This Ryan White CARE Act has always had strong bipartisan support, and I think that is why it has been successful. I don't think we want to depart from that tradition as we reauthorize the Act.

Thank you.

MR. DEAL. I recognize the gentlelady from California, Ms. Bono, for an opening statement.

MS. BONO. Thank you, Mr. Chairman. I have a written statement I will submit, but I also want to just associate myself with my colleagues from California and express my concern also, and state that I plan to be fighting on this side as much as I can for California in some of these changes. I just want to welcome the panelists and thank you very much, Mr. Chairman, and Chairman Barton as well for moving this legislation that I have been hoping would move for quite some time.

So thank you, and I yield back.

[The prepared statement of Hon. Mary Bono follows:]

## PREPARED STATEMENT OF THE HON. MARY BONO, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Good morning Chairman Deal and Ranking Member Brown. Thank you for holding this important hearing today. I would like to extend particular thanks to Chairman Deal and Chairman Barton for their tireless efforts and continued support in moving this critical legislation forward. I would also to thank each of our panelists for taking the time to speak to us today.

The Ryan White CARE Act has transformed the way that we provide care to those suffering from HIV and AIDS. Since its inception in 1990, this program has undergone multiple reauthorizations in an effort to meet this growing and frequently evolving epidemic.

As a representative from California, I have had the opportunity to work closely with many groups and individuals who benefit directly from this program. I have had the opportunity to see firsthand the impact of this legislation within my own district as organizations such as the Desert AIDS Project work tirelessly to provide those in need with access to care. I look forward to a continued dialogue with each of you to ensure the future viability of this program.

Currently, eleven states and two territories are home to 75% of the population living with AIDS. In accordance with that, these thirteen jurisdictions receive 75% of the funds distributed by the CARE Act. Funds are going to the epidemic.

I know that many proposals have included provisions that would eliminate basic tenets of the Ryan White funding structure and could have a devastating impact. Many of the proposed changes focus on the restructuring of Title I and Title II funds which provide funding for eligible metropolitan areas (EMAs). In my own state of California there are currently 9 EMAs, approximately 90% of the AIDS community within my state is estimated to live within those areas.

Restructuring of Title I and especially Title II funds could have potentially disastrous effects for my state and many other states who have their AIDS population concentrated in these metropolitan areas.

If we are to accurately address the impact of CARE Act funding, a selective analysis of only certain components is simply not adequate. We must take into account all Titles and components of the CARE Act.

It is my hope that we can continue to move forward in the reauthorization of this critical legislation in a timely manner. The efforts of this committee and the Senate HELP committee have been commendable. I would like to thank the respective staffs for their hard work and dedication. I look forward to hearing from each of our panelists today.

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

MR. DEAL. I thank the gentlelady. Mr. Waxman is recognized for an opening statement.

MR. WAXMAN. Thank you, Mr. Chairman.

The reauthorization of the Ryan White Act may be one of the most important actions by our subcommittee this year. This program has literally been a lifesaver for people living with HIV and AIDS. It has provided a critical support to cities which have been the center of the epidemic, and to States funding critical drug programs to treat the disease. I am distressed that the hearing is so limited in the witnesses that are providing views to us today. We should have the benefit of the views of stakeholders in this process: States, localities, caregivers, and people who are living with HIV and AIDS, and I hope as we move forward with the reauthorization we will hear from those parties on the record and they will have the opportunity to examine the legislative proposals this committee will vote on and to inform our actions with their views.

We know the Administration has proposed some principles that would result in dramatic changes in the Act, what it funds and who gets support. These principles are highly controversial, and today we are hearing their point of view. We know the GAO has done a study looking at funding disparities under the Act, and there is much that is worthwhile to consider in their work, but they provided only one part of the picture.

I want to state clearly one thing that is really important. In my view, this Act has been extremely effective. It is an important piece of legislation, and throughout its history it has been dealt with in a bipartisan manner and has had broad bipartisan support. Changes that have been made have been made at the margin, adjusting the bill to deal with emerging problems and developments, but without disrupting the program that was working. We all know this job has been made more difficult because we have not had an option throughout many of these years to add the necessary additional funds to the program. So when new epicenters of the disease have appeared, we have been forced to reallocate the limited part of funds available, rather than add the critical new dollars that would be needed.

In my view, we found ourselves in this position because the Administration and the Republicans who control the Congress have the wrong fiscal policies and priorities, but we will leave that aside for the moment. Even given these constraints, if we reauthorize this program with continued broad support, we must approach the issue with full attention to the need to be sure that we don't wreck what is working.

In that regard, I want to speak specifically to the issue of California, but I am pleased to note that we have many Californians on the subcommittee today who have expressed the view that we all strongly hold--we have always been one of the earliest centers of the disease, and we remain a State with more persons living with AIDS and with HIV than only one other State, New York, and we have the second largest number of minorities with AIDS reflecting the subject of the trend. It is one of the five States with the most cases outside of EMAs. Yet somehow, there is a perception that California gets too much money, that it doesn't have a problem that requires this level of funding anymore. In fact, when one looks at the funding provided under all the titles of the Ryan White Act, California's payment per person with AIDS is actually under the national average. I do not put into the record these statements because I am only concerned about the people in California. I understand and support helping people struggling with AIDS all over the country, but I can't accept the taking of necessary funds away from people with AIDS simply because there is a mistaken impression that California's programs are overfunded. Nothing could be further from the truth.

I look forward to working with all our colleagues on this subcommittee, and fashioning a strong bipartisan consensus.

Thank you.

MR. DEAL. Thank you. Mr. Pallone is recognized for an opening statement.

MR. PALLONE. Thank you, Mr. Chairman.

Since the very first cases of AIDS were reported in the early 1980s, our Nation's response to the epidemic has made tremendous strides, thanks in large part to services funded by the Ryan White CARE Act. But in spite of our efforts, 45,000 new infections are reported each year. Since the beginning of this epidemic, an estimated 530,000 Americans with AIDS have died. That number has been growing at a rate of approximately 14,000 new deaths per year, and racial and ethnic minorities continue to be disproportionately effected by HIV/AIDS, especially African Americans, Latinos, and Native Americans. Similarly, women and young people appear to be at increased risk and account for a growing proportion of diagnoses.

In my home State of New Jersey, we have the highest proportion of cumulative AIDS cases in women, and we rank third in cumulative pediatric AIDS cases and fifth in overall cumulative AIDS cases. In response, New Jersey has worked to develop a comprehensive array of medical care and treatment services, which are funded in part by private organizations, State revenues, and CARE Act funds. For example, I am proud to say that New Jersey has one of the most generous ADAP programs in the country. We have an open formulary and no waiting list. People infected with HIV/AIDS living in New Jersey have access to a host of other services, including primary medical care, mental health services, substance abuse services, oral health, case management, nutritional services, and transportation services. But I am concerned that some of the proposals put forth by the Bush Administration could severely harm New Jersey's ability to maintain these services, which I will discuss later during the question period.

Mr. Chairman, I would like to note that since it was signed into law, the CARE Act has always enjoyed strong bipartisan support from members of this committee because we all realize the importance of providing medical care to people living with HIV/AIDS, as well as their families. Along those lines, I am concerned that no one from any of the stakeholder groups was invited to testify before the committee today, in spite of Democratic requests. I was not here, Mr. Chairman, at the beginning, and I know that you did mention or make a commitment to have some kind of input from stakeholder groups. I hope that means a subsequent hearing. I am not sure what exactly it means, but I still believe that those people should have been here today for this public hearing.

My point is that we have to work together in a bipartisan fashion on this bill to reauthorize the CARE Act because it is a crucial bill and certainly, this is the type of thing where I think we can work on a bipartisan basis. And so every effort should be made to accomplish that goal.

I yield back.

MR. DEAL. I thank the gentleman. Mr. Strickland is recognized for an opening statement.

MR. STRICKLAND. Thank you, Mr. Chairman. I will be very brief.

I just want to point out something that I think we all realize, that there are few opportunities that we have on this committee and in this body to pass legislation that has a direct connection between whether or not some people survive or do not survive. I have a very close family member who has benefited from this Act, perhaps would not be living today were it not for this legislation. I am pleased, as has been expressed here, that this is something that both Democrats and Republicans have supported in the past, and I look forward to this effort for the future.

Thank you. I yield back.

MR. DEAL. I thank the gentleman, and recognize Mr. Towns for an opening statement.

MR. TOWNS. Thank you very much, Mr. Chairman. I also would like to thank the representatives of the Administration who have come here to talk to Congress about these critical issues. We welcome Dr. Duke and Dr. Fenton to discuss the Administration's principles for ensuring fair and equitable access to care for people in our Nation currently living with AIDS and HIV. I applaud the Administration for its initial positive response concerning reauthorization of Ryan White.

The President said in his State of the Union "A hopeful society acts boldly to fight disease like HIV/AIDS, which can be prevented and treated and defeated." The President then asked Congress to reform and reauthorize the Ryan White Act, and provide new funding to States so we end the waiting list for AIDS medicine in America.

I urge all of us to tackle these issues in a positive spirit that the President began with this year. Let us make that statement a reality.

However, in our endeavors I am concerned that we not target particular localities that have born the historic brunt of the HIV/AIDS epidemic. Instead, let us celebrate the new treatments that extend life for those persons living with AIDS by making sure that they are available to all, especially to those least able to afford them. The tragedy is even more heightened in minority communities. Of those people living with AIDS, 75 percent are minorities and 25 percent are women. I am also very concerned with the rate of HIV/AIDS among prison inmates. The AIDS rate among inmates in our Nation's prisons is four times higher than in the general population. AIDS is also the second leading cause of death in our prisons. Infected prisoners, particularly in urban areas like New York, may be released into the general population without receiving treatment for their condition. This forces an increased burden for care already overburdened local health facility.

I urge the Administration to take a fair approach to those States and localities that have already born the brunt of the AIDS epidemic, and if we do that, I think that we can really begin to change the situation that we now find ourselves in. I think that this is a great opportunity for this committee and a great opportunity for the Nation.

Thank you so much, Mr. Chairman. I yield back.

MR. DEAL. I thank the gentleman. I believe we have heard from all the Members who are present on opening statements, so we will proceed to the witnesses themselves. I am pleased to introduce them to the subcommittee and to the audience.

MR. DEAL. First of all, Dr. Elizabeth Duke, who is the Administrator of Health Resources and Services Administration of the U.S. Department of Health and Human Services; Dr. Kevin Fenton, who is the Director of the National Center for HIV, STD, and TB Prevention of the Centers for Disease Control and Prevention; and Ms. Marcia Crosse, the Director of Health Care of the U.S. Government Accountability Office.

Ladies and gentleman, we are pleased to have you here. I will tell you at the outset that your written testimony has been made a part of the record, and we would, of course, welcome your summarization of that in your oral testimony. We will follow the completion of your opening statements with questions from the subcommittee itself.

Dr. Duke, we will begin with you.

## STATEMENTS OF ELIZABETH M. DUKE, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES; KEVIN FENTON, DIRECTOR, NATIONAL CENTER FOR HIV, STD, AND TB PREVENTION, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES; AND MARCIA CROSSE, DIRECTOR, HEALTH CARE, U.S. GOVERNMENT ACCOUNTABILITY OFFICE

DR. DUKE. Thank you, sir. Mr. Chairman and members of the subcommittee, I am thankful for this opportunity to meet with you today on behalf of the Department of Health and Human Services to discuss the reauthorization of the Ryan White CARE Act. We thank you very much for making reauthorization of the CARE Act an important part of your agenda. It is an important Act which has long had bipartisan support, and we are here to work with you all. I do appreciate the opportunity to summarize and submit for the record my longer testimony.

The Ryan White CARE Act is a comprehensive approach to the provision of medical care and treatment and support services to individuals living with HIV/AIDS who have no other way to obtain such care. The program is administered through the Health Resources and Services Administration within the Department of Health and Human Services. President Bush, in his 2006 State of the Union stressed the importance of this program and he asked the Congress to "reform and reauthorize the Ryan White CARE Act, and provide new funding to States so we can end the waiting list for AIDS medication in America." Since its last reauthorization, we have been able to provide anti-retroviral treatment, primary care, and support services to over a half million people annually in the United States, Puerto Rico, Guam, the Virgin Islands, and eligible U.S. territories.

In 2004, an estimated 65 percent of the individuals were racial minorities, 33 percent were women, and 87 percent were either uninsured or received public health benefits. The Ryan White CARE Act programs have provided important benefits to these populations. Overall, AIDS mortality is down and lives have been extended with medications purchased through the AIDS Drug Assistance Program, the ADAP program. Pregnant women have been provided with care that has allowed them to give birth to children free from HIV infection, and thousands have received support services that have allowed them to access healthcare and to remain in care.

The structure of the Ryan White CARE Act allows for local flexibility and responsiveness in meeting the diverse needs in different regions of the country. It fosters collaboration among Federal, State, and local governments, and public and private entities to create a continuum of care for people living with HIV/AIDS.

Last July, the Administration emphasized five key principles for reauthorization of the Ryan White CARE Act. First, to serve the neediest first. Second, to focus on lifesaving, life-extending services. Third, to increase prevention efforts. Fourth, to increase accountability, and fifth, to increase flexibility. The President has made fighting the spread of HIV/AIDS a top priority of his Administration, and he will continue to work with Congress to encourage prevention and the provision of appropriate care and treatment for those suffering from this disease. The President requested $2.08 billion in '06, and the Congress appropriated $2.06 billion for the program. The President's 2007 budget request for the CARE Act is $2.16 billion, an increase of $95 million for several elements of a new HIV/AIDS initiative. Further elements of this domestic initiative focusing on testing in the areas of greatest need are requested outside of the CARE Act.

The CARE Act request will support a comprehensive approach to address the health needs of persons living with HIV/AIDS consistent with the reauthorization principles. The budget also includes a new authority to increase program flexibility by allowing the Secretary to transfer up to five percent of the funding provided for each part of the Ryan White CARE Act to any other part of the Act. Of the new $95 million requested, $70 million will address the ongoing problem of State waiting lists and provide care and lifesaving medications to those newly diagnosed as a result of increased testing efforts. The remaining $25 million will be used to expand outreach efforts by providing new HIV community action grants to intermediaries, including faith and community based organizations, and to provide technical assistance and sub-awards to grassroots organizations.

We can be proud of the accomplishments of the Ryan White CARE Act and the dedication of the people who make it work. The program has reached over 571,000 uninsured and underinsured persons affected by HIV/AIDS annually. Medication has been provided to almost 139,000 persons living with HIV/AIDS in 2004. The program strives to reach those individuals who are most in need of services. Today, people with HIV/AIDS are living longer, healthier lives in part because of this Act. To make this legislation more responsive in the future, the Administration urges Congress to take into account the stated principles it has offered for reauthorization of the CARE Act. We look forward to working with the Congress throughout this reauthorization process.

I thank you for having us here this morning.

[The prepared statement of Dr. Elizabeth M. Duke follows:]

## PREPARED STATEMENT OF DR. ELIZABETH M. DUKE, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. Chairman, Members of the Subcommittee, I am thankful for the opportunity to meet with you today on behalf of the Department of Health and Human Services (HHS) to discuss the reauthorization of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.

### Background

The Ryan White CARE Act is a comprehensive approach to the provision of medical care, treatment, and support services to individuals living with HIV/AIDS who have no other means with which to obtain such care. The program is administered through the HIV/AIDS Bureau of the Health Resources and Services Administration (HRSA) within the Department of Health and Human Services (HHS). The Federal Ryan White CARE Act was enacted in 1990; it was amended and reauthorized in 1996 and again in 2000. The authorization of appropriations expired on September 30, 2005. President Bush in his 2006 State of the Union Address stressed the importance of this program and asked Congress to, “reform and reauthorize the Ryan White Act and provide new funding to states so we end the waiting lists for AIDS medicines in America.”

Since its last reauthorization, we have been able to provide antiretroviral treatment, primary care, and support services to over half a million people annually in the United States, Puerto Rico, Guam, the U.S. Virgin Islands, and eligible U.S. territories. In 2004, an estimated 65 percent of these individuals were racial minorities, 33 percent were women, and 87 percent were either uninsured or received public health benefits. The Ryan White CARE Act programs have provided important benefits to these populations. Overall, AIDS mortality is down and lives have been extended with HIV/AIDS medications purchased through the AIDS Drug Assistance Program (ADAP). Pregnant women have been provided with care that has allowed them to give birth to children free from HIV infection, and thousands have received support services that have allowed them to access and remain in health care.

The structure of the Ryan White CARE Act allows for local flexibility and responsiveness in meeting diverse needs in different regions. It fosters collaboration among Federal, State, and local governments, and public and private entities to create a continuum of care for people living with HIV/AIDS.

The Ryan White CARE Act is organized into distinct program components. Title I provides emergency assistance to Eligible Metropolitan Areas (EMAs) that are most severely affected by the HIV/AIDS epidemic. To be eligible for Title I funding, an area must have reported at least 2,000 AIDS cases during the previous 5 years and have a population of at least 500,000.

Title II of the CARE Act provides grants to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and eligible U.S. territories. Title II grants support a wide range of care and support services. Title II also provides grants to States for Emerging Communities – that is, localities reporting between 500 and 1,999 AIDS cases over the most recent 5 years. Additionally, Title II funds the AIDS Drug Assistance Program (ADAP), which provides medications for the treatment of HIV disease.

Title III, Early Intervention Services (EIS), supports comprehensive primary health care and certain services for individuals who have been diagnosed with HIV. Services include education to prevent transmission of HIV and case management to assure continuity of care. Title III grants expand the capacity of organizations providing primary care to indigent HIV-positive individuals. One third of all Title III grantees are community health centers.

Title IV provides community-based, family-centered services to women, children, and youth living with HIV and their families. Services include: primary and specialty medical care, psychosocial services, logistical support, outreach and case management.

The Ryan White CARE Act includes Part F – the Special Projects of National Significance (SPNS), the AIDS Education and Training Centers (AETCs), and the HIV/AIDS Dental Reimbursement Program. SPNS grants support innovative programs that hold promise for improving health outcomes. The AETCs provide education and training on a variety of topics for clinicians who treat people living with HIV/AIDS, with a focus on primary HIV care for underserved populations. The Dental Reimbursement Program assists accredited dental schools and postdoctoral programs with uncompensated costs incurred in providing dental treatment to patients with HIV infection. The Community Based Dental Partnership Program funds eligible entities in their efforts to increase access to oral health care and to support oral health service delivery and provider training in community settings.

## Principles of Reauthorization

Last July, the Administration emphasized five key principles for reauthorization of the Ryan White CARE Act: (1) serve the neediest first; (2) focus on life-saving and life-extending services; (3) increase prevention efforts; (4) increase accountability; and (5) increase flexibility. The President has made fighting the spread of HIV/AIDS a top priority of his Administration, and he will continue to work with Congress to encourage prevention, and the provision of appropriate care and treatment to those suffering from the disease. The President requested $2.08 billion for FY2006 and Congress appropriated $2.06 billion for the program. The President's FY2007 budget request for the CARE Act HIV/AIDS activities is $2.16 billion, an increase of $95 million for several elements of a new Domestic HIV/AIDS initiative (further elements of that initiative, focusing on testing in the areas of greatest need, are requested outside the CARE Act). The request will support a comprehensive approach to address the health needs of persons living with HIV/AIDS, consistent with the reauthorization principles. The budget also includes a new authority to increase program flexibility by allowing the Secretary to transfer up to five percent of funding provided for each Part of the Ryan White CARE Act to any other Part. Of the new $95 million requested, $70 million will address the on-going problem of State waiting lists and provide care and life-saving medications to those newly diagnosed as a result of increased testing efforts. The remaining $25 million will be used to expand outreach efforts by providing new HIV community action grants to intermediaries including faith and community-based organizations, and to provide technical assistance and sub-awards to grassroots organizations.

In order to serve the neediest first, objective indicators must be established to determine the severity of need for funding core medical services. The Secretary of Health and Human Services (HHS) would develop a severity of need for core services index (SNCSI). This index would be based upon objective criteria and be focused on core services. It would take into account variables such as HIV incidence and prevalence, levels of poverty, and availability of other resources.

The Administration proposes focusing on life-saving and life-extending services by: establishing a set of core medical services; requiring that 75 percent of funds for Titles I, II, III and IV be spent on these core services; and maintaining a Federal list of core medications for the AIDS Drug Assistance Program (ADAP).

Requiring States to implement routine voluntary HIV testing in public facilities and working with private health care providers to implement testing will increase disease detection and further prevention efforts. With an estimated 250,000 HIV-positive individuals unaware of their HIV-positive status, testing is a key element in the Administration's prevention efforts. States will be encouraged to adopt important prevention strategies upon receipt of their Ryan White allocations.

Grantees are more likely to be held accountable if: States are required to submit HIV data; grantees are required to report on system and client –level data and progress; the payor-of-last-resort provision is strengthened; States coordinate HIV care and treatment with other federally funded programs to maximize efficiency and effectiveness; double counting of AIDS cases between eligible metropolitan areas (EMAs) and States is eliminated; and the "hold harmless" provisions are deleted.

Today, because of the way AIDS cases are counted, that is by including cases spanning the last 10 years, metropolitan areas with newer epidemics receive disproportionately less than those with more longstanding problems. In order to more accurately reflect the current status of the epidemic, the provisions that entitle cities to be "held harmless" from funding reductions should be eliminated.

Allowing the Secretary of HHS to redistribute unallocated balances based on the severity of need and allowing planning councils to serve as voluntary and advisory bodies to mayors will increase flexibility in the program. To maximize all CARE Act funding, unspent funds from Titles I and II would revert to the Secretary of HHS and the Secretary would extend those funds to ADAP programs or areas with the greatest need.

We can all be proud of the accomplishments of the Ryan White CARE Act and the dedicated people who make it work. The program has reached over 571,000 uninsured or underinsured persons affected by HIV/AIDS annually. Medication was provided to an estimated 138,834 persons living with HIV/AIDS in 2004. The program strives to reach those individuals who are the most in need of its services. Today, people with HIV/AIDS are living longer and healthier lives in part because of this Act. In order to make the legislation more responsive in the future, the Administration urges Congress to take into account the above stated principles in the reauthorization of the Ryan White CARE Act.

Thank you for the opportunity to discuss the Administration's principles for the reauthorization of the Ryan White CARE Act. We look forward to working with Congress throughout the reauthorization process.

MR. DEAL. Thank you. Dr. Fenton.

DR. FENTON. Good morning, Mr. Chairman and members of the subcommittee. Thank you for the opportunity to discuss current trends in HIV/AIDS in the United States, and the status of State HIV surveillance systems.

Twenty-five years ago, the first cases of AIDS were reported in the United States. Although the struggle to prevent HIV infections is not over, we have made substantial progress and achieved major successes. For instance, the dramatic decrease in mother-to-child HIV transmission is one of the great success stories of HIV prevention. We have also seen declines in the number of HIV/AIDS cases attributed to injecting drug use. The number of new infections annually has declined from more than 150,000 in the late 1980s to an estimated 40,000 per year today. However, the HIV/AIDS epidemic has changed in other important ways. In the early days of the epidemic, the greatest number of new infections was found among white men who have sex with men, and among injecting drug users. Today, the epidemic has a growing impact on racial and ethnic minority, particularly African Americans and on women.

CDC is responsible for ensuring the integrity of our national HIV/AIDS surveillance system. As with other diseases, individual State governments have authority for statutory and regulatory issues for HIV/AIDS reporting and data protection, including the decision regarding what type of system will be used for disease reporting. Except for HIV, all the reported infectious diseases, including AIDS, are routinely reported to States using name-based reporting systems. It is important to note for confidentiality purposes that the CDC does not receive the names of individuals.

Currently, 43 States use confidential name-based HIV case reporting, as shown in the chart to my right. The remaining seven States and the District of Columbia use code or name-to-code reporting. Among those eight areas, there are seven different codes. Several of the remaining States have notified CDC that they intend to implement name-based HIV surveillance in 2006. Only last week, the Governor of California enacted legislation which moves this State from a code-based to an integrated name-based reporting system.

There are three primary uses of surveillance data. First, epidemic monitoring; second, prevention planning to target prevention interventions; and third, allocation of local, State, and Federal funds for prevention, care, and treatment services, including the Ryan White Comprehensive AIDS Resource Emergency Act. CDC strongly supports the requirement in the Ryan White CARE Act for States to implement HIV reporting by 2007. CDC's policy is to accept HIV infection and AIDS case surveillance data only from areas conducting confidential name-based reporting, because this reporting has been shown to routinely achieve high levels of accuracy and reliability. HIV surveillance that is conducted using coded patient identifiers has not been shown to routinely produce equally accurate, timely, or complete data compared to that conducted using confidential name-based surveillance methods. Currently, only confidential name-based HIV reporting integrated with AIDS surveillance data can be used by States to identify and remove cases that are counted in more than one State before they are reported to CDC's national surveillance database. States that have implemented code-based systems consistently inform CDC that these systems are more complex, more expensive, and burdensome than name-based reporting systems. CDC is aware of one systematic quantitative evaluation which compared the relative costs of name-based systems to systems using codes and named codes. This evaluation found that a name-to-code reporting system was 15 percent more expensive than name-based reporting, and reporting based exclusively on codes was 50 percent more expensive than name-based reporting. CDC is and continues to provide technical assistance to States transitioning from code to name-based systems to ensure that their data can be integrated into the National HIV Data System as quickly as possible. CDC continues to provide funding and technical assistance to States that use code-based methods for identifying patients in their HIV surveillance system.

In summary, CDC is responsible for ensuring the integrity of the National HIV and AIDS Surveillance System to accurately monitor the epidemic in the United States. CDC continues to work closely with the States to help them adopt and implement high quality HIV surveillance systems. Having all States collect HIV information in the same manner will ensure that the Nation has reliable and valid data to monitor the scope of the epidemic, to plan for and evaluate prevention, care, and treatment programs, and to focus these programs on persons most at risk.

Thank you again for this opportunity, and I will pleased to answer any questions.

[The prepared statement of Dr. Kevin Fenton follows:]

## PREPARED STATEMENT OF DR. KEVIN FENTON, DIRECTOR, NATIONAL CENTER FOR HIV, STD, AND TB PREVENTION, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

### Introduction

Good morning Mr. Chairman and Members of the Subcommittee. My name is Kevin Fenton and I am Director of the National Center for HIV, STD, and TB Prevention at the Centers for Disease Control and Prevention (CDC). I am accompanied by Matt McKenna, Chief of the Center's HIV Incidence & Case Surveillance Branch. Thank you for the opportunity to discuss current trends in HIV/AIDS in the United States and the status of state HIV surveillance systems.

Twenty-five years ago, the first cases of AIDS were reported in the United States. HIV and AIDS remains one of the greatest public health challenges today. To date, HIV has claimed the lives of more than 22 million people worldwide, and in the United States, more than 500,000 people have died of AIDS. The number of new HIV infections annually has declined from more than 150,000 in the late 1980s to an estimated 40,000 per year today. An estimated 1 - 1.2 million people currently are living with HIV/AIDS in the United States. Due to more effective treatment, people are living longer and healthier lives after a diagnosis of HIV. Despite the growing pool of persons capable of transmitting the virus, the number of persons becoming newly infected each year has remained constant over the last 10 years, at approximately 40,000 new infections per year.

While the struggle to prevent new HIV infections is not over, there have been some major successes. For instance, the dramatic decrease in mother to child (perinatal) HIV transmission is one of the great success stories of HIV prevention. Since the beginning of the epidemic, the number of infants infected with HIV through mother-to-child transmission has decreased by almost 90%, from an estimated peak of 1,750 HIV-infected infants born each year during the early to mid-1990s to between 140 and 230 infants in 2002. These declines are due to multiple interventions, including routine voluntary HIV testing of pregnant women, the use of rapid HIV tests at delivery for women of unknown HIV status, and the use of antiretroviral therapy by HIV-infected women during pregnancy and infants after birth.

We have also seen declines in the number of HIV and AIDS cases attributed to injection drug use. For example, the number of AIDS cases attributed to injection drug use has declined by about 15% from 2000 to 2004.

In addition to the dramatic decline in the occurrence of new cases since the beginning of the epidemic, the HIV/AIDS epidemic has changed in other important ways. In the early days of the epidemic, the greatest number of new infections was found among white men who have sex with men (MSM) and among injection drug users. Today, while men who have sex with men overall still account for the largest percentage of new HIV infections, the epidemic has expanded to have a growing impact on racial and ethnic minorities (particularly African Americans). During 2001-2004 in 35 areas with HIV case reporting, 51% of all new HIV/AIDS diagnoses were in African Americans. The epidemic is also affecting more women. Early in the epidemic, HIV infection and AIDS were diagnosed for relatively few women and female adolescents. Today, women account for more than one quarter of all new HIV/AIDS diagnoses. Women of color are especially affected by HIV infection and AIDS, and in 2002 (the most recent year available) HIV infection was the leading cause of death for African American women aged 25–34 years.

Of great concern to us is the approximately 25 percent of persons with HIV who do not know they are infected. We believe that infections transmitted from this group account for more than half of new HIV infections each year, underscoring the rationale for our substantially increased efforts to reach at-risk communities with HIV testing services. When people know their status they are more likely to protect their partners from infection. Knowledge of one's HIV infection can help prevent the spread of HIV to others.

**HIV surveillance in the United States**

A robust surveillance system provides a strong foundation for good public health programs. Surveillance data are crucial to informing and guiding effective and evidence-based prevention efforts. Surveillance for HIV/AIDS has evolved over time in response to changes in the epidemic, development in diagnostics, technologies and treatments. Initial surveillance was for AIDS cases, but as new diagnostic tools have become available, and our understanding of the disease pathogenesis has evolved, so too have our methods for surveillance. Today, surveillance of HIV/AIDS is among the most complex for any infectious disease—relying upon multiple methods, data sources and analytic techniques. Having accurate information about the HIV epidemic requires obtaining information about several important events over the life of a case, from initial infection, through diagnosis, to clinical and laboratory markers of illness, through death.

CDC is responsible for ensuring the integrity of the national HIV/AIDS surveillance system to accurately monitor the epidemic in the United States. CDC provides funding, technical assistance, and coordinates activities with states to aggregate data that constitute the national system. CDC also issues recommended security and confidentiality policies and procedures to state and local surveillance programs that are consistent with the agency standards for the security of surveillance data. CDC requires that recipients of federal funds for HIV/AIDS surveillance establish the minimum security standards and include their security policy in applications for surveillance funds. As with other diseases, individual state governments have authority for statutory and regulatory issues for HIV/AIDS reporting and data protection, including the decision regarding what type of system will be used for disease reporting, such as name-based or code-based. Except for HIV, all other reported infectious diseases, including AIDS, are routinely reported to states using name-based reporting systems. It is important to note, for confidentiality purposes, that the CDC does not receive the names of individuals. This information resides with public health authorities at the state level.

Since the beginning of the epidemic, AIDS surveillance has been a cornerstone of national, state, and local efforts to monitor the scope and impact of the HIV epidemic. AIDS surveillance data, however, no longer accurately describe the full extent of the epidemic, as effective therapies have slowed the progression of HIV disease. Since 1999, CDC has advised states to conduct HIV reporting using the same name-based approach currently used for AIDS surveillance nationwide. Currently, 43 states use confidential name-based HIV case reporting. The remaining seven states and the District of Columbia use code or name-to-code reporting. Among those eight areas there are seven different codes. Several of the remaining states have notified CDC that they intend to implement name-based HIV surveillance in 2006. In fact, on April 17, 2006, the Governor of California signed into law SB 669 which has moved the state from a code-based to an integrated name-based reporting system.

**Use of HIV/AIDS Data**

CDC's HIV/AIDS surveillance system is the nation's key source of information used to track the epidemic. Surveillance activities provide demographic, laboratory, clinical and behavioral risk data that are used to identify populations at greatest risk for HIV infection. There are three primary uses of surveillance data: 1) epidemic monitoring, including estimates of incidence and prevalence of HIV and AIDS in the population, estimates of incidence of HIV infection, and changes and trends in HIV and AIDS in populations at risk; 2) prevention planning to target prevention interventions, evaluate their effectiveness, and facilitate access to health, social and prevention services;

and 3) allocation of local, state, and federal funds for prevention, care and treatment services, including the Ryan White Comprehensive AIDS Resources Emergency Act (RWCA).

CDC surveillance data for AIDS and HIV disease are used by the Health Resources and Services Administration (HRSA) to determine funding levels under the RWCA. Each year, CDC provides to HRSA all AIDS case counts for states and eligible metropolitan areas (EMAs) based on reports from state health departments for the previous 10, 12-month periods, as required by law. These data are not adjusted in any way and constitute crude, counts of reported cases as prescribed in the current RWCA legislation. CDC also provides HRSA with bi-annual survival weights to calculate the estimated living cases for computation of the Title I and II grant awards. HRSA uses CDC's surveillance data to determine Title I and II allotments as well as to identify areas that qualify as EMAs and emerging communities.

**History of HIV/AIDS Reporting**

At the beginning of the HIV epidemic, before we even knew that HIV causes AIDS, surveillance of this public health problem could only be conducted by tracking AIDS cases and deaths. In the early 1980s when all states implemented mandatory reporting for this condition, they implemented the same system used for all other reportable conditions where the name of the affected person served as the patient identifier.

In 1985, when the first diagnostic test for HIV became available, Minnesota and Colorado were the first states to begin conducting surveillance for persons diagnosed with HIV but who were not yet sick with AIDS. These states extended their existing systems and used name-based reporting for HIV diagnosis. By the end of 1994, when CDC began to support national aggregation of surveillance data on non-AIDS HIV, 25 states collecting this information were using name-based systems. Four other states (Maryland, Texas, Connecticut, and Oregon) were using codes.

Numerous formal evaluations of name-based reporting for AIDS were conducted during the late 1980s and early 1990s. These evaluations demonstrated that this was a highly accurate and reliable method for conducting surveillance for AIDS and non-AIDS HIV. Because the vast majority of states were using name-based systems for non-AIDS HIV, the fact that name-based HIV and AIDS case surveillance had been shown to be highly accurate and reliable, and no formal evaluations of code-based systems had been conducted, CDC determined that only name-based reports would be accepted into the data collection system for the national database.

In 1995, CDC convened a meeting of states conducting non-AIDS HIV surveillance (code and name-based) to review the operational, technical, and scientific challenges associated with surveillance using coded identifiers. The states recommended that CDC evaluate additional coded identifiers and assist them in documenting and disseminating the results of their findings. With CDC collaboration and support, Texas and Maryland conducted an evaluation of their code-based systems based on reports submitted during 1994-1996. This research documented nearly 50 percent incomplete reporting and other deficiencies in the accuracy and reliability of these systems. Texas subsequently switched to name-based reporting; Maryland continued to execute and evaluate its code-based system.

The other major outcome of this 1995 meeting was a request from the states that research be done to determine whether name-based reporting discouraged HIV testing. CDC and the University of California-San Francisco did several evaluations, all of which showed no impact of reporting laws on testing behavior. The two main reasons people reported for not testing for HIV were not perceiving themselves at risk and being afraid to find out that they were positive.

In 1997, the Council of State and Territorial Epidemiologists promulgated a position statement recommending the addition of non-AIDS HIV to the national public health surveillance system. In 1999, CDC published formal guidelines for the conduct of non-AIDS HIV surveillance. These recommendations provided performance standards for evaluating HIV surveillance systems (name or code); reviewed the existing evidence for the reliability and accuracy of varying methods for reporting this condition; and based on the existing evidence at that time, "advised" that states use name-based systems. However, CDC also stated that it would continue to work with states to develop and implement standardized methods for evaluating surveillance systems using name and code-based data. Throughout all subsequent national meetings, as well as in discussions with states, CDC reiterated that it "advised" states to use name-based reporting, and the agency's commitment to develop standardized evaluation methods.

In 2001, CDC funded 10 states (3 code-based and 7 name-based) to pilot methods for evaluating these systems. Two of the code-based states--Illinois and Washington--have subsequently switched to name-based reporting. Also in 2001, CDC launched a national evaluation of interstate duplicate reports (i.e. multiple reports from multiple states that provide information about the same person.) This was necessary because the great success of HIV treatments meant that persons with HIV and AIDS were living longer, healthier lives, and were more likely to move across and within states. From the outset of this evaluation, it was clear that technical problems made it impossible to efficiently include code-based reports. These problems included: 1) the variety of codes used by different states conducting this type of surveillance; 2) the lack of a central, standardized, national database with code-based reports; and 3) the inability of states using codes to adequately communicate with states using names regarding potential duplicate records. Therefore, only name-based reports could be included in this interstate de-duplication effort. The results of this assessment indicated that the number of duplicate reports for non-AIDS HIV cases varied a great deal from state to state, and exceeded the proportion of duplicate case reports for AIDS cases.

Following completion of the interstate duplication study, CDC did three things: 1) identified and eliminated all identified records attributable to duplicate reporting in the national database; 2) implemented a formal system for coordinating the ongoing identification and removal of duplicate reports in the national database; 3) published and disseminated a "Dear Colleague" letter signed by the CDC Director in July 2005 stating that the agency was upgrading the guidance for states to implement name-based HIV reporting from "advising" to "recommending." The letter also indicated that CDC would provide technical assistance to states transitioning from code to name-based systems to assure that their data could be integrated into the national HIV (non-AIDS and AIDS) data system as quickly as possible.

Additionally, the RWCA Amendments of 2000 called for an Institute of Medicine (IOM) study of states' HIV surveillance systems and their adequacy and reliability for the purpose of using such data as the basis for CARE Act formula grant allocation. The IOM issued its report, *Measuring What Matters*, on allocation, planning and quality assessment for the RWCA. The IOM did not evaluate the accuracy or effectiveness of code-based systems. The IOM Committee noted in the Report that it was beyond its capacity to evaluate the HIV case-reporting system of each state and territory. The IOM Committee determined that it was "unclear if name-based reporting is intrinsically superior to code-based reporting for eliminating duplicate reports." This Report made clear that technical problems made it impossible to efficiently include code-based reports. The Committee did not have available the final results of the interstate duplication evaluation project when it made these recommendations.

**Current Status**

CDC strongly supports the requirement in the RWCA for states to implement HIV reporting by 2007. CDC's policy is to accept HIV infection and AIDS case surveillance data only from areas conducting confidential name-based reporting because this reporting has been shown to routinely achieve high levels of accuracy and reliability. Personal identifiers are removed before data are provided to CDC. CDC provides recommended security and confidentiality policies and procedures of state and local surveillance programs that are consistent with the agency standards for the security of HIV/AIDS surveillance data. CDC also requires that recipients of federal funds for HIV/AIDS surveillance establish the minimum security standards and include their security policy in applications for surveillance funds.

HIV surveillance that is conducted using coded patient identifiers has not been shown to routinely produce equally accurate, timely, or complete data compared to that conducted using confidential, name-based surveillance methods. Currently, only confidential, name-based HIV reporting, integrated with AIDS surveillance data, can be used by states to identify and remove cases that are counted in more than one state before they are reported to CDC's national surveillance database.

States that have implemented code-based systems consistently inform CDC that these systems are more complex, expensive and burdensome than name-based reporting systems. Since states have extensive experience with name-based systems for persons with HIV who have progressed to AIDS, CDC has accepted that these assertions are valid. However, few formal economic evaluations have been conducted. CDC is only aware of one such systematic quantitative evaluation comparing the relative costs of name-based systems to systems using codes and name-to-code. This evaluation found that a name-to-code reporting system was 15 percent more expensive than name-based reporting, and reporting based exclusively on codes was 50 percent more expensive than name-based reporting.

CDC is providing technical assistance to states transitioning from code- to name-based systems to assure that their data can be integrated into the national HIV (non-AIDS and AIDS) data system as quickly as possible. CDC continues to provide assistance to the seven states that have made the transition to name-based systems since the IOM report was published in 2004. As previously noted, as of April 2006, 43 states have adopted use of name-based systems of HIV reporting.

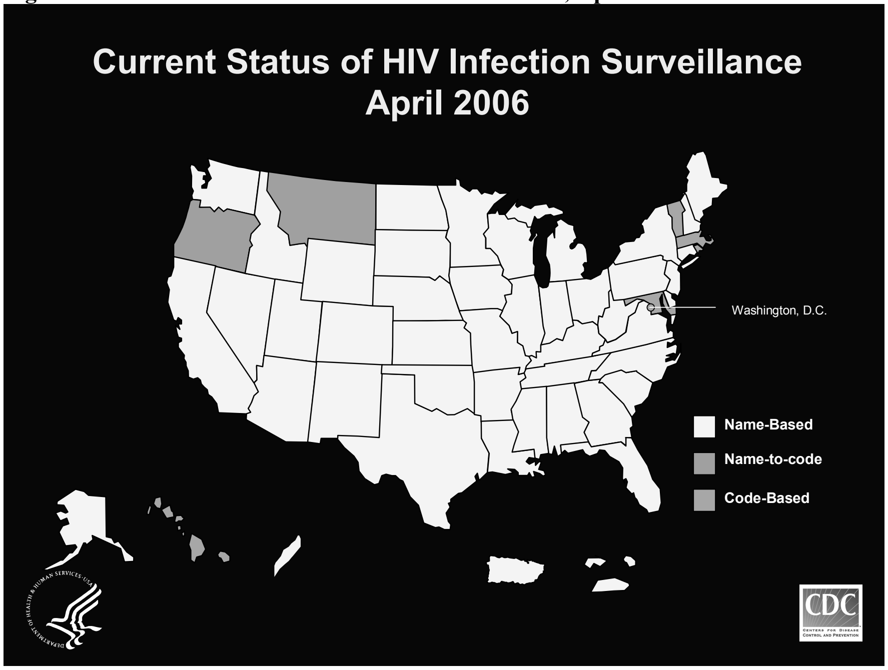
CDC continues to provide funding and technical assistance to states that use code-based methods for identifying patients in their HIV surveillance system. CDC is implementing and disseminating methods for conducting evaluations of the accuracy and reliability of reporting systems within states, regardless of reporting method. CDC is deploying data management software that integrates functions that will allow areas to use standardized methods to evaluate their systems based on recently completed pilot studies. In addition, CDC regularly offers technical assistance to areas using code-based systems that have not received this software. This assistance includes the software, and relevant documentation, that was used in the pilots.

## Closing

In summary, CDC is responsible for ensuring the integrity of the national HIV/AIDS surveillance system to accurately monitor the epidemic in the United States. CDC continues to work closely with all states to help them adopt and implement high-quality HIV surveillance systems. Having all states collect HIV information in the same manner will ensure that the nation has reliable and valid data to monitor the scope of the epidemic; plan for and evaluate prevention, care, and treatment programs; and focus those programs on persons most at risk.

Thank you again for this opportunity. I will be pleased to answer any questions.

**Figure 1. Current Status of HIV Infection Surveillance, April 2006.**



MR. DEAL. Thank you. Ms. Crosse.

MS. CROSSE. Mr. Chairman and members of the subcommittee, I am pleased to be here today to discuss the Ryan White CARE Act.

In fiscal year 2004, over $2 billion in funding was provided through the CARE Act, the majority of which was distributed through Title I grants to eligible metropolitan areas, EMAs, and Title II grants to States, the District of Columbia, and territories. Metropolitan areas qualify as EMAs if they have a total of 2,000 reported AIDS cases in the previous five years. Titles I and II use formulas to distribute grants according to a jurisdiction's reported count of AIDS cases.

My testimony today is based on our February 2006 report on CARE Act funding. I will focus on issues related to the formula-based funding under Titles I and II that account for about 80 percent of total CARE Act funding. We did not examine funding under other smaller provisions of the CARE Act, where the distribution under competitive grants may currently be different.

Specifically, today I will discuss the extent of funding differences among CARE Act grantees and how specific CARE Act funding formula provisions contribute to these differences, and what distribution differences could result from using HIV cases in CARE Act funding formulas.

In brief, multiple provisions in the CARE Act funding formulas result in funding not being comparable per AIDS case across grantees. First, the CARE Act uses measures of AIDS cases that do not accurately reflect the number of persons living with AIDS. For example, the statutory funding formulas require the use of cumulative AIDS case counts, which could include deceased cases.

Second, CARE Act provisions related to metropolitan areas result in variability of the amount of funding per AIDS case among grantees. For example, AIDS cases within EMAs are counted once for determining funding under Title I of the CARE Act, and again under Title II for determining funding for the States and territories in which those EMAs are located. As a result, States with EMAs receive more total funding per AIDS case than States without EMAs.

Third, CARE Act hold harmless provisions under Titles I and II and the grandfather clause for EMAs under Title I sustain funding and eligibility of CARE Act grantees on the basis of a previous year's measurements of the number of AIDS cases in these jurisdictions. For example, the CARE Act Title I hold harmless provision results in one EMA continuing to have deceased AIDS cases factored into its allocation because its hold harmless funding dates back to the mid-1990s when formula funding was based on a count of AIDS cases from the beginning of the epidemic.

The most recent reauthorization of the CARE Act in 2000 specified that HIV cases should be used in funding formulas no later than 2007. If HIV case counts had been incorporated in allocating fiscal year 2004 CARE Act grants, funding would have shifted among jurisdictions. Grantees in the South and the Midwest generally would have received more funding if HIV cases were used in the funding formulas, but there would have been grantees with increased funding and grantees with decreased funding in every region of the country.

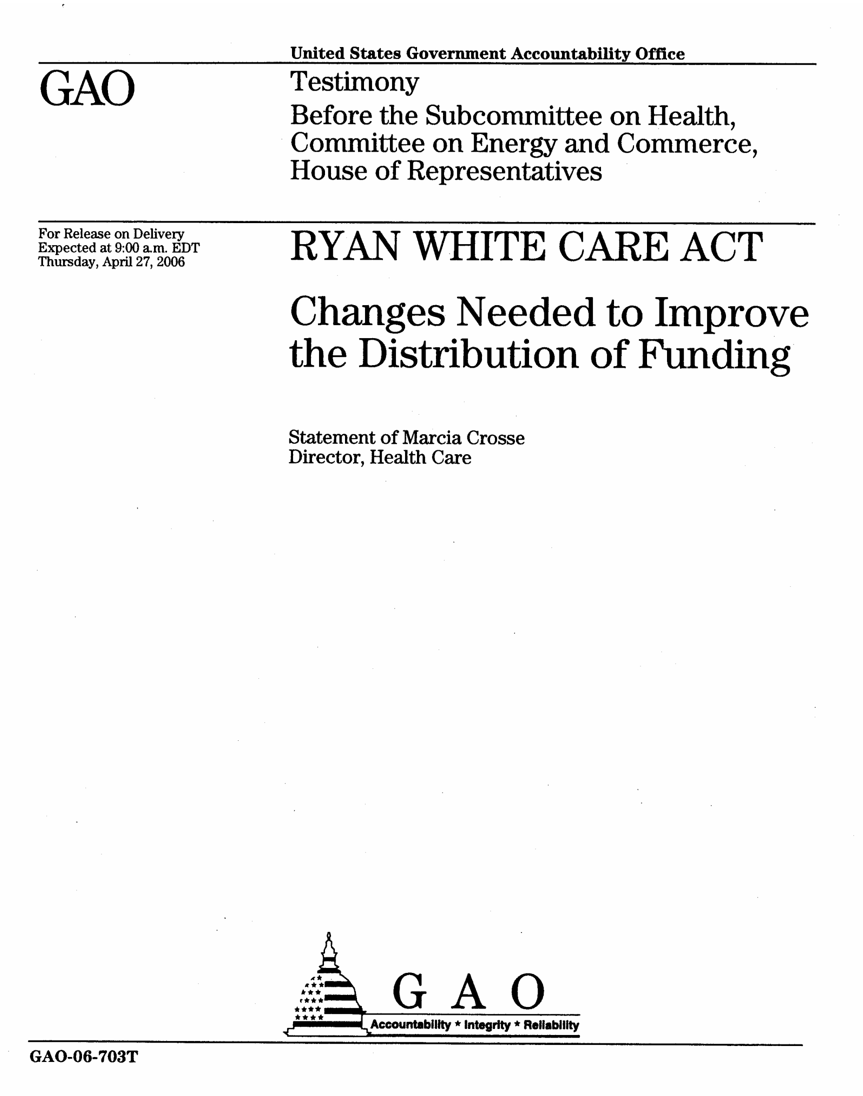
Although CARE Act grantees have established HIV case reporting systems, differences between these systems in their maturity and reporting methods, for instance, would have affected the distribution of CARE Act funds based on estimated living AIDS cases and HIV case counts. Grantees with more mature HIV reporting systems would tend to receive more funds. Further, CDC has not accepted data for use in the formulas from systems that use code-based rather than name-based HIV reporting, and as we have just heard from Dr. Fenton, there are a number of jurisdictions still using code-based systems.

We reported in February, 2006, that if Congress wishes CARE Act funding to more closely reflect the distribution of the current epidemic, it should consider taking actions that lead to more comparable funding per case by revising the funding formulas. In accordance with achieving more comparable funding per case, we raised a number of matters for consideration when Congress reviews the CARE Act.

Mr. Chairman, this completes my prepared statement. I would be happy to respond to any questions you or other members of the subcommittee may have. Thank you.

[The prepared statement of Marcia Crosse follows:]

PREPARED STATEMENT OF MARCIA CROSSE, DIRECTOR, HEALTH CARE, U.S. GENERAL ACCOUNTABILITY OFFICE



**United States Government Accountability Office**

GAO

Testimony
Before the Subcommittee on Health, Committee on Energy and Commerce, House of Representatives

For Release on Delivery
Expected at 9:00 a.m. EDT
Thursday, April 27, 2006

# RYAN WHITE CARE ACT

## Changes Needed to Improve the Distribution of Funding

Statement of Marcia Crosse
Director, Health Care

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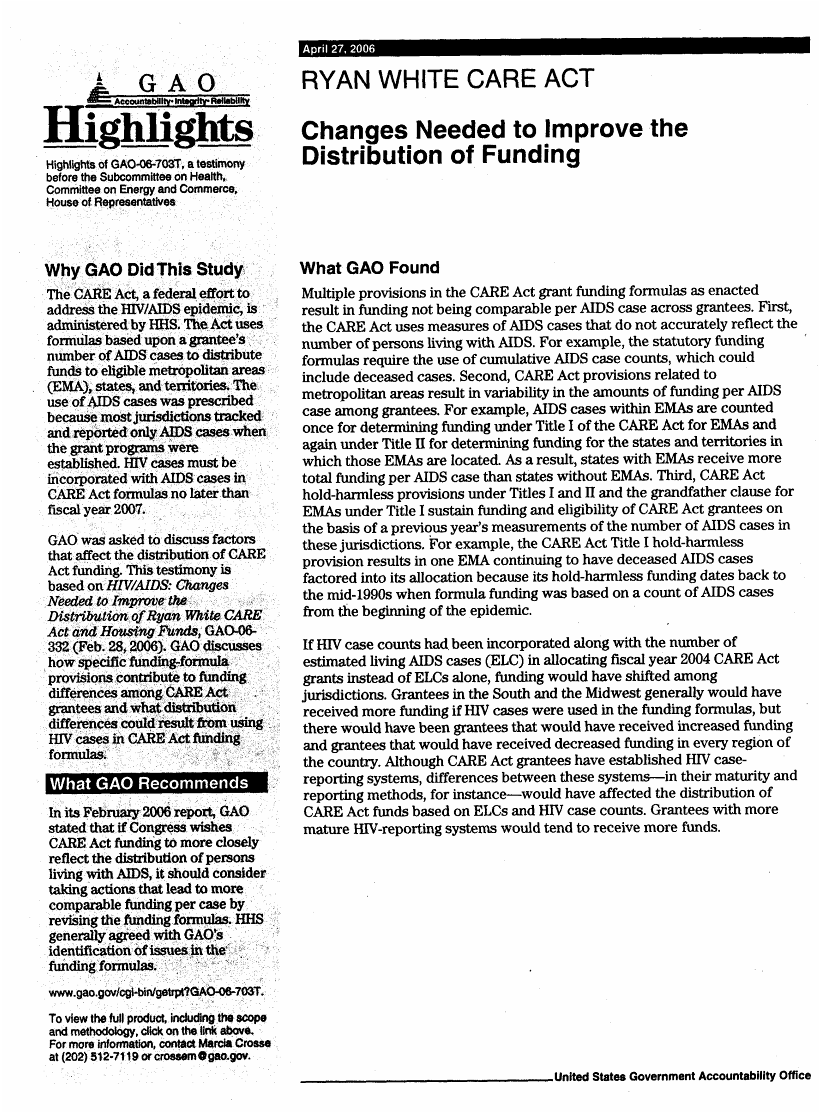
**GAO-06-703T**



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# Highlights

Highlights of GAO-06-703T, a testimony before the Subcommittee on Health, Committee on Energy and Commerce, House of Representatives

April 27, 2006

# RYAN WHITE CARE ACT

## Changes Needed to Improve the Distribution of Funding

### Why GAO Did This Study

The CARE Act, a federal effort to address the HIV/AIDS epidemic, is administered by HHS. The Act uses formulas based upon a grantee's number of AIDS cases to distribute funds to eligible metropolitan areas (EMA), states, and territories. The use of AIDS cases was prescribed because most jurisdictions tracked and reported only AIDS cases when the grant programs were established. HIV cases must be incorporated with AIDS cases in CARE Act formulas no later than fiscal year 2007.

GAO was asked to discuss factors that affect the distribution of CARE Act funding. This testimony is based on *HIV/AIDS: Changes Needed to Improve the Distribution of Ryan White CARE Act and Housing Funds*, GAO-06-332 (Feb. 28, 2006). GAO discusses how specific funding-formula provisions contribute to funding differences among CARE Act grantees and what distribution differences could result from using HIV cases in CARE Act funding formulas.

### What GAO Recommends

In its February 2006 report, GAO stated that if Congress wishes CARE Act funding to more closely reflect the distribution of persons living with AIDS, it should consider taking actions that lead to more comparable funding per case by revising the funding formulas. HHS generally agreed with GAO's identification of issues in the funding formulas.

www.gao.gov/cgi-bin/getrpt?GAO-06-703T.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Marcia Crosse at (202) 512-7119 or crossem@gao.gov.

### What GAO Found

Multiple provisions in the CARE Act grant funding formulas as enacted result in funding not being comparable per AIDS case across grantees. First, the CARE Act uses measures of AIDS cases that do not accurately reflect the number of persons living with AIDS. For example, the statutory funding formulas require the use of cumulative AIDS case counts, which could include deceased cases. Second, CARE Act provisions related to metropolitan areas result in variability in the amounts of funding per AIDS case among grantees. For example, AIDS cases within EMAs are counted once for determining funding under Title I of the CARE Act for EMAs and again under Title II for determining funding for the states and territories in which those EMAs are located. As a result, states with EMAs receive more total funding per AIDS case than states without EMAs. Third, CARE Act hold-harmless provisions under Titles I and II and the grandfather clause for EMAs under Title I sustain funding and eligibility of CARE Act grantees on the basis of a previous year's measurements of the number of AIDS cases in these jurisdictions. For example, the CARE Act Title I hold-harmless provision results in one EMA continuing to have deceased AIDS cases factored into its allocation because its hold-harmless funding dates back to the mid-1990s when formula funding was based on a count of AIDS cases from the beginning of the epidemic.

If HIV case counts had been incorporated along with the number of estimated living AIDS cases (ELC) in allocating fiscal year 2004 CARE Act grants instead of ELCs alone, funding would have shifted among jurisdictions. Grantees in the South and the Midwest generally would have received more funding if HIV cases were used in the funding formulas, but there would have been grantees that would have received increased funding and grantees that would have received decreased funding in every region of the country. Although CARE Act grantees have established HIV case-reporting systems, differences between these systems—in their maturity and reporting methods, for instance—would have affected the distribution of CARE Act funds based on ELCs and HIV case counts. Grantees with more mature HIV-reporting systems would tend to receive more funds.

United States Government Accountability Office

Mr. Chairman and Members of the Subcommittee:

I am pleased to be here today to discuss the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (CARE Act).[1] I will specifically address factors that affect CARE Act funding of services for those with the human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) and program coverage for individuals served by the CARE Act.[2] The Centers for Disease Control and Prevention (CDC) estimate that between 1,039,000 and 1,185,000 people in the United States were living with HIV/AIDS at the end of 2003. The number of people infected with HIV/AIDS is likely to have risen since then, and CDC estimates that, as of December 2004, it included 415,193 individuals with AIDS.

The CARE Act, which is administered by the Department of Health and Human Services' (HHS) Health Resources and Services Administration (HRSA), established a number of grant programs through which funds are made available to states—including the District of Columbia—territories,[3] and metropolitan areas to provide health care, medications, and support services to individuals and families affected by HIV/AIDS. In fiscal year 2004, more than $2 billion was provided through the CARE Act for these health care and support services. The majority of these funds were distributed under Title I and Title II[4] of the CARE Act through formula-driven base grants in fiscal year 2004 based upon a measure of each

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[1] Pub. L. No. 101-381, 104 Stat. 576 (codified as amended at 42 U.S.C. §§ 300ff–300ff-111 (2000)). Unless otherwise indicated, references to the CARE Act are to current law.

[2] HIV is the virus that causes AIDS. Throughout this testimony, we use the common term "HIV/AIDS" to refer to HIV disease, inclusive of cases that have progressed to AIDS. When we use these terms alone, HIV refers to the disease without the presence of AIDS, and AIDS refers exclusively to HIV disease that has progressed to AIDS.

[3] In addition to the 50 states, the CARE Act authorizes grants to the District of Columbia, the Commonwealth of Puerto Rico, Guam, the Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, the Republic of the Marshall Islands, the Federated States of Micronesia, and the Republic of Palau. Throughout this testimony, the term state refers to the 50 states and the District of Columbia, and territory refers to these listed territories.

[4] The 1990 CARE Act added a new Title XXVI to the Public Health Service Act. In general, because Part A of that new title, which authorizes grants to metropolitan areas, was established by Title I of the CARE Act, it is commonly referred to as Title I, and because Part B, which authorizes grants to states and territories, was established by Title II of the CARE Act, it is commonly referred to as Title II.

grantee's estimated living AIDS cases (ELC).[5] Title I provides for funding to eligible metropolitan areas (EMA) while Title II provides for funding to states and territories.[6] Both Titles I and II contain hold-harmless provisions that limit how much funding can decline from one year to the next. Title I also contains a grandfather clause that was added in 1996, which states that areas eligible for Title I funding at that time continue to be eligible even if they no longer meet the eligibility criteria.

The use of AIDS cases in the distribution of formula grants was prescribed because most jurisdictions tracked and reported AIDS cases instead of HIV cases when the grant programs were established. Because of concerns that a jurisdiction's disease burden is not adequately reflected by only counting cases that have progressed to AIDS, the Ryan White CARE Act Amendments of 2000 required the use of HIV/AIDS case counts in the distribution of formula grants not later than fiscal year 2007.[7] We have reported that because CARE Act grants serve 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 of persons living with HIV/AIDS.[8] Incorporating HIV data along with AIDS data would result in targeting funds more accurately according to need. However, because there is a lack of HIV data that are sufficiently adequate and reliable to serve as a basis for CARE Act formula grant allocations, as of December 2005, HIV cases have not been used in the distribution of formula grants under CARE Act programs.

To assist the subcommittee as it considers the reauthorization of CARE Act programs, my testimony provides our findings on CARE Act funding formulas. Specifically, I will discuss

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[5] HRSA calculates a grantee's ELCs by using data from CDC on the reported AIDS case counts for the last 10 years and weighting those numbers to account for the likelihood of deaths.

[6] Under Title I, a metropolitan area with a population of at least 500,000 and more than 2,000 reported AIDS cases in the last 5 calendar years is eligible to receive Title I funding, and is defined as an EMA.

[7] Pub. L. No. 106-345, § 206(b), 114 Stat. 1319, 1334–35.

[8] GAO, *Ryan White CARE Act: Opportunities to Enhance Funding Equity*, GAO/T-HEHS-00-150 (Washington, D.C.: July 11, 2000), 6.

1. the extent of funding differences among CARE Act grantees, and how specific CARE Act funding-formula provisions contribute to these differences, and
2. what distribution differences could result from using HIV cases in CARE Act funding formulas.

My testimony today is based on our February 2006 report on CARE Act funding.[9] In carrying out the work for our report, we reviewed the CARE Act of 1990, as well as the 1996 and 2000 CARE Act amendments, HRSA documents on CARE Act funding, Institute of Medicine (IOM) reports on the CARE Act, and other related reports. We interviewed CDC, HRSA, and state officials, as well as officials from the National Alliance of State and Territorial AIDS Directors. We analyzed data for fiscal year 2004, obtained from HRSA and CDC, to examine the effects of funding-formula provisions and the use of HIV cases with ELCs in making CARE Act funding allocations.[10] We also collected data on HIV case counts from state and local HIV/AIDS officials. Based on the information HRSA, CDC, and state and local officials provided regarding verification of the reliability of these data, we determined these data to be sufficiently reliable for the purposes of our analyses. We performed our work in accordance with generally accepted government auditing standards. The report's appendix I provides a more detailed explanation of our scope and methodology.

In brief, multiple provisions in the CARE Act grant funding formulas as enacted result in funding not being comparable per AIDS case across grantees. First, the CARE Act uses measures of AIDS cases that do not accurately reflect the number of persons living with AIDS. For example, the statutory funding formulas require the use of cumulative AIDS case counts, which could include deceased cases. Second, CARE Act provisions related to metropolitan areas result in variability in the amounts of funding per AIDS case among grantees. For example, AIDS cases within EMAs are counted once for determining funding under Title I of the CARE Act for EMAs and again under Title II for determining funding for the states and territories in which those EMAs are located. As a result, states with EMAs receive more total funding per AIDS case than states without EMAs. Third,

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[9] GAO, *HIV/AIDS: Changes Needed to Improve the Distribution of Ryan White CARE Act and Housing Funds*, GAO-06-332 (Washington, D.C.: Feb. 28, 2006).

[10] Our analyses of CARE Act funding-formula provisions and the use of HIV cases in making CARE Act funding allocations include the states, Puerto Rico, and metropolitan areas eligible for funding.

CARE Act hold-harmless provisions under Titles I and II and the grandfather clause for EMAs under Title I sustain funding and eligibility of CARE Act grantees on the basis of a previous year's measurements of the number of AIDS cases in these jurisdictions. For example, the CARE Act Title I hold-harmless provision results in one EMA continuing to have deceased AIDS cases factored into its allocation because its hold-harmless funding dates back to the mid-1990s when formula funding was based on a count of AIDS cases from the beginning of the epidemic.

If HIV case counts had been incorporated along with ELCs in allocating fiscal year 2004 CARE Act grants, instead of ELCs alone, funding would have shifted among jurisdictions. Grantees in the South and the Midwest generally would have received more funding if HIV cases were used in the funding formulas, but there would have been grantees that would have received increased funding and grantees that would have received decreased funding in every region of the country. Although CARE Act grantees have established HIV case-reporting systems, differences between these systems—in their maturity and reporting methods, for instance—would have affected the distribution of CARE Act funds based on ELCs and HIV case counts. Grantees with more mature HIV-reporting systems would tend to receive more funds.

We reported in February 2006 that if Congress wishes CARE Act funding to more closely reflect the distribution of persons living with AIDS, it should consider taking actions that lead to more comparable funding per case by revising the funding formulas. In accordance with achieving more comparable funding per AIDS case, we raised a number of matters for consideration when Congress reviews the CARE Act. HHS generally agreed with GAO's identification of issues in the funding formulas.

## Background

The CARE Act was enacted in 1990 to respond to the needs of individuals and families living with HIV or AIDS and to direct federal funding to areas disproportionately affected by the epidemic. The Ryan White CARE Act Amendments of 1996[11] and the Ryan White CARE Act Amendments of 2000[12] modified the original funding formulas. For example, prior to the 1996 amendments, the CARE Act required that for purposes of determining grant amounts a metropolitan area's caseload be measured by

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[11] Pub. L. No. 104-146, 110 Stat. 136.

[12] Pub. L. No. 106-345, 114 Stat. 1319.

a cumulative count of AIDS cases recorded in the jurisdiction since reporting began in 1981.[13] The 1996 amendments required the use of ELCs instead of cumulative AIDS cases.[14] Because this switch would have resulted in large shifts of funding away from jurisdictions with a longer history of the disease than other jurisdictions, due in part to a higher proportion of deceased cases, the 1996 CARE Act amendments added a hold-harmless provision under Title I, as well as under Title II, that limits the extent to which a grantee's funding can decline from one year to the next.

Titles I and II also provide for other grants to subsets of eligible jurisdictions either by formula or by a competitive process. For example, in addition to AIDS Drug Assistance Program (ADAP) base grants, Title II also authorizes grants for states and certain territories with demonstrated need for additional funding to support their ADAPs.[15] These grants, known as Severe Need grants, are funded through a set-aside of funds otherwise available for ADAP base grants. Title II also authorizes funding for "Emerging Communities," which are communities affected by AIDS that have not had a sufficient number of AIDS cases reported in the last 5 calendar years to be eligible for Title I grants as EMAs. In addition, Title II contains a minimum-grant provision that guarantees that no grantee will receive a Title II base grant less than a specified funding amount.

Metropolitan areas heavily affected by HIV/AIDS have always been recognized within the structure of the CARE Act. In 1995 we reported that, with combined funding under Title I and Title II, states with EMAs receive more funding per AIDS case than states without EMAs.[16] To adjust for this situation, the 1996 amendments instituted a two-part formula for Title II base grants that takes into account the number of ELCs that reside within a state but outside of any EMA. Under this distribution formula, 80 percent

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[13] In this statement, cumulative AIDS cases are the total number of AIDS cases, both living and dead, reported in a jurisdiction in a given period.

[14] HRSA calculates a jurisdiction's ELCs by using data from CDC on the reported AIDS case counts for the last 10 years and weighting those numbers to account for the likelihood of deaths. We used this measure as our estimate of living AIDS cases in our analyses of CARE Act funding-formula provisions and the use of HIV cases in CARE Act funding formulas.

[15] In addition to the 50 states, these grants, like ADAP base grants, are authorized to the District of Columbia, the Commonwealth of Puerto Rico, Guam, and the Virgin Islands.

[16] See GAO, *Ryan White CARE Act of 1990: Opportunities Are Available to Improve Funding Equity*, GAO/T-HEHS-95-126 (Washington, D.C.: Apr. 5, 1995).

of the Title II base grant is based upon a state's proportion of all ELCs, and 20 percent of the base grant is based on a state's proportion of ELCs outside of EMAs relative to all such ELCs in all states and territories. A second provision included in 1996 protected the eligibility of EMAs. The 1996 amendments provided that a jurisdiction designated as an EMA for that fiscal year would be "grandfathered" so it would continue to receive Title I funding even if its reported number of AIDS cases dropped below the threshold for eligibility. Table 1 describes CARE Act formula grants for Titles I and II.

**Table 1: Description of CARE Act Title I and Title II Formula Grants**

| Formula grant | Eligible grantees | Distribution | Minimum grant | Hold-harmless provision[a] |
|---|---|---|---|---|
| Title I Base Grant | Metropolitan areas with 500,000 or more in population and with more than 2,000 reported AIDS cases in the most recent 5 calendar years[b] | Distributed among EMAs according to each EMA's proportion of ELCs relative to all EMAs. | No | Grant annually declines to 98%, 95%, 92%, and 89% of the base year grant, respectively.[c] In the fifth and all subsequent years, EMA receives 85% of base year grant. The funds necessary to meet the hold-harmless requirement are deducted from funds available for supplemental grants under Title I.[d] |
| Title II Base Grant | States and territories[e] | Eighty percent of base grant funding divided among states/territories according to each grantee's proportion of all ELCs. Twenty percent of base grant funding divided among states/territories according to each grantee's ELCs located outside the EMAs within the state's/territory's borders relative to such ELCs in all states/territories. | For states with fewer than 90 ELCs, $200,000; states with 90 or more ELCs, $500,000; for territories, $50,000 | Grant declines by 1% per year from the fiscal year 2000 grant. In fifth year, grant is 95% of 2000 grant. |
| Title II ADAP Base Grant | States and certain territories[f] | Distributed according to each grantee's proportion of all ELCs. | No | Grant declines by 1% per year from the fiscal year 2000 grant. In fifth year grant is 95% of 2000 grant. |
| Title II ADAP Severe Need Grant[g] | States and certain territories[f] with a severe need for a grant to increase access to medications | Distributed according to each grantee's proportion of all ELCs: grantees must agree to match 25 percent of their severe need grant and not to impose eligibility requirements stricter than those in place on January 1, 2000. | No | No |

| Formula grant | Eligible grantees | Distribution | Minimum grant | Hold-harmless provision[a] |
|---|---|---|---|---|
| Title II Emerging Communities Grant | States and territories with metropolitan areas that are not eligible for Title I, and that have 500–1,999 reported AIDS cases in the most recent 5 calendar years | Funds are divided into two tiers: 50% distributed among communities with 1,000–1,999 AIDS cases, and 50% distributed among communities with 500–999 AIDS cases. Funding is distributed according to each community's proportion of AIDS cases (reported in the most recent 5 calendar years) in Emerging Communities within the tier. | Minimum of $5 million for each tier | No |

Source: HRSA.

Notes: HRSA has also awarded Minority AIDS Initiative grants to EMAs, states, and territories. HRSA characterizes Minority AIDS Initiative grants to EMAs as Title I grants and Minority AIDS Initiative grants to states and territories as Title II grants. These funds are allocated by formula. Title I funds have been used for grants to EMAs with greater than zero reported nonwhite AIDS cases in the most recent 2 calendar years. The funds are distributed among all EMAs according to each EMA's proportion of nonwhite AIDS cases reported over the most recent 2 calendar years. Title II funds have been used for grants to states and territories with greater than zero reported nonwhite AIDS cases in the most recent 2 calendar years. The funds are distributed among all grantees according to each grantee's proportion of nonwhite AIDS cases reported over the most recent 2 calendar years. There are no minimum-grant or hold-harmless provisions for these grants.

[a] If the distribution formula would otherwise result in a funding decrease from a prior year, a hold-harmless provision may be triggered to mitigate the decrease in funding.

[b] A grandfather clause added in 1996 provides that areas eligible at that time continue to be eligible even if they no longer meet the eligibility criteria.

[c] The base year is the fiscal year prior to that in which the EMA first becomes eligible for hold-harmless funding.

[d] Title I also includes supplemental grants, which are awarded to EMAs using a competitive application process based on the demonstration of severe need and other criteria.

[e] In addition to the 50 states, Title II base grants are authorized for the District of Columbia, the Commonwealth of Puerto Rico, Guam, the Virgin Islands, American Samoa, the Commonwealth of the Northern Mariana Islands, the Federated States of Micronesia, the Republic of Palau, and the Republic of the Marshall Islands.

[f] In addition to the 50 states, these grants are authorized for the District of Columbia, the Commonwealth of Puerto Rico, Guam, and the Virgin Islands.

[g] Funding for Severe Need grants may be reduced to maintain funding for some states under a Title II hold-harmless provision. Severe Need grants are funded by setting aside 3 percent of the funds earmarked specifically for ADAPs.

The 2000 amendments provided for HIV case counts to be incorporated in the Title I and Title II funding formulas as early as fiscal year 2005 if such data were available and deemed "sufficiently accurate and reliable" by the Secretary of Health and Human Services.[17] They also required that HIV data be used no later than the beginning of fiscal year 2007. In June 2004 the Secretary of Health and Human Services determined that HIV data were not yet ready to be used for the purposes of distributing formula funding under Title I and Title II of the CARE Act.

## Multiple CARE Act Provisions Contribute to Disproportionate Funding per AIDS Case

Provisions in the CARE Act funding formulas result in a distribution of funds among grantees that does not reflect the relative distribution of AIDS cases in these jurisdictions. We found that provisions affect the proportional allocation of funding as follows: (1) the AIDS case-count provisions in the CARE Act result in a distribution of funding that is not reflective of the distribution of persons living with AIDS, (2) CARE Act provisions related to metropolitan areas result in variability in the amounts of funding per ELC among grantees, and (3) the CARE Act hold-harmless provisions and grandfather clause protect the funding of certain grantees.

### Provisions in CARE Act Funding Formulas Incorporate Measures of AIDS Cases That Do Not Reflect an Accurate Count of Persons Living with AIDS

Provisions in the CARE Act use measurements of AIDS cases that do not reflect an accurate count of people currently living with AIDS. Eligibility for Title I funding and Title II Emerging Communities grants, as well as the amounts of the Emerging Communities grants, is based on cumulative totals of AIDS cases reported in the most recent 5-year period. This results in funding not being distributed according to the current distribution of the disease. For example, because Emerging Communities funding is determined by using 5-year cumulative case counts, allocations could be based in part on deceased cases, that is, people for whom AIDS was reported in the past 5 years but who have since died. In addition, these case counts do not take into account living cases in which AIDS was diagnosed more than 5 years earlier. Consequently, 5-year cumulative case counts can substantially misrepresent the number of AIDS patients in these communities.

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[17] 42 U.S.C. §§ 300 ff-13(a)(3)(D)(i) and 300ff-28(a)(2)(D)(i) (2000).

The use of ELCs as provided for in the CARE Act can also lead to inaccurate estimates of living AIDS cases. Currently, Title I, Title II, and ADAP base funding, which constitute the majority of formula funding, are distributed according to ELCs. ELCs are an estimate of living AIDS cases calculated by applying annual national survival weights to the most recent 10 years of reported AIDS cases and adding the totals from each year. This method for estimating cases was first included in the CARE Act Amendments of 1996. At that time, this approach captured the vast majority of living AIDS cases. However, some persons with AIDS now live more than 10 years after their cases are first reported, and they are not accounted for by this formula.[18] Thus, like the 5-year reported case counts, ELCs can misrepresent the number of living AIDS cases in an area in part by not taking into account those persons living with AIDS whose cases were reported more than 10 years earlier.

## CARE Act Funding Provisions for Metropolitan Areas Result in Disproportionate Funding

When total Title I and Title II funding is considered, states with EMAs and Puerto Rico receive more funding per ELC than states without EMAs because cases within EMAs are counted twice, once in connection with Title I base grants and once for Title II base grants. Eighty percent of the Title II base grant is determined by the total number of ELCs in the state or territory. The remaining 20 percent is based on the number of ELCs in each jurisdiction outside of any EMA. This 80/20 split was established by the 1996 CARE Act amendments to address the concern that grantees with EMAs received more total Title I and Title II funding per case than grantees without EMAs. However, even with the 80/20 split, states with EMAs and Puerto Rico receive more total Title I and Title II funding per ELC than states without EMAs. States without EMAs receive no funding under Title I, and thus, when total Title I and Title II funds are considered, states with EMAs and Puerto Rico receive more funding per ELC. Table 2 shows that the higher the percentage of a state's ELCs within EMAs, the more that state received in total Title I and Title II funding per ELC.[19]

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[18] When determining CARE Act funding for fiscal year 2004, HRSA used a survival weight of .28 for AIDS cases that had been reported 10 years earlier. This figure represents the proportion of persons who had been reported with AIDS 10 years earlier and were known to be alive.

[19] Approximately 80 percent of Puerto Rico's ELCs are in EMAs.

**Table 2: Relationship between ELCs in EMAs and Total CARE Act Title I and II Funding per ELC, Fiscal Year 2004**

| Percentage of states' and Puerto Rico's ELCs in EMAs | Average funding per ELC[a] |
|---|---|
| None | $3,592 |
| Less than 50 percent | 3,954 |
| 50 to 75 percent | 4,717 |
| More than 75 percent | 4,955 |

Source: GAO analysis of HRSA data.

[a] We excluded from our analyses the nine states that received the minimum Title II base grant awards. Under Title II, states with fewer than 90 cases receive no less than $200,000 in Title II base grant and states with 90 or more cases receive at least $500,000.

The two-tiered division of Emerging Communities also results in disparities in funding among metropolitan areas. Title II provides for a minimum of $10 million to states with metropolitan areas that have 500 to 1,999 AIDS cases reported in the last 5 calendar years but do not qualify for funding under Title I as EMAs. The funding is equally split so that half the funding is divided among the first tier of communities with 500 to 999 reported cases in the most recent 5 calendar years while the other half is divided among a second tier of communities with 1,000 to 1,999 reported cases in that period.

In fiscal year 2004, the two-tiered structure of Emerging Communities funding led to large differences in funding per reported AIDS case in the last 5 calendar years among the Emerging Communities because the total number of AIDS cases in each tier was not equal. Twenty-nine communities qualified for Emerging Communities funds in fiscal year 2004. Four of these communities had 1,000 to 1,999 reported AIDS cases in the last 5 calendar years and 25 communities had 500 to 999 cases. This distribution meant that the 4 communities with a total of 4,754 reported cases in the last 5 calendar years split $5 million while the remaining 25 communities with a total of 15,994 reported cases in the last 5 calendar years also split $5 million. These case counts resulted in the 4 communities receiving $1,052 per reported case while the other 25 received $313 per reported case. Table 3 lists the 29 Emerging Communities along with their reported AIDS case counts over the most recent 5 years and their funding.

**Table 3: Title II Emerging Communities in Fiscal Year 2004**

| Emerging Community | AIDS cases reported in the most recent 5 calendar years | Emerging Communities funding per AIDS case reported in the most recent 5 calendar years |
|---|---:|---:|
| Memphis, Tenn. | 1,588 | $1,052 |
| Nashville, Tenn. | 1,123 | 1,052 |
| Baton Rouge, La. | 1,038 | 1,052 |
| Indianapolis, Ind. | 1,005 | 1,052 |
| Columbia, S.C. | 972 | 313 |
| Charlotte, N.C. | 875 | 313 |
| Wilmington, Del. | 801 | 313 |
| Richmond, Va. | 783 | 313 |
| Raleigh–Durham–Chapel Hill, N.C. | 775 | 313 |
| Jackson, Miss. | 722 | 313 |
| Louisville, Ky. | 705 | 313 |
| Rochester, N.Y. | 681 | 313 |
| Fort Pierce–Port St. Lucie, Fla. | 636 | 313 |
| Greensboro–Winston-Salem, N.C. | 617 | 313 |
| Birmingham, Ala. | 615 | 313 |
| Oklahoma City, Okla. | 608 | 313 |
| Pittsburgh, Pa. | 602 | 313 |
| Springfield, Mass. | 588 | 313 |
| Monmouth–Ocean, N.J. | 582 | 313 |
| Buffalo–Niagara Falls, N.Y. | 581 | 313 |
| Greenville, S.C. | 560 | 313 |
| Columbus, Ohio | 558 | 313 |
| Milwaukee, Wis. | 558 | 313 |
| Salt Lake City, Utah | 555 | 313 |
| Sarasota, Fla. | 539 | 313 |
| Charleston, S.C. | 538 | 313 |
| Cincinnati, Ohio | 517 | 313 |
| Daytona Beach, Fla. | 514 | 313 |
| Providence, R.I. | 512 | 313 |
| **Total** | **20,748** | |

Source: GAO analysis of HRSA data.

Note: Emerging Communities are metropolitan areas not eligible for Title I grants and that have 500–1,999 reported AIDS cases in the most recent 5 calendar years. The 5 most recent calendar years are 1998–2002.

## Hold-harmless Provisions and Grandfather Clause Protect Funding of Certain CARE Act Grantees

Titles I and II of the CARE Act both contain provisions that protect certain grantees' funding levels. Title I has a hold-harmless provision that guarantees that the Title I base grant to an EMA will be at least as large as a statutorily specified percentage of a previous year's funding. The Title I hold-harmless provision has primarily protected the funding of one EMA, San Francisco.

If an EMA qualifies for hold-harmless funding, that amount is added to the base funding and distributed together as the base grant. In fiscal year 2004, the San Francisco EMA received $7,358,239 in hold-harmless funding, or 91.6 percent of the hold-harmless funding that was distributed.[20] The second largest recipient was Kansas City, which received $134,485, or 1.7 percent of the hold-harmless funding under Title I. Table 4 lists the EMAs that received hold-harmless funding in fiscal year 2004.[21] Because San Francisco's Title I funding reflects the application of hold-harmless provisions under the 1996 amendments, as well as under current law, San Francisco's Title I base grant is determined in part by the number of deceased cases in the San Francisco EMA as of 1995.

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[20] The funds used to meet the Title I hold-harmless requirement are deducted from the funds otherwise available for Title I supplemental grants before these grants are awarded. Supplemental grants are awarded by HRSA to EMAs using a competitive process based on the demonstration of need and other criteria.

[21] San Francisco was the only EMA that received hold-harmless funding from fiscal year 1999 through fiscal year 2002. In fiscal year 2003, 19 additional EMAs qualified for hold-harmless funding. Twenty-one EMAs received hold-harmless funding in fiscal year 2004. Eleven EMAs qualified in both fiscal years 2003 and 2004.

**Table 4: Title I Hold-harmless Funding, Fiscal Year 2004**

| EMA | Hold-harmless funding | Percent of hold-harmless funding | Hold-harmless funding per ELC | Base grant per ELC[a] | Hold-harmless as a percent of base grant |
|---|---|---|---|---|---|
| San Francisco, Calif. | $7,358,239 | 91.6% | $1,020 | $2,241 | 45.5% |
| Kansas City, Mo. | 134,485 | 1.7 | 104 | 1,325 | 7.8 |
| Santa Rosa, Calif. | 22,614 | 0.3 | 47 | 1,268 | 3.7 |
| Sacramento, Calif. | 36,456 | 0.5 | 29 | 1,251 | 2.3 |
| Minneapolis–St. Paul, Minn. | 33,770 | 0.4 | 27 | 1,248 | 2.1 |
| Bergen–Passaic, N.J. | 55,288 | 0.7 | 26 | 1,248 | 2.1 |
| Jersey City, N.J. | 58,310 | 0.7 | 24 | 1,245 | 1.9 |
| Oakland, Calif. | 50,744 | 0.6 | 18 | 1,239 | 1.4 |
| New Haven, Conn. | 42,573 | 0.5 | 14 | 1,236 | 1.2 |
| Tampa–St. Petersburg, Fla. | 44,908 | 0.6 | 12 | 1,233 | 0.9 |
| San Jose, Calif. | 12,097 | 0.2 | 11 | 1,232 | 0.9 |
| Boston, Mass. | 60,284 | 0.8 | 10 | 1,231 | 0.8 |
| Nassau–Suffolk, N.Y. | 21,212 | 0.3 | 8 | 1,230 | 0.7 |
| Middlesex–Somerset–Hunterdon, N.J. | 8,315 | 0.1 | 7 | 1,228 | 0.5 |
| Jacksonville, Fla. | 12,825 | 0.2 | 6 | 1,228 | 0.5 |
| San Juan, P.R. | 41,011 | 0.5 | 6 | 1,228 | 0.5 |
| Seattle, Wash. | 9,844 | 0.1 | 4 | 1,225 | 0.3 |
| Denver, Colo. | 6,745 | 0.1 | 3 | 1,225 | 0.3 |
| Cleveland, Ohio | 4,616 | 0.1 | 3 | 1,224 | 0.2 |
| West Palm Beach, Fla. | 8,523 | 0.1 | 2 | 1,224 | 0.2 |
| Newark, N.J. | 10,975 | 0.1 | 2 | 1,223 | 0.1 |
| All Other EMAs | 0 | 0 | 0 | 1,221 | 0.0 |
| **Total** | **$8,033,563[b]** | **100.0%[b]** | | | |

Source: GAO analysis of HRSA data.

Notes: An EMA's base funding is determined according to its proportion of ELCs. If an EMA qualifies for hold-harmless funding, that amount is added to the base funding and distributed together as the base grant.

[a] This amount was calculated by dividing the base grant, including any hold-harmless funding, received by each EMA by the number of ELCs in the EMA.

[b] Individual entries do not sum to total because of rounding.

More than half of the 51 EMAs received Title I funding in fiscal year 2004 even though they were below Title I eligibility thresholds.[22] The eligibility of these EMAs was protected based on a CARE Act grandfather clause. Under a grandfather clause established by the CARE Act Amendments of 1996, metropolitan areas eligible for funding for fiscal year 1996 remain eligible for Title I funding even if the number of reported cases in the most recent 5 calendar years drops below the statutory threshold. We found that in fiscal year 2004, 29 of the 51 EMAs did not meet the eligibility threshold of more than 2,000 reported AIDS cases during the most recent 5 calendar years but nonetheless retained their status as EMAs (see fig. 1). The number of reported AIDS cases in the most recent 5 calendar years in these 29 EMAs ranged from 223 to 1,941. Title I funding awarded to these 29 EMAs was about $116 million, or approximately 20 percent of the total Title I funding.

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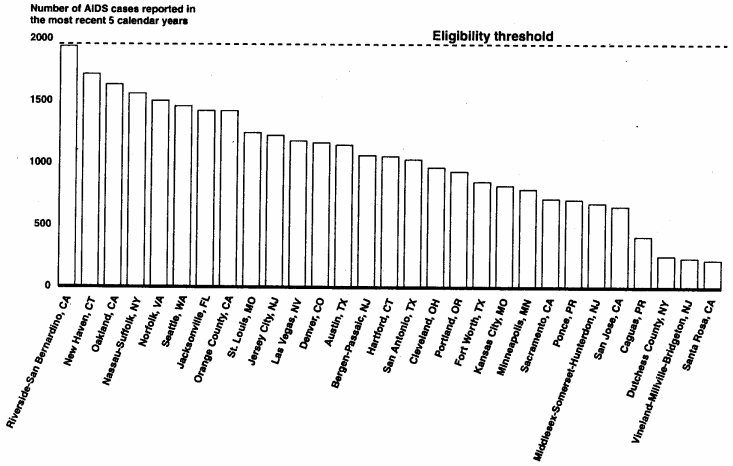
[22] To be eligible for Title I funding, a metropolitan area must have reported a cumulative total of more than 2,000 AIDS cases during the most recent 5 calendar years and have a population of at least 500,000. These criteria differ from those used to calculate base grant funding allocations, which are calculated using the number of ELCs.

Figure 1: Grandfathered EMAs, Fiscal Year 2004



Source: GAO analysis of CDC and HRSA data.

Note: The 5 most recent calendar years are 1998–2002.

Title II has a hold-harmless provision that ensures that the total of Title II and ADAP base grants awarded to a grantee will be at least as large as the total of these grants a grantee received the previous year.[23] This provision has the potential of reducing the amount of funding to grantees that have demonstrated severe need for drug treatment funds because the hold-harmless provision is funded out of amounts that would otherwise be used for that purpose.[24] Fiscal year 2004 was the first time that any grantees triggered this provision. Severe Need grants are funded by a 3 percent set-aside of the funds appropriated specifically for ADAPs. Eight states became eligible for this hold-harmless funding in fiscal year 2004. In 2004, the 3 percent set-aside for Severe Need grants was $22.5 million. Of these funds, $1.6 million, or 7 percent, was used to provide this Title II hold-harmless protection. (See table 5.) The remaining $20.8 million, or 93 percent of the set-aside amount, was distributed in Severe Need grants.

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[23] 42 U.S.C. § 300ff-28(a)(2)(I)(ii)(VI) (2000). Title II also contains a hold-harmless provision that requires HRSA to consider separately Title II base grants and ADAP base grants. For the Title II base grants, this hold-harmless provision is funded by proportionately reducing the size of the Title II base grants made to other jurisdictions that did not qualify for this hold-harmless funding or receive a minimum grant. For ADAP base grants, it would be funded by reducing the size of the ADAP base grants made to those grantees that did not qualify for ADAP base grant hold-harmless funding. 42 U.S.C. § 300ff-28(a)(2)(H) (2000).

[24] To be eligible for a Severe Need grant, a jurisdiction must have met one of four eligibility criteria as of January 1, 2000. It must have limited (1) the eligibility of ADAP clients to those with incomes at or below 200 percent of the federal poverty level, (2) the number of ADAP clients by using medical eligibility restrictions, (3) the number of antiretroviral drugs covered in its drug formulary, or (4) the number of opportunistic infection medications to fewer than 10 in its drug formulary. (Opportunistic infections are illnesses such as parasitic, viral, and fungal infections, and some types of cancer, some of which usually do not cause disease in people with normal immune systems.) In addition, a jurisdiction must also have agreed to provide a 25 percent match and not impose eligibility requirements more restrictive than those in place on January 1, 2000. According to HRSA, grantees have provided funds or in-kind services to meet the matching requirement.

**Table 5: States That Received Title II Hold-harmless Funding from Severe Need Set-aside, Fiscal Year 2004**

| State | Hold-harmless amount |
|---|---:|
| Arkansas | $23,705 |
| Kansas | 22,168 |
| New Mexico | 55,171 |
| North Dakota | 1,820 |
| Oklahoma | 96,423 |
| Tennessee | 1,300,502 |
| Utah | 119,695 |
| Vermont | 128 |
| **Total** | **$1,619,612** |

Source: HRSA.

The total amount of Severe Need grant funds available in fiscal year 2004 to distribute among the eligible grantees was less than it would have been without the hold-harmless payments. However, in fiscal year 2004 not all 25 of the Title II grantees eligible for Severe Need grants made the match required to receive such grants. In future years, if all of the eligible Title II grantees make the match, and if there are also grantees that qualify to receive hold-harmless funds under this provision, grantees with severe need for ADAP funding would get less than the amounts they would otherwise receive.

## Funding Effect of Using HIV Case Counts Would Depend on Multiple Factors

CARE Act funding for Title I, Title II, and ADAP base grants would have shifted among grantees if HIV case counts had been used with ELCs, instead of ELCs alone, to allocate fiscal year 2004 formula grants. Our analyses indicate that up to 13 percent of funding would have shifted among grantees if HIV case counts and ELCs had been used to allocate the funds and if the hold-harmless and minimum-grant provisions we considered were maintained.[25] Some individual grantees would have had

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[25] While we are aware of differences in the HIV data across jurisdictions, we conducted this analysis in light of the CARE Act requirement that HIV case counts be used for the distribution of Title I and Title II formula grants not later than fiscal year 2007. We used two approaches to examine the potential effect of including HIV cases in addition to persons living with AIDS in fiscal year 2004 CARE Act funding formulas. See GAO-06-332, app. I for more details regarding our methodology.

changes that more than doubled their funding.[26] Grantees in the South and Midwest would generally have received more funding if HIV cases were used in funding formulas along with ELCs.[27] However, there would have been grantees that would have received increased funding and grantees that would have received decreased funding in every region of the country.

Funding changes in our model would have been larger without the hold-harmless and minimum-grant provisions that we included. Changes in CARE Act funding levels for Title I base grants, Title II base grants, and ADAP base grants caused by shifting to HIV cases and ELCs would be larger—up to 24 percent—if the current hold-harmless or minimum-grant amounts were not in effect.

One explanation for the changes in funding allocations when HIV cases and ELCs are used instead of only ELCs is the maturity of HIV case-reporting systems. Case-reporting systems need several years to become fully operational.[28] We found that those grantees that would receive increased funding from the use of HIV cases tend to be those with the oldest HIV case-reporting systems. Those grantees with the oldest reporting systems include 11 southern and 8 midwestern states whose HIV-reporting systems were implemented prior to 1995.

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[26] In our analyses, we considered the Title I hold-harmless provision and the Title II hold-harmless provisions that are funded by proportional reductions in Title II base grants and ADAP base grants. We did not include the Title II hold-harmless provision funded by amounts otherwise available for Severe Need grants.

[27] We classified states in accordance with the four U.S. Census Bureau regions and the jurisdictions that constitute each region. Because Puerto Rico is not included in any of these four regions, we excluded it from our regional analyses. Additional details on this analysis are available in GAO-06-332.

[28] IOM has reported that it could take from 18 months to several years after the implementation of an HIV-reporting system before there would be valid estimates of the number of people living with HIV. See Institute of Medicine of the National Academies, *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act* (Washington, D.C.: The National Academies Press, 2004).

Funding changes can also be linked to whether a jurisdiction has a name- or code-based system. CDC will only accept name-based case counts as no code-based system had met its quality criteria as of January 2006.[29] CDC does not accept the code-based data principally because methods have not been developed to make certain that a code-reported HIV case is only being counted once across all reporting jurisdictions.[30] As a result, if HIV case counts were used in funding formulas, HIV cases reported using codes rather than names would not be counted in distributing CARE Act funds. However, even if code-based data were incorporated into the CDC case counts, the age of the code-based systems could still be a factor since the code-based systems tend to be newer than the name-based systems. As of December 2005, 12 of the 13 code-based systems were implemented in 1999 or later, compared with 10 of the 39 name-based systems.[31] The effect of the maturity of the code-based systems could be increased if, as CDC believes, name-based systems can be executed with more complete coverage of cases in much less time than code-based systems. As a result, jurisdictions with code-based systems could find themselves with undercounts of HIV cases for longer periods of time than jurisdictions with name-based systems. Figure 2 shows the 39 jurisdictions where HIV case counts are accepted by CDC and the 13 jurisdictions where they are not accepted, as of December 2005.

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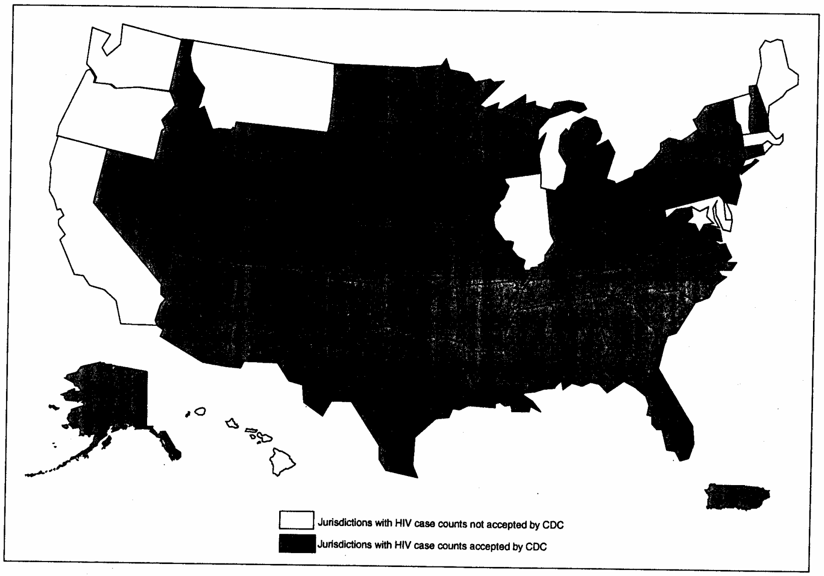
[29] CDC has established a set of performance standards for accepting case counts from HIV-reporting systems. These standards include that case reporting be complete (greater than or equal to 85 percent of cases are reported) and timely (greater than or equal to 66 percent of cases reported within 6 months of diagnosis) and that evaluation studies demonstrate that the approach must result in accurate case counts (less than or equal to 5 percent of reported cases are duplicates). CDC has determined that the only systems which have been evaluated that meet these standards use confidential, name-based reporting. In July 2005, CDC began recommending that all states and territories adopt confidential name-based surveillance systems to report HIV infections.

[30] CDC also has other concerns about code-based reporting. For example, code-based reporting places a greater burden on health care providers because submitted codes are frequently incomplete and require extensive follow-up with providers to resolve potential duplicate reports on the same person.

[31] Two of the 13 states, Illinois and Maine, established name-based HIV reporting in January 2006. Both states are in the process of having their HIV surveillance data certified by CDC and, once certified, their data will be accepted by CDC.

**Figure 2: CDC Acceptance of HIV Case Counts, December 2005**



Sources: CDC, IOM, Connecticut, Kentucky, and Philadelphia, Pennsylvania.

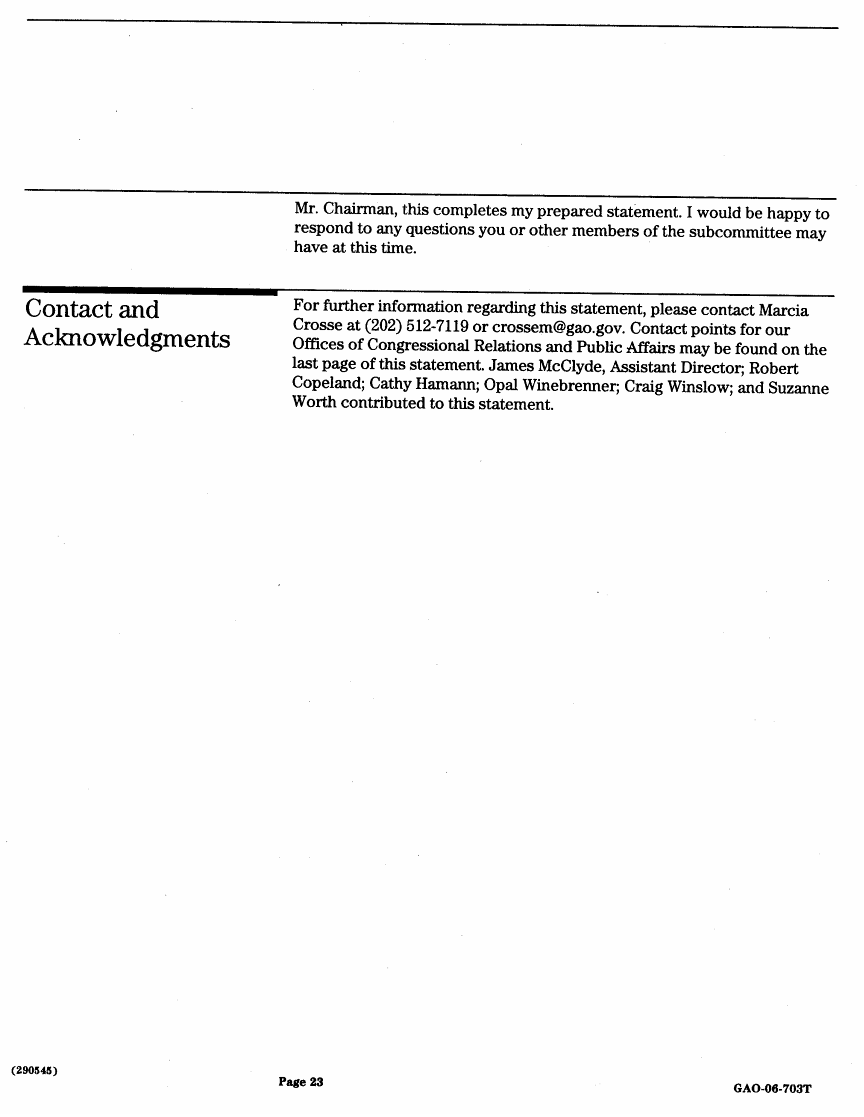
The use of HIV cases in CARE Act funding formulas could result in fluctuations in funding over time because of newly identified preexisting HIV cases. Grantees with more mature HIV-reporting systems have generally identified more of their HIV cases. Therefore, if HIV cases were used to distribute funding, these grantees would tend to receive more funds. As grantees with newer systems identify and report a higher percentage of their HIV cases, their proportion of the total number of ELCs and HIV cases in the country would increase and funding that had shifted away from states with newer HIV-reporting systems would shift back, creating potentially significant additional shifts in program funding.

## Concluding Observations

The funding provided under the CARE Act has filled important gaps in communities throughout the country, but as Congress reviews CARE Act programs, it is important to understand how much funding can vary across communities with comparable numbers of persons living with AIDS. In our report, we raised several matters for Congress to consider when reauthorizing the CARE Act. We reported in February 2006 that if Congress wishes CARE Act funding to more closely reflect the distribution of persons living with AIDS, and to more closely reflect the distribution of persons living with HIV/AIDS when HIV cases are incorporated into the funding formulas, it should take the following five actions:

- revising the funding formulas used to determine grantee eligibility and grant amounts using a measure of living AIDS cases that does not include deceased cases and reflects the longer lives of persons living with AIDS,
- eliminating the counting of cases in EMAs for Title I base grants and again for Title II base grants,
- modifying the hold-harmless provisions for Title I, Title II, and ADAP base grants to reduce the extent to which they prevent funding from shifting to areas where the epidemic has been increasing,
- modifying the Title I grandfather clause, which protects the eligibility of metropolitan areas that no longer meet the eligibility criteria, and
- eliminating the two-tiered structure of the Emerging Communities program.

We also reported that if Congress wishes to preserve funding for the ADAP Severe Need grants, it should revise the Title II hold-harmless provision that is funded with amounts set aside for ADAP Severe Need Grants. In commenting on our draft report HHS generally agreed with our identification of issues in the funding formulas.



Mr. Chairman, this completes my prepared statement. I would be happy to respond to any questions you or other members of the subcommittee may have at this time.

### Contact and Acknowledgments

For further information regarding this statement, please contact Marcia Crosse at (202) 512-7119 or crossem@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this statement. James McClyde, Assistant Director; Robert Copeland; Cathy Hamann; Opal Winebrenner; Craig Winslow; and Suzanne Worth contributed to this statement.

MR. DEAL. Well, thank you. Very interesting comments from all of you. There appear to be some issues that will probably divide our members of our subcommittee. Not necessarily along political lines, but maybe along geographical lines. So let me just jump in to some of those.

I assume, Ms. Crosse, that what you are recommending is that we go to a more equitable counting system that would eliminate some of the things that you have talked about, such as counting deceased cases in the cumulative totals. Would that perhaps equalize more appropriately in States that do not have DMAs? As I understand it, that gets you a double count on your statistical numbers. Am I generally correct on what you are recommending?

MS. CROSSE. Yes, Mr. Chairman, in general, we are suggesting that more appropriate recognition of the current epidemic's pattern should be considered in the distribution of funds and that some of the current provisions do not reflect where the current epidemic is spread across the country, and that while there needs to be consideration given to how to balance the needs of different jurisdictions, that jurisdictions with more recent spread of the disease currently receive substantially less funding per case than some of the jurisdictions that were the early focus of the disease.

MR. DEAL. Dr. Fenton, in that regard, is there any shortfall or any legitimate criticism from using the CDC surveillance data for making these kinds of determinations? What criticism, if any, would there be from using your surveillance data?

DR. FENTON. Thank you very much. The surveillance data that we have at the Centers for Disease Control and Prevention is specifically designed to assist us in tracking the evolution of the HIV and AIDS epidemic in the United States. This is a dynamic epidemic, and certainly as has been mentioned by Ms. Crosse, more recent changes in the epidemic have indicated that individuals of minority status and more women are affected by HIV. Therefore, it is very difficult for us to specifically state that our surveillance systems are going to be appropriate necessarily for informing formulas, per se, for the funding formulas.

MR. DEAL. Okay. Dr. Duke, very quickly, is there any concern on your part about using the CDC surveillance data as a basis for determining allocation of funding?

DR. DUKE. One of the principles that we put forth in looking at opportunities to serve the neediest first is the opportunity to develop a severity of need index, which would be a nationwide quantitative approach, which would allow us to inform our decisions about where the need is greatest in a way that we don't have now. So the severity of need index I think is an important element of getting to serving the neediest first.

MR. DEAL. Thank you. Mr. Waxman. I was just going to go down the line.

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

Dr. Duke, would you agree that in this reauthorization, although we certainly need to address the demands brought about by more recent changes in the epidemic, it is critical that we not destabilize the currently existing systems of care by shifting funds away from those systems?

DR. DUKE. I think that we have been very fortunate in this country that the Act has provided for the development of systems of care that are very important. One of the things that I think is critical in this reauthorization is that we all need to work together to recognize the need for both stability on the one hand, but also the need for equity for the patients on the other. I believe that in a deliberative process working together we can find that balance.

MR. WAXMAN. The Administration has proposed the establishment of a new set of core medical services. Under this proposal, grantees would be required to spend 75 percent of all their Ryan White funds on these core services. It has been difficult for stakeholders and Members of Congress to react to this principle with anything other than concern because the Administration has failed to provide any guidance on one, what exactly a core medical service might be, and two, why we might need a new definition under the Act. The Administration suggested only that a core medical service include basic primary medical care and medication needs of individuals with HIV/AIDS. It is a service that is clearly life-prolonging and essential to maintaining physical and mental health.

Based on the Administration's limited statements, I think we can safely assume that certain medical services would be included in the definition of core medical services. For instance, it is clear ADAP medications would be covered. It is less clear where the Administration stands on numerous services that we could all agree are life-prolonging and essential to maintaining physical and mental health. For example, would you agree that the following services that are undoubtedly life-prolonging and essential for many individuals should be considered core medical services: medical nutritional services, substance abuse treatment services, mental health services, and case management services?

DR. DUKE. As we look at the definitions of core medical services, we are aware that there are many definitions when you look at different articles across the list of publications. But you do find that there are certain common elements that arise in most lists. For example, you do find case management in most lists, you find support for substance abuse and mental health in most lists. What we are looking for as we work together to define this concept of core medical services is to try to find where the best balance is, and that is why--

MR. WAXMAN. Well, let me ask you specifically, would the concept of core medical services include medical nutritional services? Yes or no.

DR. DUKE. I, at this point, don't know the final answer on that. I think that is what we are in the process of deliberating.

MR. WAXMAN. How about substance abuse treatment services?

DR. DUKE. Many of the definitions include substance abuse and mental health services along with case management and medications and so forth. That is, I think, the process of deliberation that we are trying to come to a conclusion on that definition.

MR. WAXMAN. Thank you.

Mr. Chairman, my time is expired. I will have more on a second round.

MR. DEAL. I thank the gentleman. Dr. Burgess.

MR. BURGESS. Thank you, Mr. Chairman.

Dr. Fenton, if I could ask you, what would you estimate to be the number of people who are infected with HIV who are unaware of that infection?

DR. FENTON. It is currently estimated that there are between a million to 1.2 million individuals living with HIV in the United States, and approximately a quarter of these individuals, between 250,000 to 312,000 who are unaware of their HIV status.

MR. BURGESS. That obviously underscores the importance of testing.

Do you have any thoughts on the availability of a rapid test for HIV?

DR. FENTON. Yes, we are very much aware that rapid tests are actually available for HIV testing and we are, in fact, delighted with the President's initiative in the next financial year, which is seeking to invest additional funding to promote rapid testing in the United States. In fact, there are plans for an investment of $93 million into promoting rapid testing for HIV, with the explicit objective of ensuring that more individuals are aware of their HIV status. In this initiative, we are looking at promoting rapid testing, not only in community settings, but also in jails, as well as among injecting drug users.

MR. BURGESS. So it is the CDC's opinion that this would be a positive effect on controlling the spread of disease?

DR. FENTON. Absolutely. We estimate that a substantial portion of new HIV diagnoses are actually transmitted by individuals who are unaware of their HIV status. We also know from published literature that individuals who are aware of their HIV status are more likely to adopt safer sexual behaviors, thereby reducing the risk of HIV transmission. Therefore, any efforts to increase HIV diagnosis among the undiagnosed are welcomed.

MR. BURGESS. You mentioned some of them, but do you think there is a role for this rapid testing in settings such as emergency rooms, labor and delivery rooms, maternity clinics?

DR. FENTON. Absolutely. I think that all medical settings that we can avail ourselves of promoting HIV testing should be taken advantage of, and indeed, CDC is proposing new recommendations to advance HIV testing in both clinical as well as non-clinical settings. Later this year, we should be publishing revised recommendations for HIV testing in clinical settings in which we actively encourage a range of clinical settings to offer HIV testing.

MR. BURGESS. How does the testing itself fit into the overall Ryan White Act as you understand it?

DR. FENTON. To the best of my knowledge, I am not able to comment on the direct link between testing and the Ryan White CARE Act; however, clearly any initiative to increase HIV testing will have an impact on the number of individuals who are diagnosed with HIV and subsequent individuals who will be seeking care for their HIV disease.

MR. BURGESS. Thank you, Mr. Chairman. My time has expired. Are we going to have a second round?

MR. DEAL. If time permits, yes we probably will have a second round.

Mr. Pallone, you are recognized.

MR. PALLONE. Mr. Chairman, as I mentioned in my opening statement, I am very concerned about some of the recommendations that the Administration has proposed for reauthorization of the CARE Act, and specifically of concern is the recommendation of eliminating the double counting. My concern comes from the fact that the Administration has been very vague in talking about their principles and has not really provided any level of detail about their recommendations, so that is why I am glad that Dr. Duke is here today.

Correct me if I am wrong, but is the Administration proposing to eliminate the double counting in Ryan White by allocating all Title II base funds solely on the estimated living AIDS cases in the State that are located outside of Title I EMAs? That is my basic question, because if that is true, you know, I would like you to follow up with the impact that that proposal would have on States that are likely to have the highest prevalence of HIV/AIDS. And if you want to, I could explain what I am concerned about with regard to New Jersey if you like, Dr. Duke.

DR. DUKE. Thank you. That would be helpful.

MR. PALLONE. Well, in New Jersey, we have five EMAs according to the GAO report that was put out several months ago. Nearly 85 percent of estimated living AIDS cases in New Jersey reside in an EMA. Now, I have a chart that was developed by a group of our State's AIDS directors, and they say that New Jersey would stand to lose 24 percent of its Title II based grant. It could probably even be more than that. So my concern is the Administration's intention. Are they going to, because of this double counting elimination, would they eliminate 24 percent of the funding from New Jersey which is fifth in terms of reported HIV/AIDS cases.

DR. DUKE. As a native of New Jersey, I am aware of the superb job that New Jersey has done.

I think that another way of addressing this is to look at the approach that we have taken to try and address the neediest first and to ensure that we provide lifesaving and life-extending services. And that is linked to this concept of a severity of need index to replace the kind of approach we have taken in allocating funds in Titles I and II. The severity of need index that would be geared toward the provision of core medical services would provide a nationwide quantitative approach to the allocation of funds, and would then allow us to allocate the funds in both Titles I and II in a way that I think would be fair to the patients in the States across the Nation. I think that is what we are trying to do is to work with the Congress to find that way of providing a focus on the patients but gets the funding to those patients, wherever they are.

So I don't see it in terms of punishing one jurisdiction or favoring a jurisdiction--

MR. PALLONE. Well, let me ask you this. Have you estimated the impact on States with EMAs? In other words, I mean I have no information. No information has been shared with Congress about that. I mean, could you provide that kind of analysis to us about what this eliminating double counting, what the impact would be on States with EMAs?

DR. DUKE. Well, at this point to develop the severity of need index would be our first order of business, which would then be crucial to that concept. We aren't there yet in the sense of developing a nationwide quantitative approach to severity of need. So we are in a transition phase from the existing approach to the really complex formulas in Titles I and II and the complex interactions that Ms. Crosse outlined in the GAO report. It is an incredibly complex set of interactions that have happened as a result of the way that the Act has grown up.

MR. PALLONE. But how are you proposing to eliminate the double counting? I mean, how are you proposing to do that?

DR. DUKE. Well, one of the ways would be first to get to the severity of needs index, and then to work on the idea that we would provide that as the crucial element which would be the key to awarding funds in Title I and also in Title II.

MR. PALLONE. I just want you to understand, I mean, I am just concerned about the impact on States that have the highest prevalence, and it is still not clear to me, you know, what this is all going to mean.

DR. DUKE. My sense is that when you have high prevalence and high incidence, the need to get to a standard that recognizes both the incidence in the sense of new cases, plus the existing cases is where we need to go, while we are also in the process recognizing poverty and other elements to produce this--an approach that allows us to recognize cases regardless of where they are.

MR. PALLONE. Thank you.

MR. DEAL. Ms. Bono, you are recognized for questions.

MS. BONO. Thank you, Mr. Chairman. I am happy to follow after my colleague, Mr. Pallone, because I think we are on the same line of questioning, and for me, that means some confusion already as to the funding formulas.

Double counting, is that the same thing that we are talking about with 80/20 provision, or is this entirely separate?

DR. DUKE. The double counting, as Ms. Crosse indicated in her opening statement, gets at the issue of States that have EMAs get funding from the amount of money that is provided in Title I. So that $604 million gets allocated to the existing 51 EMAs. Then in Title II, the allocation to the States then is allocated to the States based on the 80/20.

MS. BONO. Okay. So based on the GAO report on Title I and II funds, there was in year 14 an overall allocation of $4,783 per estimated living AIDS case with a range from $3,338 to on the high end, $7,275 per estimated living AIDS case. My staff has taken a State and projected the impact of eliminating the 80/20 provision, and based upon that data given in the GAO report for Title I and Title II, eliminating that provision actually increases the disparities in funding. The overall allocation remains at $4,783 per estimated living AIDS case or ELC, but the range increases dramatically from a minimum of $3,511 to a maximum of $13,780. Is my staff the only one who is getting this sort of math?

DR. DUKE. If I might, I could defer that question to Ms. Crosse who has that report with her.

MS. BONO. Okay, thank you.

DR. DUKE. Thank you.

MS. CROSSE. I am afraid we don’t have the particulars of the kind of analysis that you are looking at. When we did our analysis, we examined the funding that was provided to those States that do have EMAs. We did not do an analysis that eliminated the current provisions of the CARE Act to examine what occurred if any double counting was completely eliminated. That was not part of the analysis that we carried out. We examined, for example, the States that had relatively comparable numbers of cases could receive, under the current provisions, quite different funding levels if they had an EMA or if they did not. So for example, Connecticut and South Carolina that have relatively equal numbers of cases used in the formulas do not receive equal levels of funding, because Connecticut has EMAs and South Carolina does not.

But we did not carry out an examination of what would happen if double counting were eliminated.

MS. BONO. But you are proposing that?

MS. CROSSE. We are suggesting that the Congress needs to review the impact of that double counting as it revises the CARE Act. We did not specifically recommend that it be totally eliminated.

MS. BONO. Okay. So we definitely have our battles ahead of us from California.

Turning really fast to ADAP, and Dr. Duke, again, how many ADAPs currently have waiting lists for drugs?

DR. DUKE. The last report I saw was toward the end of March, and I believe it was 13 States.

MS. BONO. And do those waiting lists represent all individuals not being treated?

DR. DUKE. They represent the individuals who have not been able to access the formulary that the State provides.

MS. BONO. So is the President in his principle for development of a Federal list of core medication, does that address the ADAP waiting list issue?

DR. DUKE. There are several features that address the waiting list issue. One is in the current '07 budget. There is a $70 million request for an increase that would address the waiting list and would address the possibility that more testing would bring more people into care, and therefore the $70 million is designed to help address those new cases as well.

MS. BONO. Terrific. Thank you, Mr. Chairman.

MR. DEAL. Thank you. Ms. Capps, you are recognized for questions.

MS. CAPPS. Thank you, Mr. Chairman.

In my opening remarks, in mentioning those of us who are from California, Mr. Waxman, Ms. Eshoo, and myself, I hadn't seen Ms. Bono come in, and I think it is very important that you recognize that there is tremendous bipartisan interest and support for the reauthorization of the CARE Act. And to underscore the fact our staff has been looking at numbers in a bipartisan way, we estimate that if this change in numbering should go into effect, and you did put the burden, and it is our responsibility on us that 62 percent of reduced funds would come to California. That is a cut and is a huge change in the kind of support that we have come to depend upon from the Ryan Act.

I want to turn my time to you, Dr. Fenton. According to current law, by October 1, 2006, all data accepted by CDC has to be accurate and reliable. CDC has stated that an accurate and reliable system is a name-based data collection; however, some jurisdictions like California that do not have a mature name-based system will be caught here. They may face the loss of Ryan White CARE Act funds for their HIV and AIDS communities. Is the CDC going to work with State AIDS offices to develop a proxy for States to submit HIV/AIDS counts so that their Ryan White programs are not drastically hindered?

DR. FENTON. Thank you very much.

May I just begin by saying that we are delighted and indeed very, very pleased that California has, in fact, shifted and now has begun progress towards name-based reporting. And yes, your concerns are absolutely on target.

One of the key issues that CDC has been doing is working with States which have recently transitioned to ensure that this transition process to name-based reporting goes as quickly and as efficiently as possible.

MS. CAPPS. Let me get real specific. Have you had discussions with the almost 20 State AIDS offices in this situation to discuss possible solutions? Can I go to them and see that they have a plan that you are working out with them for this interim basis?

DR. FENTON. I have been reassured that yes, you can. All these States have a comprehensive transition plan.

MS. CAPPS. Thank you.

If the current formula uses estimated rather than actual living AIDS cases, according to discussions with the California State Office of AIDS, using estimated cases undercounts my home State's true disease burden by approximately 30 percent. Has CDC considered using actual living AIDS cases in a proxy formula?

DR. FENTON. Unfortunately, it is the best data that we have using reported HIV cases. It is not within our purview to look at formulary for proxy cases.

MS. CAPPS. So then if you are going to continue using this system, we will estimate that there are 30 percent more cases actually in California than you are counting in this way. Is there some other proxy system that you would be willing to consider in the goal of getting an accurate count?

DR. FENTON. I am once again very guided by the law on this, and the regulations which have been stated regarding how the funding formulas are actually enacted. I would like to reiterate that we are committed to working with California to ensure that the transition to name-based HIV reporting is done as quickly and as efficiently as possible.

MS. CAPPS. So if there is no law, then does that mean that you are looking to us for guidance in this interim state, to develop a proxy counting method that we can use until we have the mature name-based system in place, which we hope we can do, that will accurately reflect the actual number of people living with HIV and AIDS in our State?

I have 20 seconds left, and Ms. Crosse, I just wanted to ask, for example, California, which is ranked 18th on the list of RWCA allocations per ELC, receives less money per ELC than States like South Dakota, Alaska, Montana, and Wyoming. Have you completed an analysis of funding in all parts of the Act that provide core medical services to people with AIDS?

MS. CROSSE. Ma'am, our review focused on the Title I and the Title II funding. The ranking that you referred to, I just became aware of yesterday. Those States, the top of the list that you mentioned, are those that qualified for minimum grant funding to be able to mount any sort of a program at all. So for example, Montana receives a minimum grant amount of $500,000 even though it has an estimated living AIDS cases of fewer than 150. And so its relative ranking in the per case funding is quite high because it has that minimum grant amount provided to it. We have not looked at the non-formula based funding amounts that are awarded through competitive grants. Some of those funding amounts are not for services to HIV/AIDS patients and their families. They are for research or for training of healthcare workers, which are very important functions, but are not part of the services that are provided to patients. Some of them are for services, some of the Title III and Title IV funds, for example, but those funds are on the basis of competitive grants, not to States and jurisdictions to control the distribution, but are based on successful grant writing by different entities throughout the country.

MS. CAPPS. Thank you. I hope we will conclude all of this data as we look at our reauthorization. Thank you.

MR. DEAL. Mr. Pitts, you are recognized for questions.

MR. PITTS. Thank you, Mr. Chairman.

Dr. Duke, are there any caps on administrative costs for grantees under current law?

DR. DUKE. Yes, sir, there are. There are a variety of caps as you go across the Titles, there are different caps in Titles I, II, and III. There is no cap in Title IV, and those vary from generally 5 percent to 15 percent.

MR. PITTS. You testified that States will be encouraged to adopt prevention strategies upon receipt of their Ryan White allocations. Do you have the current authority to require States to demonstrate this as a condition of their grant approval?

DR. DUKE. We encourage prevention as a matter of the work we do today. We believe that part of our role is to ensure that we take steps to limit the spread of the epidemic. So we take prevention steps now, we are very consistent with our sister agency's prevention initiative, and so prevention is part of what we do now. What we hope to accomplish in the future is more use of rapid testing to identify those persons who do not know their status now or who know their status and who aren't in care to get them into care, not only for their own longevity and quality of life, but also to prevent the spread of disease in the community.

MR. PITTS. Isn't it true that while there are eligibility requirements to receive EMA funding, 29 of the 51 EMAs do not actually meet this criteria today?

DR. DUKE. At this point, 29 of the 51 do not.

MR. PITTS. How do the Title IV grantees receive funds from HRSA, and how is that different from other grantees under the other Titles?

DR. DUKE. Titles III and IV are grants to community-based organizations, and they are competitive grants, that is to say, we provide guidance about what we are hoping to do in prevention, early intervention, capacity building, or services to families of those with AIDS, and we provide that guidance as a way of opening competition to serve the needs that we identify in that guidance, those competitive applications come in to us. They are reviewed by an objective review committee, and those funds then are awarded for services to the community by community groups.

MR. PITTS. Ms. Crosse, the hold harmless provisions were added in the 1996 reauthorization of the CARE Act, and you testified that they were added to accommodate the large shifts of funding from jurisdictions with a longer history of the disease than other jurisdictions that would have occurred. Can you tell us which EMAs and States would have otherwise experienced a large shift of funds from their jurisdictions at that time?

MS. CROSSE. Yes, sir. In 1996, the way in which cases were counted was changed from a cumulative count from the beginning of the epidemic to an estimated living cases, and that had the potential to impact jurisdictions. At that time, only one jurisdiction, San Francisco, was held harmless for its funding from under the Title I provision. At the current time, there are larger number of jurisdictions that are protected by the hold harmless provision, however, the bulk of that funding is still for San Francisco. Kansas City is the next largest jurisdiction EMA that receives hold harmless funding. But about 94 percent of the hold harmless funding goes to San Francisco under Title I.

MR. PITTS. And you stated that HHS generally agreed with GAO's identification of issues in the funding formulas. Did HHS disagree with any issues?

MS. CROSSE. No, sir, they did not disagree with any of the matters that we raised for consideration by the Congress as it considers the reauthorization of Ryan White.

MR. PITTS. Thank you, Mr. Chairman.

MR. DEAL. Thank you. Mr. Towns, you are recognized for questions.

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

Let me just also join some of my colleagues who have indicated about the possible loss. New York State would probably lose 60 percent of its funding, probably a little more than $23 million, which is something that we are extremely concerned about. I just want to make that point. But also again, Mr. Chairman, I really think it is important that we have this kind of discussion to be able to move forward.

Let me ask you, Dr. Duke. I notice that the Secretary has the ability to change five percent of the funding, and of course, at any point in time. What would precipitate this action, changing from one category to another? What would precipitate it?

DR. DUKE. Sir, the current structure of the Act, because it is based on a series of formulas, can produce some inflexibilities that make administration of the Act by the requirements of the law go where perhaps the Congress didn't intend it to go in the sense that because of the various provisions, some States can't actually use the money that we provide, either because they can't make the match or because their caseload is significantly lower. But we have at this point no authority to take that money and reallocate it to other jurisdictions that might need that money, so indeed, it returns to the treasury.

MR. TOWNS. I am not quite sure. If you discovered that there was a crisis in a given area, could you do it, for instance, that all of a sudden you discover that something is going on that you had no knowledge of, then could you, in turn, allocate it for that?

DR. DUKE. No, sir. The requirements of the law require us to allocate money based on the formulas, and so we have some inflexibilities which we are attempting to, in our principles and also in the budget request, to get the kind of flexibility that would allow us to respond to some unforeseen situation. The example I might use is a few years ago, we became aware of the rise of waiting lists in States, and the President announced a desire to meet those emergencies with the waiting lists, and that required a very complex set of reprogrammings and Congressional action, and took quite some time to do. And so that really was one of the things that triggered us to think that perhaps we needed to build in some flexibilities or request some flexibilities in this reauthorization that might allow us to respond to situations in the future.

MR. TOWNS. What about supplemental grants?

DR. DUKE. The supplemental grants operate on the basis of a formula also in Title II, so we don't, again, have the flexibility to move those monies to a particular area of new concern or to a crisis. We don't have that flexibility. The law requires us to allocate funds based on the formula.

MR. TOWNS. Would you like to have that flexibility?

DR. DUKE. Yes, sir, we would. We would like to have flexibility that would allow us to respond, and that is the request to allow the Secretary to shift funds across the Titles, five percent of the funds from any one Title to any other Title to respond to emergencies.

MR. TOWNS. Thank you.

Ms. Crosse, why hasn't there been a full GAO report on Ryan White including Titles III, IV, and Part F?

MS. CROSSE. We were guided by the requests that we received from Members of Congress who specifically asked for us to review the funding formulas in Title I and Title II, but in addition, that accounts for the bulk of the funding. That is the funding that is linked to specific counts of AIDS cases. The funding under other Titles, while it can be based on that in a grant application, is not linked to the prevalence of the disease in a particular community, but rather is based on the types of services that the grantee is proposing that they would provide and their successful competitive grant application. So it is only the Title I and Title II funding that automatically goes to jurisdictions based on the prevalence of the disease as encoded in those formulas. So we felt and were requested specifically to look at those components that account for about 80 percent of the Ryan White monies.

MR. TOWNS. All right, thank you.

Dr. Duke again, we know the statistics demonstrate that racial minorities are more likely to be victims of the AIDS epidemic. How effective has the minority AIDS initiative been in increasing access to prevention and care for racial minorities with HIV?

DR. DUKE. The opportunity to use those funds in a targeted way has been very useful to us. If we look at the populations we serve, we note that we serve about two-thirds of our patients are minorities. A third of them are women. And so we have been able to use those funds very well, and we appreciate having those funds.

MR. TOWNS. Do you think it needs to be strengthened?

DR. DUKE. We have been very pleased with the allocations we have.

MR. TOWNS. So you don't think it needs to be strengthened?

DR. DUKE. We believe they are very strong and we are grateful for them. We recognize the wisdom of the Congress in the allocation of those funds.

MR. TOWNS. Let me put it this way. We have a problem, as you know. What can we do to assist you in bringing about a solution to this problem?

DR. DUKE. We believe that the principles we proposed for the reauthorization will help us address those problems because we believe that the changes we propose will allow us to target our resources more to where the AIDS epidemic has gone, and therefore, we can address the needs of minority populations all across the country.

MR. TOWNS. Let me--I gather this morning--I mean, this is sort of a dialogue we had in here this morning. There are some people that are dying every day. I think we need to do everything that we can to prevent that, and that is the reason why we don't want to have a very open discussion here, because I think that we can do a lot better than what we are doing, and in order to get there, we have to have an open discussion about it and you know, I am not challenging you in any kind of way. I am on your team, and I want you to know that, but I think you have to be open and honest with each other in order to get to where we need to go, and that is the point I am going to make, Mr. Chairman.

DR. DUKE. Bless your heart. I couldn't agree with you more, sir. That is what we hope to have is a dialogue with you so that we come to a reauthorization that we know we all want that will advance the needs of our patients, and I appreciate being here to work with you and to have that dialogue.

MR. DEAL. The gentleman's time has expired.

Ms. Eshoo, you are recognized for questions.

MS. ESHOO. Thank you, Mr. Chairman, and thank you to the witnesses for their responses.

I want to walk through this--maybe this is a Ryan White CARE Act 101. I think that when we go through these hearings, it is in many ways a refresher course for the members as well.

When you go through the Titles, it is important to remember that Titles I and II deal with the EMAs, the eligible metropolitan areas. Titles III and IV pertain to States that don't have the EMAs. They work off of, as I understand it, the ELCs, the estimated living cases. Now, the GAO report, in my view, looked narrowly at the funding mechanisms for only Title I and II, which seems to be the heart of the discussion here and the responses Members have made, both in terms of their opening statements and their lines of questioning. The GAO report did not consider funding for Titles III and IV, so they have left out much of the picture. I mean, it was targeted, it was narrow, and it is interesting what they have done, but I think it is skewed because when you look at what is left out, the GAO looked at, obviously, the major cities. And that is where the heavy caseload is. That is where most of the AIDS cases are.

Now, as far as I am concerned, I don't want any area of the country left out. I mean, whether someone lives in South Dakota or in Georgia or in San Francisco, we have a collective obligation to take care of our people. But it is very interesting to look at the ranking in descending order by total award per estimated living AIDS case and the monies that flow. Those States that don't have, again, the EMAs but are funded through the ELCs, at the top of the list is South Dakota. Mr. Chairman, your State, Georgia, the total award is $66,540,052. The minimum award, $11,226.

So I think what I would like to do is to enter this report by the Communities Advocating Emergency AIDS Relief into the record, because this repot tells the other half of the story. In fact, if we are only going to consider Titles I and II and dismantle funding that is contained in that, which I think picks on the larger areas in the country and really causes the upset that several Members from both sides of the aisle have spoken about, we really have to take a look at and appreciate what other States are getting through another set of dollars that flow through what are known as the ELCs, and they are not insignificant funds, which I am pleased to highlight.

I don't think I have a question. I think it is important to get this into the record, and now, for members that represent these States, South Dakota, Alaska, Montana, these are the ones that are at the top. South Dakota, Alaska, Montana, Idaho, Wyoming, Vermont, Massachusetts, North Dakota, Colorado, Missouri, Pennsylvania, Washington, Maine, Rhode Island, Illinois, New Mexico, California, Iowa, Minnesota, I mean, these are the States that are, when you look at the funding, it really tells the other part of the story. So my point is, why are we picking on the larger cities that have the kind of funding that we have examined here in Titles I and II, with the suggestion that it is needed because other places in the country are really suffering as a result of the funding that they get? It is not the story, it is not the complete picture.

We need to enlarge on this and I think broaden the discussion, Mr. Chairman. We need to be talking about funding of the Titles across the board. I, again, appreciate the fact of what GAO did, but understand that what GAO did, it was directed by some Members of Congress to only examine those two Titles and the funding that flows from them. So it is not the complete picture. And I think that if we only limit ourselves to that, that we are going to be doing damage. We are going to do severe damage, and I don't think that that is the intention of the committee at all.

Now, if anyone on the panel wants to comment on what I have just said, I would welcome it, but you have your constraints from where you come from. I can tell by the answers. And I appreciate your professionalism, but so if anybody wants to weigh in on this, do, but I think all the members of the committee need to broaden their thinking on this thing.

MS. CROSSE. Ma'am, I will respond. We examined Title I, which is all of the funding for the eligible metropolitan areas--

MS. ESHOO. Right.

MS. CROSSE. --Title II, which is the funding for the States and territories.

MS. ESHOO. Right.

MS. CROSSE. But those are the funds that are distributed through the formulas using the ELCs. All of the funding that is distributed on the basis of ELCs is distributed under Titles I and II that we examined.

MS. ESHOO. I understand that.

MS. CROSSE. Titles III, IV, and other special provisions do not use case-based distributions of funding.

MS. ESHOO. Yes, but I want to reclaim my time. My point here is that there seems to be, at least in my view, it may just be me, that there is a suggestion here that if you don't come under these funding formulas and if there is a grab, so to speak, by larger cities in other areas, that other places in our country are suffering from it.

When you look at the funding here, that is not the case. There is excellent, which I am pleased to point out, funding for these other areas. So, this I think goes directly to this whole issue of the principles and how we need to shift the money around. I don't think we do, because it seems to me that there is excellent funding for other States, and the Chairman's State is kind of right in the middle here, but boy, when they get these grants, it is taking good care of people.

So, Mr. Chairman, I think we need to talk about the other Titles as well, and I would like to ask unanimous consent that this report be placed in the record.

MR. DEAL. Without objection.

[The information follows:]

COMMUNITIES ADVOCATING
EMERGENCY AIDS RELIEF
**CAEAR**
COALITION

# Comprehensive Analysis of All Ryan White CARE Act Programs Shows Greater Funding Equity Among States/Territories

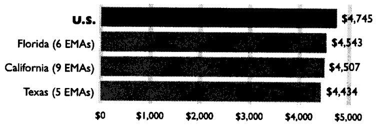
## Data Show Title I States Have No Significant Funding Advantage

An analysis of all Ryan White CARE Act funding to states/territories as compared to the number of people living with AIDS in each jurisdiction finds remarkable consistency across the country. The data are in marked contrast to partial analyses of CARE Act funding, which have created the misperception among some that states with Title I Eligible Metropolitan Areas (EMAs) are unfairly advantaged in CARE Act funding and that the South is far below other regions in its funding per person living with AIDS.

### The data show:

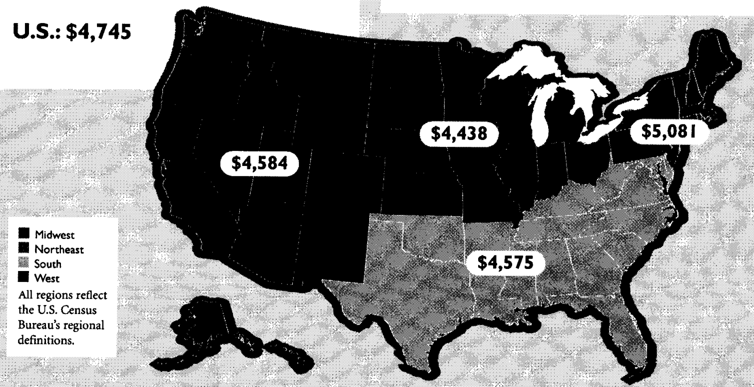
- **Of the ten states/territories with the highest funding per person living with AIDS, only three receive Title I funds.**

- **States with the most Title I EMAs receive funding per person living with AIDS at a rate below the national funding rate.**



- **Funding per person living with AIDS in each of the four regions of the U.S. is within $350 of the national funding rate.**

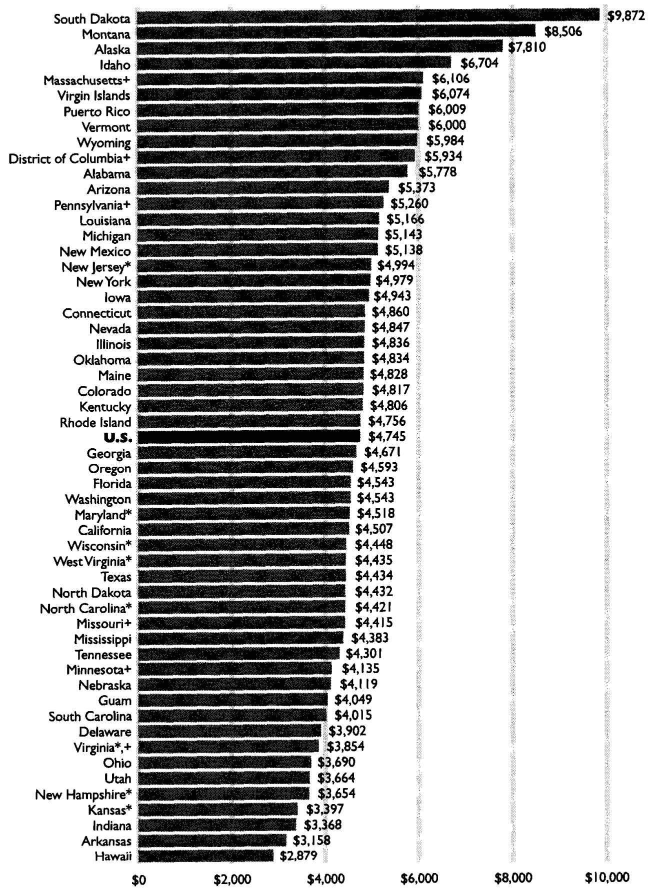
**U.S.: $4,745**



All regions reflect the U.S. Census Bureau's regional definitions.

Source: The data used to prepare these charts was downloaded from the Kaiser Family Foundation's State Health Facts website (www.statehealthfacts.org).

## Ryan White CARE Act Funding Per Person Living with AIDS All Titles and Components



Source: The data used to prepare this chart was downloaded from the Kaiser Family Foundation's State Health Facts website (www.statehealthfacts.org).

* This state received additional CARE Act funds from a Title I EMA centered outside the state and those funds are not reflected in this calculation.

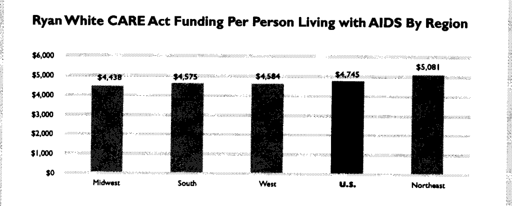
\+ A portion of this state's Title I EMA funds included in this calculation were used to provide services for people living with HIV/AIDS in a jurisdiction(s) located in an adjacent state(s) that is a part of this state or territory's Title I EMA.

# Key Facts about Ryan White CARE Act Funding Per Person Living with AIDS

- In 2004, the U.S. distributed $4,745 in Ryan White CARE Act funds for each person living with AIDS.[1]

## Comparison of Title I and non-Title I States and Territories

- The CARE Act funding per person living with AIDS for states/territories that are home to a Title I EMA is $4,799.[2]
- The CARE Act funding per person living with AIDS for states and territories that are not home to a Title I EMA is $4,356.[2]
- The four states with the highest funding per person living with AIDS are lower prevalence, non-Title I states with high enough caseloads to receive a guaranteed Title II base award of $500,000. (Note: some states with fewer cases receive a minimum Title II award of $200,000.)
- In 54% of the Title I states the funding per person living with AIDS is above the national funding rate, as compared to 47% of non-Title I states.


Ryan White CARE Act Funding Per Person Living with AIDS By Region

All regions reflect the U.S. Census Bureau's regional definitions. Some calculations of CARE Act funding in the South have excluded Delaware and Maryland, which are included in the Census Bureau's list. With those states taken out of the equation, the per person living with AIDS funding in the South rises to $4588.

Source: The data used to prepare this chart was downloaded from the Kaiser Family Foundation's State Health Facts website (www.statehealthfacts.org).

## Funding by Region

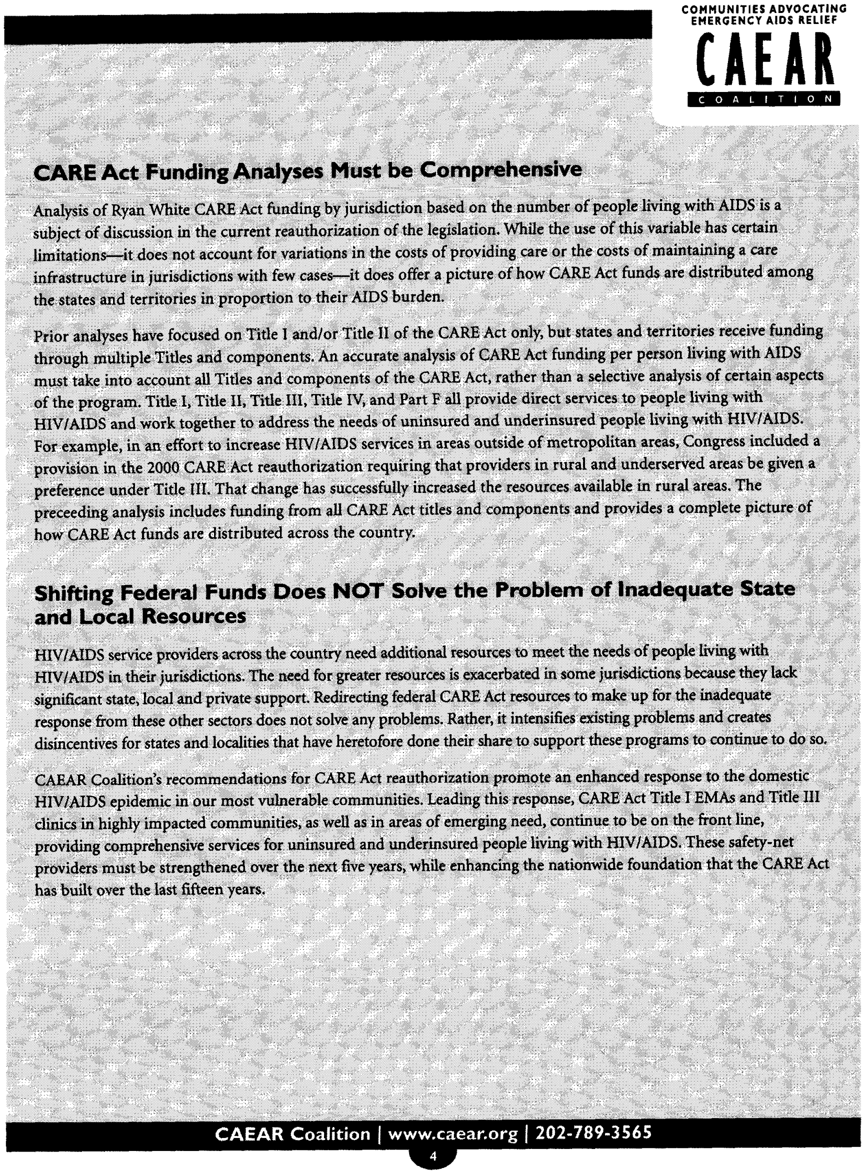
- The four states with the highest funding per person living with AIDS are in the West: South Dakota, Montana, Alaska, and Idaho. The top ten includes five Western states, two Northeastern states, and one Southern state/territory plus two territories.
- Alabama is the Southern state with the highest funding per person living with AIDS. Alabama, with no Title I EMA, receives more funding per person living with AIDS than 21 of the 24 states/territories that are home to one or more Title I EMAs.
- The Midwest has the lowest percentage (33%) of states above the national funding rate.

**Notes**

The state calculations are based on the total amount of FY2004 CARE Act funds that each state received divided by the number of people living with AIDS in that state at the end of 2004. Averages for groups of states are based on the total FY2004 CARE Act funds that those states received divided by the total number of people living with AIDS in those states at the end of 2004.

[1] This number reflects the FY2004 CARE Act funds distributed to the 50 states, the District of Columbia, Guam, Puerto Rico, and the Virgin Islands divided by the total number of people with living with AIDS in those jurisdictions at the end of 2004.

[2] The analysis of Title I funds does not reflect the distribution of Title I funds to EMA components outside of the state or territory where the central EMA jurisdiction is headquartered. For example all of the Title I funds for the Washington DC EMA are credited to the District of Columbia even though some of that funding is directed to counties in Virginia, Maryland, and West Virginia that are a part of the EMA. Thus, the funding rate for Title I states includes funds that flow to some non-Title I states and the funding rate for non-Title I states does not include Title I funds that flow into some of those states.



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## CARE Act Funding Analyses Must be Comprehensive

Analysis of Ryan White CARE Act funding by jurisdiction based on the number of people living with AIDS is a subject of discussion in the current reauthorization of the legislation. While the use of this variable has certain limitations—it does not account for variations in the costs of providing care or the costs of maintaining a care infrastructure in jurisdictions with few cases—it does offer a picture of how CARE Act funds are distributed among the states and territories in proportion to their AIDS burden.

Prior analyses have focused on Title I and/or Title II of the CARE Act only, but states and territories receive funding through multiple Titles and components. An accurate analysis of CARE Act funding per person living with AIDS must take into account all Titles and components of the CARE Act, rather than a selective analysis of certain aspects of the program. Title I, Title II, Title III, Title IV, and Part F all provide direct services to people living with HIV/AIDS and work together to address the needs of uninsured and underinsured people living with HIV/AIDS. For example, in an effort to increase HIV/AIDS services in areas outside of metropolitan areas, Congress included a provision in the 2000 CARE Act reauthorization requiring that providers in rural and underserved areas be given a preference under Title III. That change has successfully increased the resources available in rural areas. The preceeding analysis includes funding from all CARE Act titles and components and provides a complete picture of how CARE Act funds are distributed across the country.

## Shifting Federal Funds Does NOT Solve the Problem of Inadequate State and Local Resources

HIV/AIDS service providers across the country need additional resources to meet the needs of people living with HIV/AIDS in their jurisdictions. The need for greater resources is exacerbated in some jurisdictions because they lack significant state, local and private support. Redirecting federal CARE Act resources to make up for the inadequate response from these other sectors does not solve any problems. Rather, it intensifies existing problems and creates disincentives for states and localities that have heretofore done their share to support these programs to continue to do so.

CAEAR Coalition's recommendations for CARE Act reauthorization promote an enhanced response to the domestic HIV/AIDS epidemic in our most vulnerable communities. Leading this response, CARE Act Title I EMAs and Title III clinics in highly impacted communities, as well as in areas of emerging need, continue to be on the front line, providing comprehensive services for uninsured and underinsured people living with HIV/AIDS. These safety-net providers must be strengthened over the next five years, while enhancing the nationwide foundation that the CARE Act has built over the last fifteen years.

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MR. DEAL. The gentlelady's time has expired.

Mr. Shimkus is recognized for questions.

MR. SHIMKUS. Thank you, Mr. Chairman.

Ms. Crosse, can you just go over those Titles one more time? You were unable to finish and I would like to hear the rest. Just start with Title I again.

MS. CROSSE. Yes. Title I is the grants to the eligible metropolitan areas, the cities that have had a cumulative AIDS case count of over

2,000 in the past five years or who are grandfathered in because at one time they met the criteria. Title II is grants to the States and territories. Those include the funds for State programs for areas outside of the eligible metropolitan areas, and for the AIDS Drug Assistance Programs. Title III is a competitive grant program, early intervention services, capacity, development, and planning grants, and those go to primary care providers, including health centers, city and county health departments, and outpatient medical centers. Title IV is services for women, infants, children, youth, and their affected family members. That also is a competitive grant process. Those grants are awarded to healthcare facilities, public health agencies, and community-based organizations that serve the target populations. In addition, there are funds that I believe are included in the figures that Representative Eshoo refers to under special projects of national significance that are awarded competitively to university and community clinics, evaluation centers, local and State health departments, community-based organizations, and nonprofit agencies to carry out the development of innovative models of delivery of care. And there are 15 national and regional centers for AIDS education and training of healthcare workers; those funds are also included in her accounting. That is to educate healthcare workers on how best to treat patients with HIV and AIDS. And there are dental programs that are provided, both for education of dental care providers, and for the provision of services to HIV and AIDS patients.

MR. SHIMKUS. And we just had the dentists here in town this week talking about some of those provisions, and I appreciate that.

I am going to turn to Dr. Duke, but before I do that, I want to relate a story. I have been focusing a lot this month on Medicare D issues, and there are 19 days left for signup, but I have an HIV constituent who is now saving $15,000 a year by being able to access the prescription drug benefit. It has changed his ability to survive in the world today and he is very grateful. That came on the heels of--and an elderly lady who now, for the first time in years, is able to afford automobile insurance and she is back driving where she had to stop paying automobile insurance because of her prescription drug costs. So I know it is not your area, but it does talk about the ability to access prescription drugs, and not a perfect situation, but those people are accessing it. And it is just important for me to use the bully pulpit at this time to encourage people to make sure that they sign up on time to access this if they can.

Dr. Duke, I have got a question. I represent southern Illinois, a large rural district, but I actually border three States. I border the State of Missouri, I border the State of Indiana, I border the State of Kentucky. And on the AIDS Drug Assistance Program, how many AIDS Drug Assistance Programs currently have waiting lists for drugs?

DR. DUKE. The most recent report I saw was right around the end of March, and I believe there were 13 States on that list at that time.

MR. SHIMKUS. Do these waiting lists represent all individuals not being treated?

DR. DUKE. They represent those who are not able to get drug assistance from the States.

MR. SHIMKUS. So they may be getting treated, but they are just not getting the drug--that is my question. Are they getting treatment?

DR. DUKE. There is treatment available, but the treatment that is preferred is medication, and the medications are quite expensive.

MR. SHIMKUS. Is it true that an individual eligible for ADAP services in one State may not be eligible for it in another State?

DR. DUKE. The ADAP programs are set up differently in the different States.

MR. SHIMKUS. And why?

DR. DUKE. The Nation--

MR. SHIMKUS. Nice grin.

DR. DUKE. The Nation--

MR. SHIMKUS. This is a policy debate here.

DR. DUKE. The Nation is a Federal system, and we have, through the Ryan White CARE Act, a Federal system which says different States operate differently and we try to reflect the Federal system in the way that legislation is passed, and we implement that legislation as it is passed.

MR. SHIMKUS. And I am a supporter of federalism, but again, when you have an individual constituent or consumer, and again, you border three States, it really could be, you know, the metropolitan St. Louis community, but it is a metropolitan statistical area in essence, although Missouri sometimes doesn't want to accept us, many of us that live 15 minutes from Busch Stadium feel that we are as much a part of the St. Louis community as anybody else. If there is a differential and treatment options for an HIV citizen in St. Louis versus, you know, in Granite City, Illinois, then it is problematic for many of us policymakers.

DR. DUKE. One of the principles that we have worked on with the Congress in the concepts of reauthorization is to try to find some way to equalize treatment as you go across the country so that patients in any one of the three States you have mentioned would in essence be eligible for equal treatment under the provisions of the Ryan White CARE Act. So the principle you have asserted is one that we obviously agree with in our approach to this reauthorization.

MR. SHIMKUS. Great. I appreciate your testimony and look forward as we move the process forward.

Mr. Chairman, I yield back my time.

DR. DUKE. Thank you.

MR. DEAL. I thank the gentleman.

Mr. Rush is recognized for questions.

MR. RUSH. Thank you, Mr. Chairman. Mr. Chairman, I don't know whether or not you have already provided this, but I would ask for unanimous consent to insert my opening statement into the record.

MR. DEAL. Yes. I would, at this point, say that I would ask the same unanimous consent for both those people who are here or those who are absent, and without objection, that will be so ordered.

[Additional statements submitted for the record follows:]

### PREPARED STATEMENT OF THE HON. BOBBY RUSH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF ILLINOIS

Mr. Chairman:

I want to thank you for holding this hearing to give the Members of the Subcommittee the opportunity to examine the Administration's principals for reauthorizing the Ryan White Care Act, which were unveiled in July of last year (2005).

The Ryan White CARE Act is the nation's largest, most successful and most important source of discretionary federal funding for HIV/AIDS related services. The CARE Act funds primary health care and support services for people with HIV/AIDS who lack health insurance and financial resources for their care. Congress first enacted the CARE Act in 1990: the ACT was reauthorized in 1996 and again in 2000.

Each year, the CARE Act programs reach more than 500,000 individuals with or at risk for HIV in all 50 states, the District of Columbia, Puerto Rico, and the U.S. territories.

In Illinois, there are more than 35,000 people living with HIV/AIDS and our communities rely on nearly $75 million a year in CARE Act funds to provide the necessary medical and support services to low-income and under/uninsured individuals living with the disease. Chicago ranks sixth in the country for urban areas most impacted by the HIV/AIDS epidemic, with approximately 28,000 people living with HIV disease in the Chicago Eligible Metropolitan Area (EMA).

Despite the improvements in the health outcomes of AIDS patients in the general population, in communities of color AIDS is the leading cause of death of African American women between the ages of 25 and 34 and the third leading cause of death among Hispanics between the ages of 35 and 44.

It is in this reality, and in the absence of new funding to expand the provisions of the CARE Act to meet the increasing need, that this Committee is challenged to design a reauthorization bill that equitably and effectively maintains the quality of care for those who are suffering from HIV and AIDS.

I am not convinced that adoption of the set of principles outlined by the Administration will help us achieve that objective.

For example, the President's principles for CARE Act reauthorization call for no-less than 75% of all CARE Act funding to be directed to "core medical services." The debate that has ensued in my district in Chicago and the south suburbs centers on what the appropriate mix of services is and what services constitute "core medical services."

The President's principles also call for the development of a "severity of need index" that would factor new HIV cases, rates of poverty and other public and private resources available for HIV/AIDS as part of CARE Act funding-distribution formulas. For my state - Illinois - that has made significant investments of state tax dollars to expand Medicaid eligibility, keep the Aids Drug Assistance Program (ADAP) strong, and increase the availability of prevention services, a "severity of need index" would seem to penalize these investments.

These are just a few of the questions that I, and my constituent have about the administration's principles for reauthorizing the Ryan White Care Act. I look forward to the testimony of the panel before us in answering some of those questions.

### PREPARED STATEMENT OF THE HON. JOE BARTON, CHAIRMAN, COMMITTEE ON ENERGY AND COMMERCE

Good morning. Mr. Chairman, I commend you for holding this hearing. I look forward to working with you and the rest of the Subcommittee as we consider how to improve the Ryan White CARE Act to ensure persons with HIV and AIDS will continue to have access to services necessary to address their health care needs.

The Ryan White CARE Act expired last year. This hearing provides an opportunity—actually the imperative—to strengthen and improve it. As Chairman, I have not supported the creation of disease-specific prevention and treatment programs. This law is the only major federal disease-specific comprehensive treatment program in existence. In fact, this demonstrates some inconsistencies that come with disease-specific programs. The act funds non-medical services that even Medicaid or Medicare will not support, including companion services and housing. A measure of caution and oversight is warranted, therefore, in how we spend Ryan White dollars as we move forward. To put it simply, Ryan White dollars should go to prevent the spread of HIV and AIDS and for their treatment. Let me be clear: every person with HIV or AIDS should have access to core medical services. To accomplish this goal, we need to carefully examine how Ryan White funds are being used at every level—by cities, by states, by providers, and by HRSA.

We should also be mindful of other inequities created under current law. Why it is that some localities, called Eligible Metropolitan Areas or "EMAs," receive direct federal funding although they no longer meet eligibility thresholds? Why it is that certain EMAs receive a disproportionate share of Ryan White funds due to outdated funding mechanisms? Why it is that considerably more funds go to certain areas even though they have similar numbers of cases? And why it is that the estimated funding per AIDS case is around $5,500 for persons living in Texas, around $6,700 for persons living in Colorado, and over $11,000 for persons living in South Dakota? This wide variation requires some reasonable justification.

Mr. Chairman and members of this Subcommittee, these are the fundamental questions we should address as we consider reauthorizing this program. If we do not reauthorize this bill, the shortcomings and inherent inequities of this program will persist. Reauthorization must be approached responsibly, however. We have a responsibility to those who need treatment and to American taxpayers whose dollars fund this program. In order to guarantee that tax dollars are being properly spent, a reauthorized Ryan White program must be more accountable, more transparent, and more equitable.

I look forward to hearing from our two witnesses from the Department of Health and Human Services about how this program is administered and what reforms are recommended for improvement. I also look forward to hearing the findings and recommendation of the GAO with regards to improving this program. Thank you Chairman Deal for calling this hearing today and I welcome the panel of witnesses.

MR. RUSH. Thank you, Mr. Chairman.

Mr. Chairman, I want to ask Dr. Duke. I want to continue a line of questioning that Congressman Waxman initiated, because I, too, have concerns that Title IV would be severely damaged if funds were set aside for core medical services which are articulated in the President's principles as basic primary care and medications needs. Title IV is successful because it offers a broad arrangement of family-centered services that are essential to getting mothers to take care of their own health, to keep children in care, to give the mom the support she needs, like childcare and transportation, to get her kids and herself to doctor's appointments and the pharmacy, and to reaching out to the HIV infected youth and keeping them in care also.

So the question I have for you, Dr. Duke, is what changes would the Administration like to see for Title IV, and more specifically, I would like to ask, do you want this Congress to apply or set aside a provision for Title IV funds for core medical services?

DR. DUKE. The principles that we brought to this dialogue about reauthorization did not envision the dismantling of the Title structure of the Act at all. Title IV, which has been very successful, would be an important part of the Act as it is reauthorized, and as we work with the committee around the provision of services, we would see that as part of the dialogue what would be included in Title IV.

MR. RUSH. In another sense, there was a time in past discussions about reauthorization of the Ryan Act I have heard from some constituent organizations about disparity in terms of funding going to organizations that were primarily based out of minority communities. Is that an ongoing problem or is that problem been pretty well eliminated now? Have there been any causes that you have recently heard of of where there have been some problems with Ryan White CARE funds going to, say, organizations that are located in minority communities as opposed to some of the older, more experienced, more mature community-based organizations and health clinics?

DR. DUKE. Sir, I haven't heard any criticism along those lines. Indeed, we have tried to elicit engagement of all communities in assisting with making their members aware of their own health interests in being tested that early diagnosis is a good thing. So we have actually encouraged outreach into communities and in the additional $25 million that we have requested for Title III for '07, one of the themes of that money is that we need to engage all communities in reaching out to their members to help their members become aware of their HIV status so that we can bring them into care.

So I am unaware of the concern you have raised.

MR. RUSH. Let me ask you this. Newer CVOs, health clinics, are they treated any differently than more established health clinics in terms of applications for Ryan CARE funds, Ryan White CARE funds?

DR. DUKE. Title III capacity building planning grants, all of those are competitive and when those applications come in, they are reviewed by an objective review committee relative to the guidance we have put out, and there is no discrimination as to whether they are newer or older clinics. The issue is can they meet the need of the population which we recognize needs their services.

MR. RUSH. Are there any particular handicaps to newer organizations that might prevent them from quickly getting into the funding stream?

DR. DUKE. I think there are always challenges to new grantees in the sense that they need to perhaps physically get up and running in different space. They may need some time to set up appropriate business apparatus or to hire needed personnel, particularly the medical personnel who are in short supply.

MR. RUSH. Dr. Levine, I believe it is, the Secretary of HHS--

DR. DUKE. Secretary Mike Leavitt.

MR. RUSH. Yeah. He came and testified before the committee based on the budget, okay, and he indicated that there would be 70 new community-based health clinics, FQHCs, that would be authorized in the budget for this year. Are you aware of that?

DR. DUKE. We are bringing up 88 new health clinics that have competed and are up and running in '07--'06, and we have requested from the Congress $181 million additional, bringing our primary care health center request up to almost $2 billion. Of that, $181 million is a request to provide new health centers in 2007 so that we would reach the culmination of the President's expansion initiative to award 1,200 new health centers over this five to six-year period. Within that request is a request to provide 80 of those health centers as focused on high poverty areas, either in urban areas or in rural areas. So we are anxious to have more health centers, and many of our health centers are also providers of Ryan White CARE Act as well, even--

MR. DEAL. The gentleman's time has expired.

MR. RUSH. Thank you, Mr. Chairman.

MR. DEAL. We are pleased to have the Chairman of the full committee, Mr. Barton from Texas with us, and he is recognized for questions at this time.

CHAIRMAN BARTON. Thank you, Mr. Chairman. I apologize for not being here for the entire hearing. I have another hearing going on, a press conference, and several private meetings. That is why I was not here at the beginning. This is a very important hearing. I have some statements to make, more than really questions. I want to let our audience know and our witnesses know that we are going to reauthorize this Act. There are some rumors that we wouldn't reauthorize it, but we are. Having said that, it is not my intent to do a straight reauthorization. I do think we need to take into account the President's priorities as have been enunciated in the GAO study that has been put out. I think it is a given that we want to do everything humanly possible for those individuals that have contracted AIDS. If we can save their life or extend their life, that is a good thing, but we do need to look at these formulas. We do need to look at some of the non-medical services and see if there is a way that we can make the formulas more fair and make sure as many dollars as possible go to healthcare and prevention, and not to some of the extraneous things that have generated some of the negative headlines.

I guess I would ask our HHS witness, do you generally support the findings or the recommendations of the GAO study in terms of formulas and things like that?

DR. DUKE. Yes, sir. We find that the inflexibilities in the formula create some inequities so that patients in one area of the country have less access to healthcare as a result of the formulas, and so our principles ask that we treat the neediest first, and that we extend life and save lives. And the way to do that, I think, is to increase the flexibility and also the accountability in the Act, and we greatly appreciate your support in looking to reauthorize this bill.

CHAIRMAN BARTON. A general question to Dr. Fenton. Would you say that the number of cases of AIDS has stabilized in this country and do we seem to have a pretty good handle on the disease now? Or is it still a disease that is growing in its impact on our population?

DR. FENTON. Thank you for your question. Although we believe the number of new cases of HIV has remained relatively stable over the past 5 to 10 years, we are continuing to see evolutions in the epidemic. So indeed, more individuals who are communities of color are being affected by HIV. We are having increasing concerns about young MSM, manual sex with men, especially manual sex with men of color. So the epidemic is, in fact, a dynamic epidemic. Although we may be seeing some of the numbers of new infections occurring each year, we are seeing changes in the character of the epidemic and the individuals who are affected by HIV.

CHAIRMAN BARTON. Thank you, Doctor, and thank you, Mr. Chairman. I yield back.

MR. DEAL. I thank the gentleman.

I had an error on our timing in the first go around, and I intend to equalize the timing on Mr. Waxman, Dr. Burgess, and myself. We got shortchanged on the first go around. With both of your indulgence, since you are here, I have had a request from Mr. Markey. He is a member of the full committee, and I would ask unanimous consent that he be allowed to question the panel at this time.

Without objection, you may proceed.

MR. MARKEY. Thank you, Mr. Chairman.

First of all, it just seems to me that if we are now going to debate whether or not we should be shifting money over from States with big cities over to States without big cities, but keeping the money relatively level-funded, that that then gets to be part of the debate about how big should the tax cuts be? And otherwise, we wouldn't be having this discussion because we would have more money to help the States without big cities. And so you get into a fight over limited resources, when we know that the problem is actually mushrooming as each year goes by, as we identify an additional 30 or 40,000 people who have been infected. So I think that is, you know, something that everyone should understand. The President should just stop his plan to continue to increase these tax cuts until we have enough money to take care of these problems instead of having States fight amongst each other.

Now, Massachusetts has, under pressure, agreed to change from having a code-based system over to a name-based system. And my question for you, Dr. Fenton, is it is going to take 3 to 4 years in order to complete this process. What is the status as a result of Massachusetts beginning this October in terms of receiving the $15 million or so that the State of Massachusetts fears it is going to lose because it will not have completed the conversion?

DR. FENTON. Thank you very much for the question.

We are aware that Massachusetts has recently made the decision to shift to name-based reporting, and CDC remains committed to supporting Massachusetts to ensure that this occurs as quickly and as efficiently as possible. We are very much committed to promoting name-based reporting because we do believe it is--

MR. MARKEY. I know that, I'm talking just about the funding. Will we receive the funding this October, even though we will not have had enough time logistically to convert over from code-based to name-based identification?

DR. FENTON. Again, I cannot comment on the amount of appropriations that you receive; however, I can say that we will follow the law as--

MR. MARKEY. Under the existing law, will Massachusetts be eligible for that $15 million beginning in October, or will it not be eligible?

DR. FENTON. I would like to defer to my colleague.

DR. DUKE. We are in the process right now of trying to sort it out. We strongly endorse reauthorization and we are in the process right now of trying to sort out with the lawyers what our options are in terms of funding the States in transition. And so we will have to get back to you for the record.

MR. MARKEY. In other words, if we do not reauthorize Ryan White and change the law, under existing law, can you continue to give that $15 million, which is about 30 percent of all the money spent in Massachusetts on AIDS and HIV patients?

DR. DUKE. We are in the process of trying to sort out exactly that question. The law requires us in ‘07 to go to HIV reporting and to do HIV reporting, we have to have a CDC certification that the State system meets CDC standards. If we don’t have that CDC certification, that is what the lawyers and my staff are trying to sort out right now.

MR. MARKEY. Well, let me go back over to Dr. Fenton then. Dr. Fenton, can you certify that Massachusetts, having made the commitment to make the switch, knowing that logistically it is impossible to complete it before October, won’t have all of these thousands of people victimized by having a cutoff of funding, even though the State has indicated its intention to comply?

DR. FENTON. Again, we are committed to ensuring that the process of transition occurs as quickly as possible.

MR. MARKEY. And so we are going to, in fact, do it and change the system. The question is do we lose the funding while the process is ongoing as we make the transition?

DR. FENTON. Thank you for your question. We will have to get back to you on that question for the record.

MR. MARKEY. What is your inclination, though, from your heart, Doctor, in terms of how these people in Massachusetts should be treated? I know it is going to take three or four years to get all the names.

DR. FENTON. I truly empathize with the situation, the difficulties that the transition causes all of us at the moment. I can honestly say that we are working as hard as we can to ensure that it does occur as quickly as possible.

MR. MARKEY. I hope that you find a way of ensuring that the interpretation of the law takes into account the impact it will have on thousands of HIV and AIDS victims.

Thank you.

MR. DEAL. I am going to go back and, as I said, three of us got shortchanged on the first go around on the time. We set it at three minutes instead of five minutes. We should have had five minutes for questioning. Since we are going back and forth, I am going to reserve mine until the end and I will recognize Dr. Burgess at this time for an additional two minutes of questioning.

MR. BURGESS. Thank you, Mr. Chairman. I did think the time went by rather rapidly, but I wasn’t going to question the Chairman.

Ms. Crosse, really the only other thing I would like to ask at this point is in your testimony, you said that Health and Human Services generally agreed with your identification of issues and funding formulas. Was there any area where you and the Department of Health and Human Services differed over that opinion?

MS. CROSSE. Not as they expressed to us in their written comments on the report. I believe that there may be details as you negotiate with the Department in working out exactly how this should be structured that might be more specific or vary to some extent from what we have recommended, but in principle I believe that they--and in their comments indicated that they were supportive of the concept of revising the funding formulas to better reflect the current distribution of the epidemic.

MR. BURGESS. And what about as asked by Mr. Markey, was there any heartburn with the timeline that was devised?

MS. CROSSE. Well, we were not indicating at what point this needed to be incorporated. We do believe that it is important that HIV case counts begin to be incorporated in order to better reflect the distribution of the epidemic, because many individuals now who are HIV-positive do not progress to AIDS or do not rapidly progress to AIDS, and under the current structure of the formulas, they are not considered in the allocation of funding because it is based on an estimate of living AIDS cases. However, we do acknowledge in our report that there is a period of time of transition before a system that switches to a name-based reporting system has comparable data to a system that is fully mature, and we recognize that that could take as much as three years for that to occur.

And so how that is incorporated and what consideration that the Congress gives to States that do not have mature reporting systems I think is something that warrants consideration as you reauthorize this Act. As I understand the current statute, if you do not reauthorize, beginning in October, those States that do not have accepted case counting systems will have their allocation based solely on the AIDS cases as currently exist. They will likely lose funding, however, because that will be balanced against States where both AIDS and HIV cases are counted. So if the pool remains the same, funds will shift to those States that have larger case counts because the HIV cases are included. And so how you would want to structure any period of transition is certainly something that you have to wrestle with, I believe, as you consider reauthorization of the Act.

MR. BURGESS. Thank you. Mr. Chairman, I would also just like to take a second to point out, I think they have all left now, but we had a number of students from the University of North Texas Health Science Center here with us this morning to hear part of this discussion. I always want to encourage those in medical school to be part of the formation of public policy.

With that, I will yield back.

MR. DEAL. I thank the gentleman.

I recognize Mr. Waxman.

MR. WAXMAN. Thank you, Mr. Chairman.

Let me, first of all, ask Dr. Fenton and Dr. Duke, you indicated you are going to get back to Mr. Markey to answer the question of if we do not reauthorize the Ryan White CARE Act, how you are going to distribute the funds regarding States that are moving to a name-based system. When will you get back to him?

DR. DUKE. The process of discussion is ongoing, as you can see from Ms. Crosse's response. There is one thought that talks in terms of--

MR. WAXMAN. I don't want the alternatives. I just want to know if you are going to make a recommendation and you are going to have to make that decision, would you tell us what the decision is going to be and how fast are you going to make that decision so we can know it? I am just asking the timing.

DR. DUKE. I don't exactly know a date certain that I can give you. I am working with staff and the lawyers, and I will give you a call later this afternoon to give you a much more precise date after I have discussion with the lawyers.

MR. WAXMAN. I would appreciate that.

Dr. Fenton, certainly CDC should be able to give us some estimates what the situation would be in those States that are in the process of changing to a name-based area. How fast can you give us your estimates that might be helpful? What we want is the appropriate proxy so that we can figure out the numbers to do this in a fair way.

DR. FENTON. We will do this in as timely a manner as possible, but we do have to follow the law on this issue.

MR. WAXMAN. I am not asking you to follow the law, I am asking you to follow the science. That is what CDC is all about. If you can't give us an estimate for proxies, who do we rely on, other than the Centers for Disease Control?

Mr. Chairman, I am just very frustrated because it sounds like the Administration sent its proposal but they haven't thought it through. They want to work with us, but we don't know what they are proposing. The CDC is not willing to give us their expertise. So this makes it more difficult.

And along those lines, Dr. Duke, I guess the biggest problem is that the Administration has proposed distributing Title II funds only on the basis of people living outside of EMAs, and since most States that have EMAs have a large proportion of their population inside EMAs--in California, it is nearly 90 percent, for example. This would mean a radical shift in funds. According to the CARE Coalition, Dr. Duke, your proposal would mean Missouri would lose 78 percent of its Title II funds. Does the Administration support that? The District of Columbia would lose all of its Title II funds. Is that what the Administration supports? New York would lose 56 percent. Is that what the Administration supports? Illinois and Massachusetts would lose half of their Title II funds, and of course, California would lose 62 percent of its Title II funds. Is that what the Administration really proposes?

DR. DUKE. The proposal is to move to a new way of allocating Title I and Title II funds, which is based on the national scientific quantitative severity of need index, which moves away from some of the current--

MR. WAXMAN. But the consequences, from what we have seen of the Administration's proposal, would have those kinds of cuts. Is that the policy the Administration would support in your new formulas that you are proposing?

DR. DUKE. The approach that we have tried to take is to reach some kind of balance that would take into account both prevalence and incidence of new cases that would identify the significant elements such as poverty--

MR. WAXMAN. But if it resulted in those kinds of cuts, do you think that would be reasonable?

DR. DUKE. I think that is the kind of discussion around the relationship of stability, which is very important, which we talked about earlier, stability, and at the same time, trying to move with the epidemic and serve the needs of individuals or patients.

MR. WAXMAN. Part of the problem we have with the Administration's proposal is to try to understand certain concepts, and I didn't get a clear answer on what these concepts are of these core medical services. And so it is difficult for us to determine what that means. That has, of course, a big impact on funds. How can you justify asking us to make such a significant change in this program without sharing all this critical information with us? Can you provide us with your list of grantees that are not currently spending 75 percent of their funds on the basis of the Administration's definition of core medical services? That's first, and what portion of their funds are spent on core services, in your view, and how dramatic a shift in funding are you proposing, and then lastly, has HRSA conducted in the analysis to estimate the impact of the shift of funding that would occur if 75 percent of all Ryan White funds are spent on core medical services?

I don't expect you to answer that now, but that is information we ought to have before we make some of these decisions.

DR. DUKE. We will provide as much information as we possibly can for the record.

MR. WAXMAN. And how soon would we get that information?

DR. DUKE. We will have it for you within the week.

MR. WAXMAN. Okay, thank you.

And let me ask you about Medicaid coverage, because one way to deal with the press of funding that we have, a very sensible way would be to allow the States to provide Medicaid coverage to persons with HIV who are not now covered. They have to have full-blown AIDS and be disabled. But if we allow Medicaid to provide HIV coverage, this would take a lot of pressure off the Ryan White funds.

I wonder if you could tell me if the Administration would support legislation to do that?

DR. DUKE. I don't have a position on that, sir.

MR. WAXMAN. Do you have a recommendation that you would make to Secretary Leavitt to consider?

DR. DUKE. I will take that back for discussion.

MR. WAXMAN. On Medicare, we have a very strange situation because we have many States that are on waiting lists for coverage of the AIDS drugs under the ADAP program, and similarly, there is a concern that not every State covers the appropriate array of drugs, so we need more money in that area. One way to get more money is that when people who are covered under Medicare and are age-eligible for the Medicare drug program, they get into that donut hole, and then the ADAP program continues to pay for their drugs, which means they never get out of the donut hole, so the catastrophic coverage comes into effect. That is the catch, that ADAP is paying for their drugs, and under the Medicare rules, they never incur the necessary out-of-pocket costs to trigger the catastrophic. That makes no sense. Shouldn't we be making it clear that although ADAP is paying for the drugs that it should qualify as an out-of-pocket expenditure, and would the Administration support that change?

DR. DUKE. Sir, the interaction of different pieces of legislation is a concern, and we will have to take it under consideration to answer that for the record.

MR. WAXMAN. Well, you are responsible for ADAP and making the best use of those funds. Don't you think that would be the best use of those funds, if we counted them so that Medicare comes in and picks up the catastrophic costs?

DR. DUKE. I will have to get a position back to you, sir.

MR. WAXMAN. Have you raised the issue with Secretary Leavitt?

DR. DUKE. There have been many discussions of interactions of laws, sir.

MR. WAXMAN. Have you raised it with Secretary Leavitt?

DR. DUKE. We've had many discussions.

MR. WAXMAN. Now, I would like clarification--Ms. Capps asked the question. Dr. Fenton, CDC uses statistics on actual living AIDS cases, does it not?

DR. FENTON. That is correct.

MR. WAXMAN. And when you are looking at the epidemic, you don't use the formula written in the Ryan White Act that only looks back 10 years. For example, you use actual living AIDS, is that right?

DR. FENTON. We provide data on a variety of indicators to our colleagues at HRSA, including HIV reports as well as 10-year, 12-month AIDS case reports for consideration.

MR. WAXMAN. Well, I think Ms. Capps' point was two-fold. One, actual living AIDS is a more accurate count of persons with AIDS than the Ryan White estimate, and two, using data on actual living AIDS cases provides the best data for use for any proxy to estimate persons living with HIV until the name-based system is mature. Don't you agree?

DR. FENTON. I would like to consider that with colleagues and get back to you for the record.

MR. WAXMAN. Well, Mr. Chairman, I appreciate your generosity in letting me pursue these questions, but I must express my frustration. We want to work with the Administration, but if they give us a proposal, they ought to be able to back up the proposal. They ought to tell us what it means, and if they can't figure that out, it makes it difficult.

And if you will let me have just one point with Ms. Crosse. This may have been beaten to death, but I guess the question is you have been criticized for using only Title I and Title II. Would you agree that another valid way to understand the complete picture of funding under the CARE Act would be to look at the distribution of funds under all the Titles, and would you also agree that GAO's conclusions and recommendations might have been very different had the funding across all Titles been taken into account?

MS. CROSSE. Sir, I cannot go so far as to say that our conclusions and recommendations would have been different absent any examination of those other factors. I would have concerns about linking the non-formula based distributions that rely upon competitive grants and that could change from year to year--

MR. WAXMAN. Well, you obviously decided you didn't want to do it that way. Could you see someone else doing it that way, since we are talking about massive redistribution of money if we don't take those other Titles into consideration? You may not agree with that formulation, but don't you think that is another valid way to do it, or do you think it is completely invalid?

MS. CROSSE. I would be concerned about including some portions of those other fundings. Some parts of it, I think, could validly be included.

MR. WAXMAN. Okay, thank you.

Thank you, Mr. Chairman.

MR. DEAL. Thank you. I will use my time that I didn't give myself at the beginning, to sort of wind this whole thing up.

First of all, with regard to Ms. Crosse, the survey, and the report that you did, do you know what percentage of overall funding in this Ryan White program is included in Titles I and II?

MS. CROSSE. I believe it is approximately 80 percent of the funding, or at least in the fiscal year that we examined it was about 80 percent.

MR. DEAL. So that is where the bulk of the money is going?

MS. CROSSE. That is where the bulk of the money is going, and that is the funding that is linked to the cases.

MR. DEAL. Are the others linked to grant programs based on the justifications of the applications that are submitted?

MS. CROSSE. That is correct.

MR. DEAL. Am I correct that those communities, cities, and States that are eligible under Title I and II are also eligible for the grant programs? Is that correct?

MS. CROSSE. That is correct.

MR. DEAL. So they are not discriminated against in the other Titles?

MS. CROSSE. No, those funds go to successful grant applicants, including some local health departments, State health departments, depending upon what funding they have applied for.

MR. DEAL. Okay. Dr. Fenton, how long have the States known that they needed to go to a name-based reporting system? How long has that been out there?

DR. FENTON. CDC included the shift to name-based reporting in its 1999 guidelines.

MR. DEAL. So that is quite a while that States have known it. I mean, it is not something that is the fault of the CDC or anyone else to say that they didn't know it. That is my judgment, based on those kind of timelines, and most everybody has complied, is that right?

DR. FENTON. Well, currently, as I have said in my testimony, 43 States have currently shifted over to name-based reporting and we are anticipating that more will do so by the end of the year.

MR. DEAL. Right. There have been several things talked about, and I think we go back to the idea under Title I and Title II. How is the most equitable way to determine who needs the services? I think that Dr. Duke's suggestion that one of the things, even within the numbers, that needs to be considered is the severity of need. Even though you may be counted in the numbers, the need on a case-by-case basis varies significantly. Is that the general gist of the severity of need criteria, Dr. Duke?

DR. DUKE. The severity of need criteria is designed to try to understand how we could distribute funds, you know, in a way that would be consistent with a picture of what the epidemic looks like today. In here, we are talking about the prevalence of the disease, the incidence of the disease, the new cases coming in, the level of poverty, and other factors that would help us understand on a nationwide basis how to distribute it so that the patient, the individual patient is treated fairly across the United States.

MR. DEAL. Of course, you know, in a simplistic world, it would seem to me that the idea of letting us just come up with an actual count and I guess one of the things that disturbs me, and I will spare you the full extent of my political story. It is one that is prevalent in my State for a long time about the fellow out on Election Day walking through the cemetery with absentee ballots writing the names down off the headstones. He was asked about it and he said well, they deserve to vote just like everybody else. It bothers me that we are allowing a system that counts deceased individuals, and as I understand it, with the EMAs, you actually may count those individuals twice. Am I correct, Ms. Crosse?

MS. CROSSE. That is correct in one jurisdiction.

MR. DEAL. Okay. Is that San Francisco?

MS. CROSSE. Yes, sir.

MR. DEAL. Okay. So we have got things built in to what we have done over the past that have distorted getting to the same treatment for individuals, regardless of where they might live in this country. One of the phrases that was used was the hold harmless communities. How many of those are now built in to the law?

MS. CROSSE. For the EMAs, there are 29 of the 51--I am sorry. I am not speaking to hold harmless, I am speaking to the grandfather clause. I am sorry, I don't have that figure at my fingertips. There are, I believe, about 15 that are held harmless under Title I. Only two of those receive significant funding, the remainder receive very, very minimal funding under the hold harmless provision.

MR. DEAL. So we have got the hold harmless, which really distorts the counting individuals. We have got the grandfather clause, which also distorts the way you count individuals. Is the name-based reporting system, Dr. Fenton, designed to eliminate some of those inconsistencies in the way we count who is eligible for assistance, or does it have another purpose?

DR. FENTON. Well, name-based reporting really is the gold standard of reporting, and all of infectious diseases in the United States are reported using this mechanism. The beauty of the name-based reporting is that it enables States to de-duplicate their numbers much more effectively. It is also a much more cost-effective system, and it is a much more cost-efficient system as well. So the key benefit is the ability to de-duplicate at the State level, and also to de-duplicate between States as well.

MR. DEAL. All right. Well, I have exhausted my time, too.

This has been a very good panel. As I said at the outset, we will expect to have a roundtable discussion from others who are in the community of providers and those who may be affected by the disease, and we will try to have that in the very near future so that the concerns that Mr. Pallone has addressed will be able to be heard by the committee at that time.

I would also add that any questions that committee members would like to submit may be allowed to be submitted to you in writing, and I think you have heard some today that probably will ask for follow-up on that.

Thank you all for your attendance today, and with that, the hearing adjourned.

[Whereupon, at 11:35 a.m., the subcommittee was adjourned.]

# RESPONSE FOR THE RECORD BY DR. ELIZABETH DUKE, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

**Rep. Bobby Rush (D-IL)**

1. Do you support the recommendation that reauthorization legislation specify the amount of funding that should be dedicated to core medical services, and if so, what rationale do you use to justify the percentage of funding - 75 percent – that you recommend?

*Under current law, providers funded under the Ryan White CARE Act may offer a broad range of services to their patient, but only some can be considered life-saving and life-extending. In addition, the services offered to CARE Act clients vary across geographic regions. The proposed change is intended to foster health among HIV infected individuals and uniformity of services across the country by designating a basic set of core health care services for all CARE Act clients. The components of core services would, at a minimum, include health care services and medications for which 71% of CARE Act funding was directed in 2004. An additional 9% of CARE Act funding in 2004 supported case management services, a health-related service key in helping persons gain and maintain access to treatment. Thus the 75% minimum is in line with program expectations and supported by program data. Both Title I and Title II program guidance describe the elements of a continuum of care and utilize the term "core services." In the 2005 Title I guidance, grantees were asked to prioritize essential core services, describe the priority setting and allocations processes, and how data was used in this process to increase access to core services. The guidance also asks grantees to justify other sources of core services if funds are not allocated to these services. For the top services, including core services, grantees are asked to develop one or more service goals for each priority with time-limited and measurable program objectives.*

2. What services do you believe constitute "core medical services" and what is your rationale?

*Various groups have developed lists of "core medical services" for people living with HIV and AIDS. In particular, the Institute of Medicine (IOM) study, "Public Financing and Delivery of HIV/AIDS Care," published in 2004, defined eight broad areas that capture the critical components of HIV care as listed below.*

- *Outpatient primary care medical services*
- *Medications, including highly active antiretroviral therapy (HAART)*
- *Other drug therapies*
- *Laboratory and radiological services*
- *Oral health care*
- *Obstetrics and reproductive health services of HIV-infected women*
- *Outpatient mental health and substance abuse services*
- *Home health and hospice care*
- *Medical case management*
- *HIV prevention services*

*We will continue to work with Congress during the reauthorization process to evaluate what services should be included.*

3. In its 2004 recommendations to Congress on maximizing Federal funding for HIV/AIDS care, the Institute of Medicine (IOM) defined core medical services as including primary care services, medications, mental health and substance abuse treatments (in-patient and out-patient), case management, prevention education, and obstetric/reproductive health services.

   Please comment on this recommendation and your rationale if you propose a different mix of "core medical services"?

*The Administration is still working closely with Congress on the final definition of "core medical services," and recommendations from the IOM study that defined a list of eight broad areas as "core medical services" have been incorporated into the discussions.*

4. The President's principles also call for the development of a "severity of need index." Why would Congress create disincentives for State and municipal governments to invest in Medicaid, the AIDS Drug Assistance Program (ADAP), and prevention, especially at a time when Federal dollars are not keeping pace with the epidemic?

   Please comment on the "severity of need index" idea and your specific recommendations to leverage more State, municipal, and private investment in AIDS-related services?

*The President's Principles call for more equitable distribution of CARE Act funds. Important provisions in the law, such as maintenance of effort and the matching fund requirement, will continue to safeguard against the diversion or reduction of State and local funds away from critical HIV/AIDS services. A severity of need index, as proposed in the President's reauthorization principles, calls for the establishment of objective indicators in determining severity of need for funding core medical services and proposes that such an index take into account HIV incidence, level of poverty, availability of resources including local, State and Federal programs and support, and private resources. Such index will allow for better targeting of CARE Act dollars while assuring that State, municipal, and other investments in HIV/AIDS related services continue to support Federal efforts in HIV care and treatment.*

5. Title IV of the CARE Act provides an important link to care, services and research for women, children, youth and families affected by HIV/AIDS and have led the way in reducing mother-to-child transmission from more than 2,000 babies born HIV-positive each year to fewer than 200. Title IV programs bring HIV-infected pregnant women into care and help them adhere to their treatment regimens for the duration of their pregnancy and delivery. Following delivery, Title IV nurses and case managers follow up to ensure the mother is administering the required six-week treatment regimen to the newborn.

   Given these successes, performed each and every day by Title IV projects across the country, do you agree that the Title IV model of care should be continued, strengthened and expanded in reauthorization?

*We continue to work with Congress during the reauthorization process to ascertain the appropriate services and activities under Title IV of the CARE Act.*

6. I have concerns that Title IV would be severely damaged if funds were set aside for “core medical services,” which are articulated in the President’s principles as “basic, primary care and medication needs.” Title IV is successful because it offers a broad range of family-centered services that are essential to getting mothers to take care of their own health, to keep children in care, to give mom the support she needs – like child care and transportation – to get her kids and herself to doctor appointments and the pharmacy, and to reaching out to HIV-infected youth and keeping them in care.

   My question is what changes would the Administration like to see made to Title IV? Specifically, do you want Congress to apply a set-aside of Title IV funds for “core, medical services”?

*Although the Title IV program of the CARE Act is structured differently than the other Titles, in essence the main goal is to assure that its clients receive core medical services, including primary medical care and medications. Because there is no final definition of core medical services as yet, it is difficult to predict which, if any, of the Title IV-funded services may face a possible reduction in funding. It is anticipated that many CARE Act programs may have to make modifications to their programs based on the application of the requirement to spend 75% of their funds on “core medical services”. However, the change is intended to assure quality health care for HIV-infected individuals and uniformity of services for CARE Act clients across the country.*

7. Given the rise in HIV and AIDS infections in African American women, we need to look at ways to reach this population more effectively. The President spoke about this in his State of the Union Address, yet the Administration’s principles were virtually silent on the fact that 88% of people serviced by Title IV are people of color.

   What plans does HRSA have for making sure that the Title IV family-centered care model, which has been a lifeline for women of color and their families since 1988, is able to serve more families of color?

*The Title IV program will continue to reach out to communities of color through its programs, as well as through the use of the Minority AIDS Initiative funding, to identify, enroll in services and retain in services women of color and their families. The program has utilized many unique approaches to outreach in these communities, including through faith-based and community-based non-clinical programs that provide HIV prevention and education services and make referrals for counseling and testing. Utilizing these approaches reaches people in settings that are non-threatening and conducive to open and honest exchange of information about issues such as HIV.*

8. My city and State have and will continue to contribute to the care of our residents living with HIV/AIDS. We are also committed to ensuring that every American living with this disease has adequate health care and understand the need for a more equitable funding distribution. Yet, in the absence of new funding to adequately address the epidemic in all areas, the Administration has proposed changes to funding formulas that would shift funding from needy individuals in urban areas to needy individuals in rural areas.

   Shifting funding from hard hit urban areas like Chicago where more than 80 percent of those living with HIV/AIDS reside would not address existing disparities across the country, but would instead do double harm: it would destabilize the existing health care networks in large cities, and it would put funding for health care where no health infrastructure exists to deliver these services.

How does the Administration propose to address these concerns?

*The President's principles call for more equitable distribution of CARE Act funds, which is paramount in the reauthorization. Proposed changes in the CARE Act are not intended to destabilize services, but are designed to assure that persons in need of HIV services and unable to pay for them will be able to receive those services. By maintaining important provisions in current law, such as maintenance of effort and matching fund requirements, the Administration will ensure that states continue to contribute state and local funds to critical HIV/AIDS services.*

RESPONSE FOR THE RECORD BY DR. KEVIN FENTON, DIRECTOR, CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

**Question for the Record from Representative Rush.**

1. In January of this year, the Illinois Department of Public Health began to implement the transition from code-based to name-based HIV surveillance data. Even with this change, our State may lose millions of CARE Act dollars because its name-based database will not be as complete as other states when funding distributions area made.

   Will CDC support provisions in the CARE Act reauthorization to allow code-to-name based states to phase in their name based reporting programs without funding penalties?

*CDC will implement the provisions contained in the law as enacted for the reauthorization of the Ryan White CARE Act. CDC is committed to assisting states to move from code-based to name-based surveillance systems as quickly as possible.*

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