

AMERICAN FOUNDATION FOR AIDS RESEARCH

14TH NATIONAL HIV/AIDS UPDATE CONFERENCE

IS THE MONEY DRYING UP, OR DOES IT JUST LOOK THAT WAY?

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DR. MARK WINIARSKI: Good morning. This is the session, “Is The Money Drying Up, Or Does It Just Look That Way,” and the cameras are here because this will be webcast later today courtesy of the Kaiser Family Foundation on kaisernetwork.org. I am Mark Winiarski, the moderator, and a psychologist at Montefiore Medical Center in the Bronx.

Since 1991, I have been the Project Director or Principal Investigator of federally funded HIV mental health programs. These grants enabled us to simultaneously study new models of care for HIV affected persons, and to provide thousands of psychological and psychiatric encounters that would not otherwise have been available to the people of the Bronx.

But, when I look at the future on behalf of those people of the Bronx, and to my eye the future is very cloudy and very grim. Funding is complicated. We need to know the basic concepts, such as what is meant by mandatory and discretionary funding.

There are a host of participants and systems, from Congressional staff to elected officials to federal agencies and foundations, to project officers and, of course, those whose lives are enhanced, or who suffer because of the availability or lack of funding.

Our panelists today will address the basic issues and give us an important view into current and future HIV/AIDS funding. The panelists include Scott Boule, a participant in the federal budgetary process, Jennifer Kates, one of the most astute and knowledgeable observers and analysts of HIV funding, and Patricia Bass, a Philadelphia heart--Health Department official and a strong and committed advocate for HIV services. Our--we'll have time at the end for questions, and we'll ask that questioners come to the microphone for the benefit of the viewers of the Webcast.

Our first speaker is Jennifer Kates. She is Senior Program Officer, HIV/AIDS Policy, at the Kaiser Family Foundation. Ms. Kates manages the Foundation's HIV-related policy projects, conducts policy research and analysis, and provides HIV/AIDS expertise to the Foundation's public health information campaigns and media partnerships, and to numerous stakeholders, including the media, policymakers and community members.

She manages the Foundation's ongoing “Capitol Hill Briefing” series on HIV/AIDS, as well as its national HIV/AIDS policy initiative, a joint initiative of the Kaiser Family Foundation and the Ford Foundation.

Ms. Kates?

MS. JENNIFER KATES: I'm also short, so I've been told to stand on this thing, and I hope it will be astute. Thank you for that.

Hello, everyone. Can you hear me through this? Very happy to be here today with such good company and, as Mark noted, I'll be providing an overview of federal spending trends on HIV/AIDS. That's what I'm gonna focus on.

And I'm here representing the Kaiser Family Foundation but, Marcia Bonner (sp), who was going to be here with us today as a representative, sort of wearing her hat representing funders concerned about AIDS, which is the Council on Foundation's HIV/AIDS affinity group of funders, is ill and could not be here. So, I am also on that Board, so I'll put that hat on a little bit and try to give you some information about some recent trends in private philanthropy as it plays a role in HIV/AIDS funding.

Okay, see if I can do this sideways. Okay. The first thing I wanted to highlight when we think about funding for HIV/AIDS is that there's a lot of different sources of funding that we're--we have to think about, and funding spans both domestic and global epidemic. Funding is both funding and private and, on the domestic side, the public sector is the federal government, obviously, state and local governments; the private sector, individuals, philanthropy, corporate.

And similar breakdowns in the global funding have--includes bilateral, multilateral aid and many other mechanisms of funding. It's just important to recognize all the different sources, because they're all different points of leverage, as well as information that needs to be gathered to really understand the full budget picture and spending picture.

And one note about individuals and the private sector in funding providing support for HIV/AIDS: as you know, in the history of this epidemic, that's been a very critical part. It might not be as much in terms of dollars in the early history, but it's been a real critical part of the response to the epidemic.

So, as I mentioned, I'm going to focus primarily on federal funding for HIV/AIDS. Specific federal appropriated funding for HIV began in 1981, the year that the first AIDS case was identified in the U.S., and funding for the global epidemic began later, in the late '80's.

So, here's my little note on philanthropy, and this is actually drawing from a report that you can get from funders concerned about AIDS, which is called "Voices From The Field: Re-mobilizing HIV/AIDS Philanthropy For The 21st Century."

What this report found--it came out last year--is that between '96 and 1998, funding for HIV/AIDS from private philanthropy actually fell. It rose again in 1999 to a higher level, and it's remained fairly stable since. But, some increases on the international side have begun, largely due to Gates Foundation grants and from very large international initiatives.

But, funding on the domestic side from private philanthropy has still remained relatively constant and stable. And we also have heard lots of anecdotes. All of us have them, and Pat probably from the Philadelphia perspective of eight service organizations that are really struggling to get private support and fund-raisers that aren't as successful as they have been in the past in the current state of the economy, and then sort of a post-9/11 environment.

Okay, back to federal spending. I'm gonna be presenting some data on attitudes towards federal spending just to give you a sense of what the U.S. public feels about federal spending on HIV/AIDS, and I also will be presenting some budget data. The budget data that I present should be considered preliminary. We'll be releasing a new report on federal budget spending on HIV/AIDS. We release this report every year, and the new report will include fiscal year 2001 data and trends back to 1995.

But, the reason I say they're preliminary is that we are still calculating estimates, and the federal government's method for estimating spending and recalculating estimates changes every year. And this year there was a very important change that I want to highlight for everyone: the way in which the federal government estimates how much Medicaid, Medicaid being one of the most important programs for people with HIV, the way in which the federal government estimates how much Medicaid spends on HIV changed.

Believe it or not, for the last several years, the way that the government was estimating that was based on sort of an old model of how many people there are living with HIV and AIDS, how much--how many costs there are, and they finally went back and re-estimated that, saying, "Well, we know that since 1995 and 1996 number of deaths have been decreasing and the number of people have--living have been increasing," and there's more people, and costs have shifted, as well. And so, they re-estimated what Medicaid is spending, and the cost went up. So, the budget data that we will be releasing and that I'll be referencing today reflects that. But, it's different than some older numbers that some of you may have seen.

I will also show a little bit of data from the fiscal year '02 budget and from the President's fiscal year '03 proposed budget. And I just want to highlight a few documents that, for those of you who are really into this topic and budget numbers and really get excited about it, you can also find, in addition to our forthcoming federal budget analysis on HIV, we just put out an analysis of the President's budget--fiscal year 2003 proposed budget. Not specific to HIV, but has a lot of information about health programs, including HIV, what is in the budget, and this is on our Web site.

We are also doing several analyses on federal spending on HIV/AIDS that will be coming out in the next several months, including an update of a document that came out last year called "Global Spending on HIV/AIDS," really trying to, for the first time, collect all the different sources of spending on the global epidemic and try to figure out what we are spending. And I'm happy that a representative of Progressive Health Partners, Priya Alagiri, who is working on that for us, is here today. So, if you have any questions about it, she's probably the one to ask.

Okay. So, let me set up some data. Attitudes: this just shows you from a recent survey we did what does the U.S. public feel about federal spending on HIV/AIDS and, as you can see, the majority feel like spending is too little, 55 percent. About a quarter say spending is about right, and 5 percent say spending is too much. That just gives you some context and background for what the U.S. public feels.

Next couple figures are try--to provide some more context. This one just shows you when we think about federal spending on HIV/AIDS, we have to think about multiple departments and agencies. A lot of us think about HHS, Health and Human Services, and maybe HUD. But, we don't always think about all these other agencies and departments that do play a role, some not a big role, and sometimes their role changes over time in terms of dollars. But, all of these entities are involved in the federal response, and it's important to understand their different roles and what the dollars are that are associated with that.

Next, when we think about federal spending, we tend to put it in categories. These are the major categories that we use, and that the government usually uses, the first being care and assistance. By assistance, what we mean is income support. So, when we think about the care side, we think about Medicaid, Ryan White, Medicare, the programs that provide healthcare to people. We think about income support, it's SSI, SSDI, the programs that provide cash assistance to help people live.

Then, the second category is prevention, primarily in this country at CDC, but there's other agencies and entities that do prevention work in the federal government. Research, again primarily at NIH, but there are other agencies that do research, and international. And I also want to point out that these categories are--the numbers I'll be presenting are discreet, so you would add them up to find out total spending.

So, what did we spend on care, what do we spend on prevention, etc. But, that--those are somewhat artificial distinctions, and it's important to know that when we talk about prevention, for example, some of those prevention activities are on international prevention. When we talk about research, some of those research activities are international research, and it's very hard to sort of pull--tease out what's really going on.

Okay. The next distinction that I really want to hammer home, if you take home one message today, this is a really important one, and I think Scott and Pat will also be talking a little bit about it, is the distinction between mandatory and discretionary spending.

Mandatory spending, or you might hear of it as entitlement spending, is spending that's assured to be there, for the most part, unless Congress changes the law. In general, that means that each year spending will change based on the need for a service or the cost of that service. So, if there are more people living with HIV and they're eligible for an entitlement program, there will be more dollars available to serve them. If the cost of prescription drugs goes up, there will be more dollars there to pay for that, in general.

And the main programs we--that are the entitlement programs that provide care and assistance to people with HIV are Medicaid being the largest, Medicare, which is really quite important and is the second largest, and then the cash assistance programs, SSI and SSDI. And, in general, while they're not completely invulnerable to changes in the economy, they are entitlement programs. And again, so if people--if there are more people and services cost more, more money in general will be available.

On the discretionary spending side, it's a very different story. In there, the money that is available depends on annual appropriations by Congress. And so, the level of funding may not correspond with the need, based on number of people or the cost of service. It may, but it may not. It's discretionary. And the main programs there are sort of all the rest that we think about, Ryan White being the main one on the care side.

All CDC prevention and other prevention funding at any other agency, it's all discretionary, NIH research and several others that you might have seen on the list. So, it's very important to maintain that distinction in your head when you're thinking about the budget and what's happening to the budget.

Okay, a little more context. This just shows, in terms of thinking about need, which is hard to quantify, and you all know that this is what is occurring. This shows estimated number of persons living with AIDS in the U.S. and AIDS-related deaths over the last several years. And as we know, AIDS-related deaths have been going down--that's sort of the left side bar there--and then, access there, and then the right side people--living--are going up.

This is just the U.S., and this is just AIDS cases. When we think about people with HIV and AIDS in the U.S., it's more like a million people living. When we think about the global epidemic, there's 40 million. So, it--really just to give you a sense of the scope that we're talking about, an increasing number of people.

Also--and we're getting into some actual budget numbers now--HIV/AIDS spending, which has been increasing, and I'll show you some charts that show how it's been increasing over time, it's really a very, very small part of overall federal spending. And in fiscal year 2001, it represented less than a percent of overall federal spending.

Okay. Federal spending on HIV/AIDS over time--and these are the recalculated totals. So, those of you who are really into this and have been paying attention to these numbers in budget chart books that we've put out and work that Scott and his office have put out, these might look a little different because they've been revised. As you can see, spending is increasing over time, and it more than doubled between fiscal year 1995 and fiscal year 2001.

I will also note for those of you who pay lots of attention to these numbers, fiscal year 2001 includes a one-time mandatory appropriation for the Ricky Ray Hemophilia Act. That's a number--that was 580 million, so not insubstantial number, that will not appear in subsequent budget numbers. So, it's--raised that bar a little bit.

Okay, bringing back our mandatory and discretionary spending distinctions. So, now you've seen the number in 2001, 14.2 billion, and we see how that's risen over time. So, look at that 14.2 billion. What proportion of it is mandatory spending and what proportion is discretionary? So, in other words, what proportion is generally guaranteed to be there if there are more people or higher cost of services, and what proportion is discretionary?

That's really going to depend on what happens in Congress, and budget priorities. The right side shows you the mandatory which--about half, and the left side shows you discretionary. So, 50/50 of our AIDS spending is mandatory and discretionary. I'm not showing you later years. The mandatory proportion's increasing slightly, relative to the other, and that's reflecting the fact that there are more people living with HIV and AIDS who are qualifying for mandatory programs on the care side. But again, this distinction is really important.

Okay. Now, I want to talk about those categories again. When we talk about fiscal year 2001 spending on HIV/AIDS, how does it break down by type of spending? And as I mentioned earlier, most of it is care and assistance. That's the bulk of spending, of which most is mandatory, and I'll show you a chart on that in a little bit. That's followed by research dollars, which are 17 percent, and then prevention, little less than 7 percent, 6 percent really, and international about 4 percent. And remember that there are some international activities that are occurring in some of the other categories, and vice versa. But, this is--these are the broad categories.

Okay. How has this been changing over time? Hope you can see it from there, but what I've done here is show you the different bars by those categories over time. And as you can see, they've all been growing. Care and assistance is the largest piece. So, if that goes up, it's really going to affect the bottom line number the most.

But actually, if you look--if you do the calculations, the category that has increased by the greatest percentage over time is international spending. But, it's still a very small part of the overall budget. That's the last bar on each of those years, the tiny little bar. So, even though it's increased the greatest percentage, it's a small, small part of the budget.

The next category that's increased at the slightly less rate is care and assistance, which has increased quite a bit. And because it's so big, again, it's going to really up the numbers. Then is research, which has increased over time, as well, but not as much, and followed by prevention. Prevention's last. It hasn't increased as fast as any of the other categories.

So--okay. I want to pull out the care and assistance piece for just a minute because that is such a huge part of the budget, and I know that Pat and Scott will be talking a little bit about Ryan White, and Scott will be talking about Medicaid and Ryan White. But, let's just look at that care piece.

When you pull out care and assistance for fiscal year 2001, that itself totals 10.3 billion. So, of that 14.2, 10.3 billion is care and assistance. Two-thirds of it are mandatory spending, just bringing that back again. I mean, that's, again, Medicaid, Medicare, SSI and SSDI. About a third is discretionary,

not an insignificant amount, and that's Ryan White and a few other healthcare programs. So, I just want to point that out again.

Okay. Moving on to some more recent data. What I did here was pull out some of the discretionary programs and agencies that are not on the mandatory side. So, these are really, you know, important for people to focus on to see what is Congress deciding about them and what is the President proposing about them.

And so, here you see in fiscal year 2001 through 2003 what has happened with NIH research dollars, what has happened with Ryan White and what is happening with CDC prevention. Research has been increasing and, in fact, between--in the President's current budget proposal it's the only category that does have a proposed increase. HRSA, Ryan White spending has not increased very much between '01 and '02, and has--the budget proposes no increase now, and CDC prevention dollars, similar there, as well.

Okay. So, I'm summing up now. Some key trends and themes. First, federal budget for HIV/AIDS is increasing, and it's largely due to this mandatory entitlement spending on care and support services, the biggest category. Again, about half is discretionary, half is mandatory.

The mandatory proportion is increasing slightly over time. International spending has grown the fastest, but it's still a very small part of federal spending on HIV/AIDS. There are smaller percentage increases in research and prevention and, as I mentioned earlier, the only proposed increase in the President's budget is for research at NIH.

So, is this meeting the need? Just a few pieces of data, if you--to help us and form that question. We know on the domestic side in care, for example, that ADAP programs across the country, several of them continue to have waiting lists and face restrictions, and I think Pat can also talk about some of the current impacts of budget cuts in general on Ryan White.

On the prevention side, we know that we've pretty much maintained our 40,000 new infections annually for several years now. We haven't been able to reduce that further. And then, globally, the numbers are increasing, and people are aware of that.

So, the outlook for fiscal year 2003 and beyond, just a few things to think about. Historically, spending on HIV/AIDS has fared well in Congress through the appropriations process. As we saw earlier, there's strong public support for federal spending, but it's not really clear how that support would compare to other priorities. If you put other priorities to the public and said, "Okay, choose, or would you still support HIV," we don't know. And we also don't know how that would translate at the voting booth. So, would people really vote based on their feeling that HIV/AIDS spending is important? We don't know.

And we're in an economic downturn. The current fiscal environment is much more challenging. There's new budget priorities, and I've listed a few of the issues there. The President's '03 budget has proposed decreases in other health programs, not just in HIV.

So, I think a challenge for all of us is to really link our response to HIV/AIDS to this current environment and help demonstrate not just how--what the need is and how the programs that have--that already exist are meeting that need needs--have more to meet that need. But also, how HIV/AIDS connects to some of the other budget priorities that are on the table right now, to the new globalism that people are talking about, bioterrorism and strengthening the public health infrastructure. All of these things are things that we all--all of us working in HIV know that our response to HIV can be very helpful in forming those other decisions, as well as we know that what happens in those realms will affect what happens to people with HIV and to the programs that serve them.

So, I'll end there, and I look forward to your questions. Thanks.

DR. WINIARSKI: Okay. Scott Boule is a participant--an active participant in the federal budgetary process. He's beginning his third year as Appropriations Associate on the Labor, Health and Human Services Education Appropriations Subcommittee for House Democratic Whip Nancy Pelosi. His position with the Minority Whip focuses on appropriations and health issues, such as expansion of access to healthcare, environmental health, vaccine developments and improvement of HIV/AIDS services.

In addition, Scott is also responsible for policy work in the Whip operation on budget, tax, social security, gay rights and health issues pending in the U.S. House of Representatives. This morning, he'll discuss the federal budget outlook as it relates to funding for HIV/AIDS prevention, care, research and treatment. He'll also focus on challenges and opportunities in the current fiscal environment and ways to advocate effectively for additional resources.

Scott?

MR. SCOTT BOULE: Get situated here. Thank you. Thank you very much for inviting me here today. Thank you to amfAR for putting this conference on. In particular, I'd like to thank Jane Silver for all the work that she does, and many of the groups that are a part of the conference today, Kaiser Family Foundation, Care Coalition. The work that you all do, the expertise that you bring to us, really informs the debate on Capitol Hill and helps us move these issues forward, helps us move the budget forward, and we're really very grateful. So, I'm very happy to be here today.

The way the Congressional schedule played out this week, I wasn't able to leave DC until late last night, so I got here kind of in the middle of the night. So, if I sound a little incoherent at points, please pretend like it's not happening, and we'll just try and make it through. I guess some would argue--I've been asked to speak about the federal budget outlook, and I suppose some would argue that incoherence is a good fit with that topic, particularly these days.

The budget outlook is not good this year and, unfortunately, the next several years are gonna be very challenging. The federal budget surplus has disappeared, and that's created a difficult situation, particularly on the discretionary side of spending.

Jen just outlined the differences between discretionary and mandatory spending. In terms of the discretionary programs, Ryan White, CDC prevention, are much more--are global--all of them are global funding--is very reliant on having resources available. We're very much at the mercy of what is in the federal coffers because, if the pie shrinks, then there's less to work with. And, of course, the need has not been shrinking.

We have significant levels of unmet need in--across the board in those programs. So, the challenge is growing and, unfortunately, the resources have been shrinking which, frankly, is a frustrating situation for members of Congress like my boss, who have been advocating to address these unmet needs, not just in terms of HIV/AIDS, but in terms of environmental protection, housing, education, across the board. We've got a lot of unmet needs, and the disappearance of the surplus was predictable.

A year ago when my boss was out speaking about this and when I would do these panels, we would talk about the proposed tax cut and, you know, talk about what that would do to the budget and what that was going to mean for our ability to address unmet needs. Usually, I start off when I talk, I give a disclaimer that, you know, I'm bringing in Democratic perspective. But, certainly always encourage groups to bring someone from the other side, as well. So, I wanted to make sure I said that.

But, this is--created a situation that makes for a bleak budget outlook. A year ago, we had a surplus that was estimated over 10 years at \$5.6 trillion, and now that surplus is gone. And, you know, that creates large challenges for Social Security, for Medicare, the baby boomer generation starts retiring in 2008, and the cost of those entitlement programs is going to expand dramatically. And, as Jen showed, you know, the mandatory side of the budget impacts what is available on the discretionary side.

So there's a real concern about where we're headed, in terms of resources, and the reason I said that, you know, this is something that goes beyond what we're going to be debating this year in terms of the budget.

Most of the factors that have caused the turnaround from surplus back to deficit are continuing through this year. The way the tax cut works, it's more fully implemented each year. So, each year over the next 10 years, it takes a bigger bite out of the overall pie of what's available in terms of federal resources.

The other factors in that equation are the situation with the recession. I'm not an economist. I know there are sometimes that that might be turning around. But, certainly when the economy is bad, that means there's fewer tax dollars, fewer resources coming into the federal coffers.

And then, the other thing is the ongoing cost associated with the war on terrorism, with homeland security, our bioterrorism needs. All those needs are likely to continue, as well. I will say that, you

know, on the other side of the aisle, the Republicans tend to emphasize those last two pieces, the recession and the costs associated with the war on terrorism and de-emphasize the impact of the tax cut.

But, when you look overall at the 10-year surplus and where it disappeared to, about 43 percent of that is a result of the tax cut, and then a little under 40 percent has to do with the recession, and then the remaining 20 percent has to do with the defense needs and some other aspects.

So, in terms of what that means for our HIV/AIDS programs, care, prevention, global, as I said and as Jen mentioned, that it's gonna impact the amount of money that's available for discretionary spending. And there are some other factors that haven't even been incorporated into that equation, things you've probably heard about, adding a prescription drug benefit to Medicare is a high priority, and there are significant costs associated with that.

Over the next 10 years, we're likely to have natural disasters that require emergency spending that can really--can total in the billions. We don't think about that when we, you know, consider where the budget is happening. But, when there's a hurricane, when there's a tornado, when there's a flood, a significant amount of federal resources--when there's an earthquake--are needed in those areas of the country to address that. And then, of course, you know, as we saw last year, unforeseen events can increase needs in terms of defense, bioterrorism and other areas.

So, there are a lot of needs competing for that pie that is shrinking, in terms of overall federal resources, and the impact on discretionary programs is seen in the President's budget. If we look at healthcare in total, the resources are increased by about \$2-1/2 billion. But, the increases for those primarily go to bioterrorism and what we term as homeland security needs in relation to terrorist threats and research at the NIH.

There's been a real strong bipartisan effort over five years to double NIH's funding for research. And so, this year, NIH will receive an increase of--this year, the proposed increase for NIH, which I think has strong support from both Democrats and Republicans, is about 3.7 billion. The increases for homeland security and bioterrorism are about 1.3 billion. So, that's five billion in proposed increases, but the amount for health only went up by 2.5 billion. So, we've got 2.5 billion in cuts to other programs and other areas of the health budget.

And what that's meant in terms of HIV/AIDS care and prevention is proposals for flat funding across the board. The Ryan White Care Act in the President's budget is flat funded, prevention at the CDC, both domestically and internationally, is frozen. There is a small increase at the U.S. Agency for International Development for global HIV/AIDS prevention and care, and then flat funding is also proposed for them in Minority HIV/AIDS Initiative.

In each of those programs, as I said at the beginning of my presentation, we have needs that are growing. In her presentation, Jen mentioned that the situation with ADAPs across the country, the fact that we have 10 states that have waiting lists that aren't able to serve everyone who's eligible. And, of

course, in terms of prevention, then we've had 40,000 new infections each year and, in certain specific sub-populations, the numbers of new infections have been increasing. So, the need is not shrinking, and that creates a situation where flat funding is gonna be a problem.

So, what my boss is trying to do to address these concerns, there are really two categories when we look specifically at HIV/AIDS care. She is a member of the Labor, Health and Human Services, Education Appropriations Subcommittee, and that's the Subcommittee that allocates all of the federal resources to those three departments: Labor, Health and Human Services and Education. So, in that role, she is able to advocate for additional resources and propose that we do better than what is in the President's budget.

Last year, we were in a similar situation. Flat funding had been proposed for Ryan White. We ended up at the end of the process, after much negotiating and pushing from outside groups, which is vital to the process and from the inside, we ended up getting an increase of 103 million for the Minority Initiative. The Administration had proposed a 1 million increase; we ended up getting a 31 million increase for prevention at the CDC. The Administration had proposed a \$23 million increase; we ended up getting a \$77 million increase. And we'll, of course, again this year be making those programs a priority in an effort to do better than what's in the budget.

But, in the appropriations process, where you start has a huge impact on where you finish. For all the programs that are either flat funded or cut, the Appropriations Committee has to try to come in and find additional resources to make up for those cuts, or to, you know, provide some increases where there's flat funding. And so, it means that, at the end of the process, we're only going to be able to get so far.

So, the--two years in a row of proposing flat funding for Ryan White and basically proposing flat funding for prevention certainly has an impact on where those resources end up. We do, because of the strong grassroots support, because of the strong support in Congress, we do end up doing better than where the budget starts out. But, it certainly creates a challenging situation. And in that battle, in that effort to increase appropriations from what's in the proposed budget, the importance of the grassroots networks are really, really key.

One advantage that we had in terms of our HIV/AIDS programs is that we have kind of a built-in grassroots network. We have AIDS service organizations across the country, we have grantees from Ryan White and from CDC prevention dollars across the country, and it's very important for all of the communities that rely on this funding to provide services to know the power that they have to advocate. There's nothing more effective than having a constituent from a member's district come in and highlight the need for additional resources, or to talk about what it means to freeze Ryan White funding.

Inflation occurs each year, and medical inflation is--inflation for healthcare costs is higher than the average inflation rate. And, of course, with 40,000 new infections each year, we have more people living with HIV and AIDS. So, to come in and talk to members of Congress about that really has an impact.

You can imagine if you just look at the funding Bill that includes HHS, incorporating the Department of Labor, the Department of Education and the Department of Health and Human Services, there are a lot of programs and a lot of accounts to look at. And one of the ways you can highlight the needs in a certain area is through meeting with members of Congress, and I know it's not always possible for groups to come to Washington, DC. But, every member of Congress--every House member has a district office, and most members typically spend one or two days a week in that office. And, of course, they have staff in that office at all times.

My boss, for instance, typically returns from Washington to San Francisco either Thursday or Friday morning and will stay until Monday. So, often Friday and through the weekend into Monday, she's here in San Francisco. And as I said, we--you know, there are staff in those offices at any time. So, the grassroots mobilization can really have an impact, and members of Congress need to understand the impact of flat funding, the impact of proposed cuts, specifically what it's going to mean to that community.

Again, you know, these numbers are in the midst of so many competing needs in so many programs that the work that you all do to explain what this is really gonna mean for access to care in a given community makes a huge difference. It really does, and the importance of that can't be overstated.

And in terms of the national coalitions that are working on these funding streams, I think that, because of the limited resources, you know, or the--because of the situation with the budget and the--all right, this is the incoherence that I mentioned earlier--understanding that national organizations themselves have a limited set of resources to deal with. Certainly, members of Congress can be targeted to, you know, effectively use what's available if the issue is sending people to DC, if the issue is writing letters or doing some mobilization in a specific community. Certainly, members of the Appropriations Committee on both the House and Senate side are key in this process, because those are the members who, again, look at what's in the federal budget and allocate it among the different programs.

I can say that there's certainly strong support for all these programs on the Democratic side, so I always emphasize groups to find Republican members who are on the Appropriations Committee. It's even better if they're on one of the Subcommittees that fund either HHS or USAID, or one of the departments that plays a key role in HIV/AIDS care services, prevention and research. But, to target those members is a good way to make sure that people know what the needs are and know how the money's being used, and know what the future challenges are.

The other thing, aside from the appropriations process that Congresswoman Pelosi has been doing to try and address the current situation where we've got shrinking resources and expanding need is a Bill that she introduced with the House Democratic leader, Richard Gephardt. It's called the Early Treatment for HIV Act.

Right now, we have a difficult situation on the mandatory side in terms of Medicaid spending. In order to qualify for Medicaid right now, a person with HIV has to wait until they've progressed to full-blown AIDS, because you have to meet the definition of disability that's included in Medicaid requirements.

And, of course, when we've got AIDS medications that can delay that progression--significantly delay that progression, it's not good healthcare policy from a humanitarian standpoint, also from a fiscal standpoint. The cost savings, when you treat people early and keep people healthy are significant.

So, what the Early Treatment for HIV Act would do is give states the option to allow people with HIV to qualify for Medicaid before they've progressed to full-blown AIDS, and then meeting the definition of disability. And the number of the Bill is H.R. 2063, in the Senate it's S-987. The lead sponsor in the Senate is Senator Torricelli. We're working to build support for the Bill right now, trying to put together a strategy to try and move it this year. One key aspect of that is the number of co-sponsors. Every Bill that's introduced has members who sign on to lend their support.

Our Bill right now in the House has 136 co-sponsors, which is a good number. Unfortunately, we only have three Republicans and, certainly over the years, the list of Republicans who have been supportive of HIV care and treatment issues is larger than three. And so, to strengthen our chances to move this Bill forward, bringing on additional Republican co-sponsors would certainly put us in a stronger position. And that's another situation where the folks in all the various communities that these members represent have tremendous power in terms of highlighting the need for this Bill and the need for that member to become a co-sponsor. And, of course, this is a similar situation on the Senate side. We need to have more co-sponsors, we need to have more Republicans join Senators Torricelli and Kerry, who are working on this right now.

So, I will end there. I know it's kind of a bleak outlook. But certainly, this process can be impacted. When we hold the Administration accountable for budget decisions that are made, then that applies pressure by pointing out, as I mentioned before, to your members of Congress, to your Senators, what it would mean if we flat fund these programs. If we don't meet the additional unmet need, can have a tremendous impact.

In the President's budget this year, there's another \$600 billion of tax cuts proposed. Again, that's money that will be taken from the resources that will go to other programs. So, there's still many opportunities to improve that 10-year outlook and make sure that we do better.

The other thing in terms of working with Republicans, I think it's really important to get more moderate Republicans to speak out. Again, we've had folks on the other side of the aisle, members of Congress who have been supportive of the work that you all do and of our issues. And, unfortunately, some of the members who are on the far right and who criticize some of these programs and, frankly, sometimes mischaracterize how the money's being used, they--you know, the squeaky wheel phenomenon, those members tend to speak out more.

So again, I'd encourage you to work with moderate Republicans for them to make their voices heard and, certainly, for Democrats, for Congresswoman Pelosi, for Representative David Obey, who is our top Democrat on the Appropriations Committee. These programs are gonna be a high priority. And, hopefully at the end of the process, we'll do better than the flat funding that's been proposed.

Thank you.

DR. WINIARSKI: And just a reminder, Nancy Pelosi will be speaking at 11:30 today in the plenary session.

The view from the trenches will be expressed by our next speaker. Patricia Bass is a nurse by training, and co-Director of the AIDS Activities Coordinating Office in the Philadelphia Health Department. So, she helps direct a Title I EMA, Emergency Metropolitan Area, that comprises two states and nine counties. But, as importantly, she is Chair of the Care Coalition, which is comprised of cities advocating for Title I or Title III funding.

I welcome you and look forward to hearing about how it is in the trenches.

MS. PATRICIA BASS: I guess, Scott, that's a disclaimer for me, too, that I am the Chair of the Care Coalition, talking primarily about Title I and Title III. So, I hope today I can present a model of how those of us who are out there advocating for these dollars can begin to work collaboratively and move towards having some way of saying, okay, how do we go about making sure the dollars are there for our folks who need these services?

On the plane last night--I, too, came in from the other side of the world last night. I should have been in my "back in the day" scenario. My kids always accuse me of always making my audiences deal with me back in the day.

So, let me just suggest to you that we've--if we go back before--not before, but certainly when this epidemic became an epidemic in our local areas, and before we had the Ryan White Care dollars, most of our public health systems were almost at a point of disarray. Had we not had the Ryan White Title dollars, in fact, most of our public health systems would have imploded.

So, they were talking about 9/11, but I would suggest that the--sort of the AIDS epidemic presented this same kind of challenge to public health. And so, I think, certainly, I am going to do my presentation today as an Administrator of a Title I EMA, we are a two-state, nine-county EMA, and talk to you a little bit about the challenges of how I see this perspective, and so that--I actually re-framed the question.

The question is, "Is the money drying up," and for me, the question really is, "Is the money for HIV and AIDS on the radar screen for those of us who are in Washington?" And my answer to that would probably be no. I mean, I think, certainly, we have many friends, and we talk to our friends all the time.

But, on the other hand, we have folks that we hear only about--we hear mostly about global AIDS. I would suggest that, in most of our cities, we have areas that look just like areas of Africa. I could take you to some spots in Philadelphia that would make you say, "Oh, this is the States, huh?" So, let us be careful about where we go with all of that.

So, the question for me as an Administrator is, "What would happen if the Ryan White Care Act dollars were to go away?" And in some respects, this year it was almost like that, you know. We talked about what happened and the increases that were not easy for us. But, many of us saw level funding, many of us saw decreases, and so that the dollars that we saw, and the new dollars were really absorbed. So, let me put it in a context of why some of that happened.

I guess it was about--many of us in this room are recovering from reauthorization. We still have our Band-Aids on from reauthorization. And, folks, you better get 'em out again, because in about 18 months you'll need to put 'em back on because, certainly, the reauthorized--it was a struggle getting the Bill reauthorized the last time.

But, there were some clear things that happened with that Bill that were opportunities for us. I think the major opportunity was for us to move public--move HIV disease from a reactive stance of sick care to a proactive stance of public healthcare. It gave us an opportunity to talk about primary, secondary and tertiary care in a way that no one ever talked about it before.

And so, all of a sudden--I mean, I was amazed at the number of partners that we listed on that--on your overhead--on your--it's not an overhead, whatever that thing was--that you presented us with. And I'm thinking, okay, those are our partners. But, they don't talk to one another most of the time, and we have, in fact, taken it to our local areas where we don't talk to one another. Those of us that are coalitions nationally who advocate for these dollars don't always talk to one another.

And so, in the long run, what happens to our clients? And so, I think that, certainly--I think the reauthorized Bill was one time--was, certainly for me a time when we had to begin to say, okay, this was really a battle for us.

But, with the reauthorized Bill, I think some other things happened. I think all of a sudden we were given some challenges. We were given the challenge of looking at loss to care and unmet need. We began--given the challenge of finally saying to folks it was time to get past anecdotes about quality care. I would suggest that we've always been providing quality care. But, we gave information about quality care as anecdotes. And so, all of a sudden now, we're being held accountable and I think it's a very positive piece about that.

So, I think that, certainly as I look at what happened with the reauthorized Bill, now looking at what's happening with funding, it sort of scares me. So, but if we assume that there are about a half a million people who are, in fact, infected or--affected who are either not in care, who do not know their HIV status, then how do we provide care to those folks when they come to us?

If we are, in fact, going to encourage utilization, what do we do when they come to our door? I don't want to go back to the days of the waiting lists. You know, most of us have gotten to the point now where, yeah, there are some waiting lists. But, the days for the two and three month waiting lists in many of our EMAs in our larger areas have gone away. They have gone away because we've had the dollars. Do we really want to go back there?

We're saying that about 75 percent of the folks living in U.S. cities in Title I areas receive those services through the Title I Care Act, whether it's Title--whether the multiple titles. But, it's certainly--folks are--we have been--we're seeing increasing number of folks who are uninsured or underinsured. Well, where do they go for their care? It is, in fact, to the Title I--well, to the Ryan White Care Services.

We're seeing more and more folks of color. Certainly, we've seen the impact on women. We're seeing more and more folks who are on waiting lists for ADAP. As the drugs change, how do we keep up that pace? Better yet, how do we treat folks with the co-morbidities? We're no longer just talking about people who have HIV disease. We're talking about people now who are presenting with multiple co-morbidities, and how do we treat them all?

What do we do about women, you know, women with a Title IV? Women who, in fact, for them, their HIV care is not the day for them. Their HIV care becomes last on their list when they talk about their daily living.

I have a colleague here who runs one of my favorite centers in Philadelphia. It's called St. Mary's Day Respite. And whenever I want to get some TLC, I go visit her babies. It's a preschool program. And I go and I look at these wonderful little children who are there, and who are there because of the Ryan White Care dollars, multi-titled.

So what do we do about folks with dental? I mean, I have a hard time getting dental care, and I think I have pretty good healthcare until they send me that bill for what's not compensated. So what do we do for folks who need dental care?

I think that there is certainly no question that there's an increased need for the dollars. I would also suggest that, without the dollars, we will not be able to provide those very valuable services. I think we've gone past the point of trying to talk about what are the important services. There are no soft services for our folks.

Our folks need primary care. But, certainly without the wraparound services, they would not be able to maintain their care. So we don't need to talk about people who are non-compliant. People don't choose not to be compliant. Most of us would choose, in fact, to be adherent to our care.

I think certainly, as we face cuts in our state funding for low income, what do we do then? Scott talked about the mandatory systems and what happens if and when we ever get Medicaid expansion. But, there are states that are, in fact, facing real tragedies around those dollars. What would happen to them?

I think certainly as we look at these effective treatments, that they're expensive--we're talking about a continuum of care now that is no longer seeing folks today come into our system, and when they are dying. Yes, in some areas we're seeing folks who are coming into our system who are sicker. But,

once we get them there, if we wrap around them, in fact, we can help them maintain a lifestyle and, in fact, be as healthy as they can be.

I think as we see HIV/AIDS continuing to affect communities of color in this country, those communities that are economically deprived, and those communities where folks don't know how to navigate systems, certainly we need to talk about the discretionary dollars, and it is the discretionary dollars that make this possible.

I don't want to think about what would happen if we had the lack of those resources. I don't want to think about having to help folks talk about navigating systems.

I think that there are certainly some challenges. You know, we've gone through a primary care business that lasted 15 minutes to one that last now, what, three hours? Four hours? All day? We're talking about folks who come in in the morning and they're not just seeing their primary care physician. They're seeing the nutritionist, they're having lab work, they're--you know, there are all these other things, and there's costs associated with that.

We're seeing an increased need in those who--needing supportive services. I don't know about your area, but I can't keep enough case managers. I can't keep enough bilingual case managers.

The administrative costs--I mean, folks don't want to talk about that. But, as a grantee, I need to talk about that a little bit. What happens when my funder tells me that my data collection systems need to change, my reporting systems need to change? That I have to now do an evaluation? And also, how do I put that in the context of my own staff and my ongoing staff training?

Okay, And then, what about those computers? You know, just when you buy one and you plug it in, they tell me it's 18 months too late. Well, what do you do with systems like that? I think that, certainly, our system is moving away from being a data-driven system to a system that should, in fact, be using data as an accountability and as a planning. If we don't do that, folks, we're doing a disservice.

So I think that, clearly, the goals of 100 percent access and 0 percent disparities are important goals to have. I think that, certainly, we need to be sure that we continue the successes that we are having.

We've seen reductions in HIV-related hospital admissions. We've seen a reduction in AIDS mortality. We're providing primary medical care to significant numbers of people. We're providing access to the important medicines. We have all--we have curbed mother-to-child transmission of HIV. So then, in fact, we've seen some things that happened.

But on the other hand, now we're having to deal with the things, the challenges of people who are healthy. So what do you talk--what do you say to the woman who comes in and she's 30 years old and she's Spanish, she's having an internal summer (?) ? I can relate to that, but I'm 59 years old. So, how do you talk to a woman who's 30 years old who's having, you know, early menopause?

Are we not beginning to talk to folks about pre-conceptual counseling? Should we not be doing that? And I would suggest that this is exactly what the Ryan White Care Act dollars allow us to do.

I think that certainly the '02 allocations were a struggle, and we've spent a lot of time in DC. And we didn't get--and we did not get enough. But, in light of that, how do we continue to provide those services?

I was talking to a colleague recently about a waiting list for mental health services. Well, how do you have a waiting list for mental health services or for services for substance abuse? How do you do that?

So I think that, if you look at what happened this year, yeah, we had an increase. But remember that there were 17 EMAs that had decreases in their funding. Seventeen. There are how many of us? Fifty-one, fifty-two? That means that 17 of our EMAs are having to talk about cutting their services. So how do you tell someone, "I'm sorry, but I can't provide you that service today?"

The questions that we need to address is that we don't need to just talk about level funding but, how do we continue to fight to have the fundings increased. I think, certainly, that we cannot allow the system to go away. Clearly, the Ryan White Title dollars are the safety net for folks who have HIV disease.

The funding is not an entitlement. It is not an entitlement, folks, and so I say to the folks in Philadelphia all the time, "It's a gift." And--but, what happens if the gift goes away? So that yes, the President's budget was flat, and there are a number of us who are gonna go to DC in a few weeks and challenge that. But, what can you do locally?

I think the time is right for us to stop doing anecdotes. I believe the time is right for you to articulate at the local level to your members what our needs are, what your needs are.

I think that the Bill certainly has made a difference for us, okay? It's made a difference for all of us. But, certainly, I think the largest challenge is how do we begin to work collaboratively?

I was saying to a colleague this morning that I've only been in the AIDS world for about six years. I've been in nursing--I'm a nurse, and I've been in healthcare for many years. And I didn't realize the whole issue around turfs, you know, and don't step on my side of the street, you know. Don't take my clients. Well, I want to say, they're our clients, folks. We can all benefit from this. And so, how do we begin to get past this?

I think, certainly, time is right for a change. It's time for us--there was a movie, once again back in the day. I don't remember the name of it, but it--I remember this man. There was something--"I'm mad as hell, I'm not gonna take it any more." Well, if you're not mad as hell, you need to be, okay? You need to be. You need to be saying to someone, "Sorry, we cannot do this with limited dollars." But, more importantly, you need to begin to put on your armor, because reauthorization starts in another 18 months, folks.

Thank you.

DR. WINIARSKI: We'll have questions from that microphone. I want to thank the speakers for their clarity, for their glimmers of hope, for their passion and for their call to action. That's their gift to us. It's now our responsibility to use that gift and to go out and advocate in new and effective ways.

I'm gonna take the first--the opportunity to ask the first question, and then I'll ask people to come to the microphone. And that is that the theme that we should be linking our advocacy to the current environment has been repeated here, and Scott talked about the effectiveness of coming to Congress.

I'm a little bit of a skeptic about whether my letter to my local Congressman or Senators really is effective. It might be, but I get a form letter back. I'm wondering if there are ways that the panelists could suggest how to be a little bit more creative and be able to advance our agenda in a way that, perhaps, goes outside of the current boxes?

MS. BASS: I'm actually gonna take--is this on? Okay.

I'm gonna take the first go, and then--I mean, tell your story. Go into your local--I don't know if--I mean--let me back up a little bit.

This is a re-election year, and I do think that people are listening. I think it's—I think this is a good opportunity for us to tell our stories. And so, I talked a little bit about St. Mary's, and I think in all of our cities we have these programs that are success programs.

We need to tell those stories. We need to say to folks, "This is what happens to folks." And I don't think--you know, if the letter's going to DC, that's one thing. If the letter's going to your offices--your local offices, that's another.

The fact that you could pick up the phone doesn't--the fact that you can go to the office is another factor. And we need to--while Washington is an important feature, and this is a re-election year, and re-elections don't happen in DC They happen in your local area. And this is a real good time to begin to address some of the matters.

MR. BOULE: Yeah, I would certainly agree, and there's no question that a meeting--a face-to-face, whether it's in Washington or out in the district, is the most effective advocacy tool. But, I would certainly encourage folks to write letters and to make phone calls and to send e-mail. Whatever you get back, to keep track of those. And if there is a significant ground swell on an issue, that's something that the member will take note of.

But, nothing can replace having the opportunity to tell your story or to talk specifically about, you know, what this will mean for New Orleans or Atlanta or Miami or--you know, for the member's local community in terms of services that won't be there if Ryan White is flat funded or cut.

And again, I know it's hard for people to come to DC sometimes, but I think that the access to the district offices is really a underutilized resource in that regard.

But, I think the key is going to be accountability, to--again, talk about what this is gonna mean for the community. And if that person's not out there fighting to increase the resources, or if they're taking the Administration's line that flat funding is okay because we've gotten increases in the past--I was on a panel earlier this week, and an official from HRSA used that line that, "You know, well, we've had, you know, some increases over the past four years so we could probably use a year to slow down and catch up." And you know, my jaw dropped. I couldn't believe that.

We were just talking about the fact that we have a third of people not in care, and a third of people who are HIV positive but don't know their status. And the notion that we would be slowing down should be offensive to everyone living with HIV and AIDS, and everyone who's out doing the work in these communities.

DR. WINIARSKI: We'll entertain questions from the audience, and you need to use the microphone.

UNIDENTIFIED MAN: I'm a Title I/II/III grantee, and I have a couple questions.

First, Scott, this actually goes outside of Ryan White Title I, II or III but, the treatment Bill that you talked about, which allows early treatment, which I think is a really good Bill and, of course, I'll be supporting that. But, one of the questions I really have that just popped in my head when that was said was, well, what about prevention? We're not even talking about people--we don't even want to get people into treatment. Let's start with prevention and, as we saw some of the numbers from Ms. Bass, those numbers are not increasing for prevention costs. And so I just--that just floored me.

MR. BOULE: Yeah. I don't think, though, that we have two distinct categories. I think getting people into treatment and care is an important aspect of that type of prevention, when people know their status.

There's a CDC study showing that behaviors change once people know their status and, certainly, access to care is a perk; creating incentives to know your status, you know. If there's not going to be healthcare available, medications available, that naturally lowers the incentive for someone to know their status.

And care is also an opportunity for prevention education. I mean, people are coming to a community health center or their doctor's office. There's a--such an important opportunity there for education about how to prevent the transmission and respect.

But, having said all that, I mean, I certainly agree that, you know, things--they need to be more focused on prevention and, you know, that reflect the interest of those that get it. It is a problem, and I think it is easier to talk about things like ADAP because it is more concrete, you know, and we can lay out, here

are the numbers, here are the waiting lists, here's what's gonna happen to those waiting lists if the numbers go down, or the number--specifically of people who are gonna be certain.

With preventions that, you know, age-old problem of prevention works, and we can help them, you know. It's historic, and it's been--it's a great economic (inaudible) what it's gonna mean for your district. But, I think there are ways to do that. I mean, that's a challenge that we have to meet.

UNIDENTIFIED MAN: I totally agree with what you said. I just wanted to make sure that there was--that I was clarifying what my question was, was I agree with it, particularly with prevention for HIV-positive people. What I was more concerned about was the Bill addresses a very good concern. My concern was about prevention for people who are not HIV-positive. I didn't want people to get into care, but I don't want people to get HIV-positive, and that's what was a very disturbing number for me.

Ms. Kates, I have one question for you. The numbers that you brought up about the American statistics for people--about supporting HIV and AIDS care, or HIV/AIDS as a general topic, what were the numbers--or, how--when was the study done, and was it--what were the numbers of people that you studied?

MS. KATES: It was a survey that was done last year, and it was a nationally representative telephone survey. So, it was a survey of representative sample of U.S. households. And so, that gives you a sense of what the American public, on average, feels about an issue. That--those are the data I showed.

And there's been some recent survey work done post-9/11 that has also showed still strong support for federal spending on HIV/AIDS that some other organizations have done. But again, it's very hard to then pin down, when push comes to shove, are people going to support that in light of other things that they may support? Will they change how they vote?

We've done a little bit of polling on that. You know, would you support a candidate who advocated an increase in federal spending on HIV/AIDS, or would that affect your vote? And in general, what people say is, "It won't affect my vote that much." I mean, it won't--if someone didn't--supported an increase, they wouldn't not vote for them, for example. But, we're not really picking up a real strong, "This is gonna change how I may act at the voting booth," so--the polling booth. So--but, that was from last year, and we are going to be repeating those surveys in the fall.

UNIDENTIFIED MAN: Do you have numbers of people that were surveyed?

MS. KATES: Yeah. It's a nationally representative sample. I think it was over 2,000 individuals.

UNIDENTIFIED MAN: And the other question I had in regards to that is, are you planning on testing your hypothesis against other--you actually mentioned that there was--that there had been a test done against other, you know--.

MS. KATES: We're hoping in our next survey round we can try to get a better sense of that, to do some comparisons.

UNIDENTIFIED MAN: And Ms. Bass, I'm not a religious person, but amen, amen, amen.

MS. BASS: But, there was no question for me.

MR. BOULE: Just blessings.

MS. KATES: I actually wanted to add one thing, which picks up from what Scott was saying about prevention in the care setting. There have been some recent data showing that a not insignificant number of people learning that they're HIV-infected for the first time are on Medicaid. So, the numbers I saw were like 20 percent of people when they find out that they have HIV are already in Medicaid. And that makes a really strong case for why providing for prevention within the treatment setting can affect people who aren't infected yet. So, understanding those programs and those linkages, and we tend to separate care and prevention artificially, can really help on the prevention side.

MR. JOHN SEQUIN: Hi. I'm John Sequin (sp) from New York State Department of Health AIDS Institute. And I just wanted to comment in that I think I've seen--I don't know if this is--it's not an illusion, that in the Ryan White Care Act, there seems to be more linkage to prevention.

For example, we just had--we had 1.2 million, I think it was CDC Congressional funds for ADAP. It was education and outreach to minority communities to increase their enrollment into ADAP or into care. And that was mainly targeted--definitely minority communities.

But, the first whole part of it was the outreach and the education, which was the prevention. So part of that was to get people educated, counseled, tested, and then link them into care. So, that is under the Ryan White--under the ADAP for me.

And we do see the linkage also in New York State. We have the--I think you have in other states also the prevention planning process, where we also see CDC and state dollars channeled to prevention efforts. But, definitely, you have the linkage to care throughout the entire state. So I do see that trend. I don't know if you have observed it and it's just that's a reality, and maybe it's because the funds are dwindling.

MS. BASS: I think more and more we're seeing race collaboration between our--in our—and local proposals in our community planning groups for prevention, as well as our HIV planning through Ryan White. I can certainly--that's (inaudible) out of necessity of us to work together (inaudible).

And I think also in terms of the Minority Health Initiative, we focused on outreach--really does go back to that fund that people have been raising as a primary, secondary, tertiary care, primary being to those

folks who are either positive or those folks who are not in care. But either way, we can quickly get them into care so that we can--they can maintain their health status.

And I think, certainly, that has--we've seen that change in a very positive way. I still would like to see--for there to be more of that. I think that we still don't always talk enough. But, I do think that that's our health initiative.

And I think you were talking about, you know, the Title II. But, we've seen that in terms of the Title I also, in fact, (inaudible). The importance of--we intend as a Title I EMA. I mean, Title I, by our definition, (inaudible) minority organization, but to also give them the capacity for them, you know, to build the infrastructure so they can provide the services. And that goes back to, I think, our CBOs that are in the communities, the folks who will probably go in care before going to those large institutions that, you know--with high walls.

MS. KATES: Just to add one thing. I'm going back to prevention unto itself. I mean, clearly, linkages are important, and understanding how they both--we can use the current treatment system to foster prevention is critical. But, prevention funding has increased at a much slower rate. And one graph I didn't put up there, but the CDC has shown it, and numerous venue shows the number of new infections in the United States every year.

And in the '80s and very beginning of the '90s, was 150,000 new infections each year. And now, we know it's 40. And you--if you put funding next to that, and you see when funding started to increase for prevention, there was a correlation with a decrease in new infections. It may not have been the cause, and there's a lot of factors that go into people's behavior change and success in that area, but it is something to consider, and--.

MR. BOULE: That link between care and prevention was something that we tried to emphasize during the last re-authorization of the Care Act. So, that's increased, (inaudible) people have seen that. You know, that key (inaudible) specifically not really intervention, which there's something in this (inaudible) some ramifications, so that we do a better job of not having specific system partners (inaudible) between the two, you know, sides of the organization.

DR. WINIARSKI: Okay.

MR. KENNY GARB: Comment and a question. Kenny Garb (sp). I'm with Tulane University Health Science Center, and a brand new Title III grantee.

Prevention dollars are available through Title III funding, just for people who are concerned with cuts. My concern is how are we to protect that one-third, you know, the CDC estimates of people with HIV who are not in care, if the dollars are not gonna be increased? And, you know, we plan for increases in our budgets to capture that population and, if there is no increase, what protection do we have? What insurance?

MS. BASS: Well, and there are a lot of (inaudible). There are a lot of contextual concepts (inaudible), that if we don't (inaudible) increase in the (inaudible) dollars, that we will do what we are mandated to do, which is to bring that third in. And then we have them in a system of care, but can't provide the services. We don't have the funding to provide the services.

But, actually, that is just the question that we can see addressing. How do we make sure that we can? Because I really do fear it's going back to the time when we are not going to be able to provide services, or that public health was going--will have the burdens of what it can't do (inaudible) the strong areas.

MR. BOULE: You should have everyone you know (inaudible). And let us know (inaudible).

MR. GARB: Do we seek out dollars in the private sector? And then, what happens to funding of last resort?

MS. KATES: I think that's one reason why federal initiatives like the Early Treatment For HIV Act can play a role in this because, if Medicaid eligibility is expanded, that could free up the funds on the discretionary side for Ryan White, to treat individuals who are coming in who don't know their status now, or are not in care. And that's—I mean, part of that initiative is to relieve that pressure a little bit, as well as make good public health sense, you know. Let people get into Medicaid before they're disabled if there are medications that could prevent disability.

MR. GARB: Thank you.

DR. WINIARSKI: Additional questions?

UNIDENTIFIED MAN: I just had to make this additional comment. Maybe Scott or the young lady can clarify. There's been a shift in HRSA policy also over the last years, hasn't there? For example, the--now, you can do outreach for the purpose of case finding. So, you can do that prevention effort.

Years ago when I started working in the AIDS field, you couldn't use Ryan White Title II dollars for condoms. Now, you can. So, there's a shift also at the agency level, right?

MS. BASS: I think that's true, and I think, certainly I'm--if we can sort of toot our horn. The Coalition that we've selected here is talking, as well as HRSA. We now have HRSA come from behind their big tall building at (inaudible) or something, and so they're beginning to hear us. I think, certainly, that's--we can change. I think that, right now, there are multiple groups of activities going on at HRSA. There's a group about (inaudible), there's all kinds of studies of people that are going on. But, they're beginning to be more responsive to what we were seeing out in the community. So, I think there's been a shift.

Has it been enough? Oh, probably not because they're not doing everything that our funders doing--to where we always (inaudible). I think there's been a little bit of a change.

I was gonna surprise everybody, but Scott made me promise that--and it was--I don't know who that person was who said that, "Well, maybe it's okay not to have as much (inaudible)," because if there's any group that knows that we cannot--that is not the stance on which (inaudible) our project officers deal with all the time. How do we make ends meet. So, I'll bet it's one of those people (inaudible) project officers that said that.

MR. BOULE: Another comment. Someone else has said that. But, in response to the question from my boss during last year's conference--appropriations hearing about what would end up--goes to (inaudible) in Title II. My boss asked Secretary Thompson the same question. How can we address (inaudible) without funding, and he basically gave us the same answer. He said, "You know, we've had significant increases in Ryan White over the past few years, and we've built it, you know. It's time to slow down, rather than increase."

MS. BASS: Well, then I think all those 17 EMAs that had cuts should send a letter to Secretary Tommy Thompson and say, "Okay, we're one of those EMAs that--we had level funding, and we are doing what we were mandated to do by the re-authorized Bill, and can you top this?"

DR. WINIARSKI: We have time for one more very quick question. We have about two minutes left.

UNIDENTIFIED WOMAN: Hi. First of all, just a quick comment, and my question would be addressed to both to Pat and perhaps Scott.

I am with a CBO/ASO in Palm Springs, California, and our ED of this agency is really, really active in the Care Coalition and AIDS Action Council. And I can tell you, through his activity, and I do a lot of it with him, we do make a difference back in DC; a whole lot of difference. But, it is a lot of letter writing, a lot of phone calls, a lot of faxes and a lot of grinding.

And we were lucky. In our EMA, we're Title I/Title III. We got a 7 percent increase. We're surprised as hell that we got it. But, I'd like to encourage any of you here today that can talk to your--whomever, or do it yourself, start writing those letters.

Quick question, and I know we're running out. When you're--with the re-appropriations, and I know it's gonna get tougher each year, how closely, Scott, do the Representatives in Congress and the Senate--how closely do they look at distribution of the HRSA funds, 'cause there seems to be a great discrepancy in some of the EMAs between, like, San Francisco, LA County, Riverside County area. Is there any readjustment, or--you know, who makes the final decision on that? And I'm keeping it really light, I have to tell you.

DR. WINIARSKI: Real quick response, because we have to end exactly on time. So, you have about a minute.

MR. BOULE: those decisions are made by the authorizing side. The reauthorization that were mentioned earlier was (inaudible) in 2000, and that's where we laid out how the formula was gonna work, how the--you know, it's divided up into income (inaudible) formula and supplemental, what the criteria are gonna be in terms of the supplemental. So, we're considering the last (inaudible) authorization. (inaudible). As you know, that's a huge discussion--.

UNIDENTIFIED WOMAN: --Correct--.

MR. BOULE: --(inaudible). And in terms of appropriation, what we focus on is getting more resources into the program so that they, you know--.

UNIDENTIFIED WOMAN: --More equitable distribution.

MR. BOULE: --The authorizers do determine that (inaudible).

UNIDENTIFIED WOMAN: Then, we need to start talking to the authorizers. Thank you.

DR. WINIARSKI: Okay. Well, thank you.

MS. BASS: Well, we'll have in 18 months they'll be reauthorizing the Bill again. So, start getting your remedy together.

DR. WINIARSKI: That's--not too soon.

Well, again, a reminder that Nancy Pelosi will be speaking at a plenary at 11:30, and her topic will be "Politics of Prevention."

And so I want to thank the panelists at the 14th National AIDS Update Conference and folks in the room, and wish you good luck in seeking funding for our constituencies.

Thank you.

END

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