

**The AIDS Drug Assistance Program:  
A Policy Forum and Release of the Latest Survey  
Findings from the National ADAP Monitoring Project  
April 10, 2007**

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[START RECORDING]

**DIANE ROWLAND, SC.D.:** Oh, my goodness. You just stand up here and the room gets quiet. That's pretty impressive.

Well, welcome to our jam-packed event. I'm Diane Rowland, the Executive Vice President of the Kaiser Family Foundation. And I'm extremely pleased to both welcome you here to the Barbara Jordan Conference Center, but especially to welcome you to this discussion of the ADAP program and our seminal report that we continue to do because we believe that monitoring the impact of this program and the scope of its coverage is one of the main parts of our mission as both an organization that works to try to improve health care delivery and services and coverage in the United States as well as now more globally as well, but also has a source of information to others who are trying to make improvements in the programs and to move forward with at least helping to meet some of the growing needs for health care in the United States. Most of the work that the Kaiser Family Foundation engages in I think focuses around people and their health care. And, of course, the ADAP program fits perfectly into the group of programs that we look at that affect vulnerable populations, those with low incomes, those with the greatest needs. And so I'm very pleased that we continue to have events like this that help shine a light on a program that helps so many people and that

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could help so many more if the resources were there to provide some more extended care.

I think this event, really, is a landmark event for us. It is one of our most continuing projects. We started it in 1996. It is both a long standing project, and I'm proud to say a long standing partnership. It has been terrific to work with NASTAD. They have been a true project partner through the years. They are uniquely situated to help us reach the states as the national organization that represents them. And, of course, I want to particularly thank Julie Scofield, NASTAD's Executive Director, and Murray Penner, the Deputy Executive Director for Domestic Problems, and their whole team for the work they put in to pulling together these statistics, providing this report. But I especially want to thank everyone in the states who cooperate with them and with us to provide the information and the data that allows us today to provide the statistics that can help frame the discussion of the future of the ADAP program and where we should be going.

But it really is also a measure of the commitment of all of you to working on the front lines in the fight against HIV. And we really depend on your ability to tell us how things are going in the states and in the local communities, to understand where the impact of this epidemic is and how we can best address it.

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And that's why I'm so pleased that today we're being able to coordinate this event, even though it's created a little more of a packed audience than we'd anticipated, with the national meeting of the ADAP coordinators. And I understand that we have—I was told there were going to be 75 of you. I think there are a lot more than 75 of you here with us today. And we welcome you all. And if you haven't gotten anything to eat yet, I think more was on its way or being ordered.

And I just really wanted to close with saying what a critical initiative the work on ADAP and on HIV is for the Foundation. It is at the core of our health policy work about vulnerable populations. It is part of our look at the safety net in this country, the shredding of that safety net and maybe the mending of it, we hope. I do a great deal of work, obviously, on the Medicaid program, and I know how important the ADAP program is as a complement to Medicaid, where Medicaid falls short at being able to meet the needs. And that's why this project has really been a central and continuing project for the last 10 years. I think it really offers us not only a way to look at how we deliver care and how we are caring for people with the need for drug assistance with HIV/AIDS, but also for the structure of all of our health care programs, especially those that care for some of the lowest income

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populations. And clearly waiting lists, state variations, funding problems, allocation problems that you face in the ADAP program are instructive lessons for all of us in how we can better meet the needs of the lowest income and most vulnerable Americans.

So I think this is a critical study. It's an important area for us to stay on top of. It's one I know we will remain committed to over the coming years. And I'm very glad, therefore, to be able to both introduce Julie and let her proceed with some comments.

But I'd also like to offer one other set of thanks before I turn to Julie, and that's to the staff here at Kaiser, who worked so heroically to put together our end of this partnership: to Jen Kates, to Jackie Judd, who you will see some of her work in the next few minutes, and to Craig and Alicia for all of the help that they give us in putting together these reports.

So, without further ado, I'll turn it over to Julie. And I want to thank everyone for both coming and for their tremendous participation in this report and in developing the very important information on which to base future policy. Thank you. [Applause]

**JULIE SCOFIELD:** Good afternoon, everyone. It's great to see a full room. And I believe, you know, this is the first

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time—actually, the second time we did the release of this report in this room. It seemed packed last year, and this year it's even more packed. We put more chairs in and we're overflow in a couple of rooms. So, welcome to this fabulous event. We're so happy to see you all.

I'm Julie Scofield. I'm the Executive Director of the National Alliance of State and Territorial AIDS Directors, otherwise known as NASTAD. I hope, as you all know, NASTAD represents the state health department AIDS program managers from around the country. These are the folks out in the state health departments that really administer the continuum of prevention and care programs for people with HIV and AIDS out across the states. That means they often oversee the prevention portfolio, the surveillance portfolio, care and treatment, the new Part B of the Ryan White Program, as we get used to our new language related to the Ryan White Care Act.

They also increasingly oversee adult viral hepatitis programs. And NASTAD has really made a point of embracing that as part of our core mission. And you'll see that now as part of our strategic map. And you'll also see the implications for that in some of the work, including this particular report, where we're trying to look at the intersection between HIV and AIDS and hepatitis.

I also have the great honor to be able to say some

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thank you as we get started with this afternoon's program. I really want to thank the Kaiser Family Foundation, Diane Rowland for being with us here today; Jen Kates, who sometimes feels like she's very much a part of the NASTAD family.

Everybody knows Jen Kates. It's been so much fun to work with her through the years, and the staff here at Kaiser. And as Diane mentioned, since 1996; I mean, how many reports do you know that get done every single year like clockwork. Our members know come August to be looking for that email that has that survey, and to be looking for those reminders.

We do tons of surveys, and this is the one we get the best results on. And so it's also really important to thank the ADAP coordinators and their AIDS directors for their commitment to this project, because without the data and the time and energy that it takes them to put it together each and every year, we wouldn't have this long term project to show you. And we wouldn't be able to say with as much precision what's been happening to this program over the years. So I really want to thank you, the ADAP coordinators and AIDS directors. [Applause]

And just to single out one among you, I'd like to introduce our chair, Kevin Cranston, the AIDS director from Massachusetts, and ask him to wave and say hello. He's here for our conference. Welcome, both last night, and we're really

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happy—he is counting down the days until his reign comes to an end, and he passes the tiara or the gavel or whatever we decide to pass this year, to Andre Rawls from Illinois who is our incoming chair.

Of course, you know, this report wouldn't get done without our staff also working very, very hard. And we have a fairly new team who has really taken over in doing the nuts and bolts of this report. Our lead NASTAD staff author is Beth Crutsinger Perry. And Beth, I'd like you to stand up as well, along with her team: Britten Ginsberg, Angela Seegars, Celeste Davis, and Lanny Cross, who all are instrumental in putting this together from NASTAD's perspective. [Applause]

I think, as many of you know, we started this project around '96 because things were changing and happening back then. You know, we were leaving the days of AZT only, and we had the great new therapies being introduced in '96. And we knew that it was a good time to start tracking what was happening with this program.

At the same time, as we've tracked the growth of the program, we know that federal support in particular has not kept pace with the program, and so we've really needed to keep track of how states are grappling with the very tough job of keeping the doors open to as many people as possible with as vast a formulary as they possibly could. And we all know this

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is an appropriated program. It's not an entitlement. And that is sometimes a very tricky challenge each and every year, as the states look at what funding they have available and how far they can stretch that dime. And I think this report has really helped us see the complexity of the states as they grapple with that particular problem.

You know, this year I think is going to be really important, in that we hope you'll see kind of the progress we made with this program over the last couple of years. As I was thinking about my remarks this morning, I think next year is going to be even more important, for a couple of key reasons. Remember when we were here last year, we had guests from the House of Representatives and from the Senate talking about reauthorization. And at that point in time, they hadn't started really the process yet. There was no bill in either the House or Senate. But within the month there was, and we launched into reauthorization of the Ryan White Care Act, as you know, that was eventually passed in the middle of the night on the last day of the last session of the last Congress. I think we all were counting down the minutes, hoping that vote was going to get done. We'll see the implications of that for the ADAP program not in this report but hopefully more in the next one for sure. And so I think it's going to be really important.

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We're seeing some of the impact of the Medicare Part D program. We're also going to see, I think, over time the impact of the CDC's new testing initiative. Their guidelines were released in September of last year. There's a lot of discussion now about how to really increase testing in clinical care settings. Many of you are involved in that initiative. And if we're successful in that initiative, we know we're going to find people who need access to care, and it's going to be our job to see what we can do to keep the doors open to this program. And I expect we're going to see some impact of that initiative in the next year or so.

I think this year we're also particularly challenged that in reauthorization and in '07 appropriations, we did a lot of things that needed to be done. But one of the things that did not happen was an increase for ADAP programs in fiscal year '07. And as a result of all of those changes, we've seen ADAP programs—30 jurisdictions actually have cuts in ADAP this year. That's going to be a significant challenge for all of us.

So, as we see these changes occurring over the next year, and we see the results of this year's report, it's going to be really important for all of us to come together with some shared advocacy messages. And this is a great crowd. I know many of you are going to be going to the Hill, have been on the Hill, and work it regularly. And I'm really asking you here

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today to join with us to make sure in '08 we get some of these increases that we're desperately needing for the ADAP program, so that we can keep our doors open and continue to have this program having a vast array of medicines available to people who need them.

So, on that note, it's time to turn it over to the panel. I want to welcome you and thank you again for being here, for your commitment and support for this program, and turn it over to Jen Kates. [Applause]

**JENNIFER KATES, M.A., M.P.A.:** Thanks, Julie. And I want to add my welcome to Diane's and Julie's as well, and echo their comments about the importance of this report and this project for Kaiser. As Diane mentioned, our job at Kaiser is to shed light and provide information on programs and the people that they serve. And this effort has been critical to us to be able to do that and profile a program that without the ADAP program, many people would fall through the cracks. And we know that. So I will just add my thanks to NASTAD, especially Murray and Beth and the team there, and to the states. And I do feel like I'm part of the larger NASTAD family after all these years working on this report. I also want to thank Alicia Carbo [misspelled?] on my team, who saw this project from start to finish and really made such a tremendous effort to get--well, you'll see the results of that

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today.

So, very briefly, the order of the day: we're going to be able to show you a new video. It's the world premier of this video on ADAPs. You will see it. And then we'll provide an overview, very briefly, of the main findings of this year's report, and then go right into our discussion.

So, before we get started, I'm going to start with the video and just say a couple of words about the video, and then I'll introduce our panelists. The video that you're going to see, it's about eight minutes long, it looks at the role of ADAPs for people. We are very fortunate that here at the Foundation we have Jackie Judd, who is a former ABC News correspondent and is now a vice president and senior advisor on communications here at the Foundation. And Jackie has created/produced several videos on the different programs that we focus on, to really add richness to them. We'll see lots of data later on and statistics, but it's really the programs and people that manage them and the people they serve that we all need to remember and focus on. This video, as you will see, does that. And we're very excited that we have it.

And we also want to emphasize that it's available to all of you for free. You can access it on our website as of noon. And you can also request a copy of it, or as many as you would like, DVD copy to use as you see fit. If you want to

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show it to people in your jurisdiction, use it to learn more about ADAPs, please do. We want to make this available to you as part of our trying to provide information on this program.

Before we go to the video, I'm just going to say a brief word about our panelists, so that we can keep the flow going. Their full bios are in your packets, but very briefly, we're excited that Doug Morgan is here from HRSA. Doug is the Director of the Division of Service Systems at HRSA's HIV/AIDS bureau. And most importantly to everyone here, he oversees Parts A and B of Ryan White Program. And we know Part B includes ADAP. And we're very excited that Doug could be here today to talk about the federal perspective on the program.

We also have three state representatives. We always, of course, have state representatives on the panel to try to give a sense of what the program means from their perspective. I always see the ADAP coordinators and AIDS directors as sort of the heroes on the front lines of the programs. So, we have Jay Adams, the ADAP director from West Virginia, Beth Dillon, the AIDS director from Colorado, and Andre Rawls, the AIDS director from Illinois. There's no way that three states could represent the entire country, but we think we have a good set of three states today.

And finally—and Murray will join me soon—we have Murray Penner, who as Diane said is the Deputy Executive Director of

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Domestic Programs at NASTAD. But more importantly to me, he's been a great colleague and partner on this project over the years and is very committed to working with states.

Okay, so without further ado, we will show this video, and then we will present the findings from this year's report.

[Video playing] [Applause]

**JENNIFER KATES, M.A., M.P.A.:** Thanks, Jackie. It's probably the only time I'll have credits up on a screen, too.

[Laughter]

Okay. So, we are now going to turn to the findings. You should all have the summary findings in your packets, and the full report is available on our website as well. In addition, all of the data, for those of you who don't know this, are available on our state health facts site, and you can download them, you can access them for free. So, feel free to access this information and use it as you need to.

We already talked about our longstanding partnership with NASTAD. Very briefly, on this year's report, every year when we survey ADAPs, we survey the programs that are eligible for and receive federal earmark funding through ADAP, through Ryan White. That was 54 jurisdictions in '06. And I just want to note that as of '07, that is now going to be 58. There is something in the reauthorized program that made it clear which jurisdictions would be eligible. So there will be 58 going

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forward. It was 54 in '06, and we had 51 respond. The ones that didn't respond were very small population and AIDS case sizes. So we really feel like we captured most people living with HIV and benefiting from this program.

A couple of things about the way we go about this. We are surveying and obtaining data primarily from a one month snapshot. And everyone knows how that is. We look over time at a month compared to the month over several years. And we can see trends, but we also know that there could be impacts that are unique at a given time. And one of those times is this year, as you will see soon.

We also have data from the whole fiscal year for budget purposes. And we try to collect some more recent data for some of the key policy variables that we're all quite interested in, like Medicare coordination, waiting lists and other cost containment. So we have some more recent data.

So, some highlights and major themes that—you've already heard some of these in the video; I think we'll hear them as we go forward in the discussion. You'll see them in the data, but just ones that we want to highlight for you going forward: in addition to what we've already stated about ADAPs being the prescription drug safety net in this country for people with HIV, for low income people with HIV who have limited access, it's a variable safety net. It's one that

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varies by state, varies probably within states. And that's just a permanent part of this program.

But one of the trends that we've tracked over time and really wanted to highlight this year because it was quite noticeable was the role played by states in terms of providing budget support to ADAPs. States, as you may know, are not required to provide funding from the state to ADAPs except in a very limited sense. And most states we see now are doing so. And in fact state funding for ADAP was the main driver of the budget increase that we did document between the periods. There are many reasons for that, and we can probably hear from the states that we have today here with us about the decisions that go into a state being able to do this, or what some of the AIDS programs have to do behind the scenes sometimes, and the competing issues that occur at the state level.

But beyond ADAP, we know that in general states are experiencing greater fiscal health. And so we weren't totally surprised that we would see an increase in support from the states. The other thing that states are playing an increasing role in is being more active in coordinating with drug companies around rebates. So that's another factor here.

But we always see that states are a bit in what we call a delicate balance. There's program capacity on the other hand and demand on the other. And I think we'll talk a little bit

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later about the challenges of projecting demand. But states have a limited set of levers available to them to manage this delicate balance.

Waiting lists: clearly a big issue that we've looked at all these years. What we did see, and we have been seeing over the most recent few months, first that waiting lists, in terms of number of states and number of people, have indeed declined. That is a good sign. There are lots of factors for that. Medicare Part D is one. The president's ADAP initiative is another. States increasing fiscal health; there are lots of factors. This is good. Unfortunately, in the last few months, it looks like there might be an uptick again. And we will continue to monitor that.

Probably one of the biggest stories that you'll see going forward with the data is Part D, the implementation of the data of the Medicare prescription drug benefit. We really saw the impact of that with the data that we're going to show you.

And then finally reauthorization: we won't be able to see the impacts, both positive and potentially negative going forward, but we can start to think about what it might mean. And states are already actively looking at it. And I know that HRSA has been working very furiously to implement the changes that were made in the program.

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So, our June 2006 snapshot finding on clients: in general, the big thing here, ADAPs are reaching about a quarter of people with HIV who are in the CARE system in the US. So, the safety net below the safety net is reaching a significant number of people that are enrolled in this program. Some go on and off. In a given month, not everyone who's enrolled will get prescription drugs. They might not need prescription drugs every month. They might go on and off the program. But in general, we see that ADAPs consistently are reaching a significant portion of people with HIV in CARE. The number of clients served is primarily concentrated in 10 states. Those are the 10 states with the biggest populations of people with HIV and AIDS.

A big thing that we saw—and this is the Part D impact—is that when we look at June 2006 compared to June 2005, historically we've always seen an increase at those of [inaudible]. We did not see that. In fact, it was a less than 1-percent decrease. As you will see later on when we show some other information, ADAPs were required by May 15<sup>th</sup> 2006 to enroll all of their Medicare Part D eligible clients into Part D, or not pay for Part D eligible services. They could keep them on ADAP for things that Part D might not provide. And so June 2006 was just a couple of weeks after that, and we really saw that impact. We believe it's a one time impact for the

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most part in terms of clients, but there's a lot of uncertainty about what will happen.

Looking at clients, and we've seen this over the years of the report, most of the clients served by ADAPs are people of color, 61-percent. Most are low income, and most are uninsured. Some have other insurance. But that insurance may be limited. Most of the clients are men, and between the ages of 25 and 44. And we see that a large share of clients actually have low CD4 counts, which could be an indication of advanced disease. We try to capture that data, and it's at different points in time in a year period, but it is an indication that ADAPs are serving people really in need.

Looking at drug expenditures, in the month of June 2006, \$95 million was spent by ADAPs across the country on prescription drugs. And in addition, about \$5 million was spent on insurance coverage through ADAP, using federal ADAP dollars, which we'll talk more about later. We do believe that this month snapshot may be a lower estimate or a lower average than spending on drugs in a given month. We did see a decrease, looking at June 2006 compared to June 2005 in drug expenditures for the first time ever. And we believe, again, that's Part D implementation. And there are lots of complex issues to figuring out what that means. But using the June 2006 snapshot, we get a per capita drug spending estimate of

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about \$1,000 a month, which is about \$12,000 a year.

And looking at drug expenditures by drug class and prescriptions, just a couple of things to highlight here: antiretrovirals are clearly the biggest portion of drug expenditures, as we would expect. They're the most expensive and utilized by most people on the program. You can see that both in the spending and in the prescriptions. But because antiretrovirals tend to be more expensive than other non-antiretrovirals, they take up a greater share of expenditures than the number of prescriptions. And here you can actually see ADAP expenditures per prescription by the different classes, just to give you a sense of—one thing to think about influencing ADAP expenditures is utilization, but the other is the cost of particular types of drugs. And you can see fusion inhibitors, for example, are the most expensive per prescription. And ARVs generally are about five times more than non ARVs.

The next few set of slides try to give a picture across the country of who ADAPs are serving and how their eligibility and their program variables. This looks at income eligibility. And at the time that we did the survey in June, there was one state that had the low income eligibility, lowest of all the states, was 125-percent of the federal poverty, with several states, a few states having 500 or more. After the survey, the

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one state, North Carolina, that had that 125 actually increased to 200. And it's the first time, I think, in the history of the program that there is no state with a FPL below 200, which is good. Again, I think it's part of this larger story around increased fiscal health in general. And that's a good sign.

We also looked this year at several other eligibility variables, so I encourage you to look at the report. We looked at asset requirements. We always look at clinical eligibility requirements. And we looked at state proof of residency requirements, which is becoming an increasing issue in other programs, too.

Formulary coverage: in general, formularies vary across the country. And as you will hear—and I think there's been some confusion about the new Ryan White requirement around minimum formularies—that new requirement will lead to some changes. But there will still be tremendous variation, we believe, in the formularies, because the requirement really focuses on classes of antiretrovirals, but not within a class how many medications. So there will continue to be variation. As you can see here, there's pretty good coverage. The dark blue—it's 35 ADAPs—are covering all approved antiretrovirals and all four classes of antiretrovirals. And then from there, there are handfuls that aren't covering one or two. There's one state that covers not a single protease inhibitor, and

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hasn't for several years. In terms of fusion inhibitors, that's the medication that is the newest class and the most expensive. And it's a sort of second line treatment. Many ADAPs, most ADAPs, are actually covering it now. A few are not, and that will have implications for Ryan White reauthorization requirement.

This looks at drugs that prevent and treat opportunistic infections associated with HIV. And as you can see here, we looked at the 29 that are highly recommended by the public health service. And there is tremendous variation in number of states providing all 29, 15 more of those, and there's one state that provides none of them. There could be many reasons for that. This picture we don't think is going to be—it won't be affected by the new formulary requirement. But if fiscal health continues for states, we might see greater, more expansiveness in this part of the equation as well.

Waiting lists: we already talked about this a little bit. As of March 2007, so very recent, because we track this every couple of months with NASTAD, there were four states that had waiting lists. Two of them, South Carolina and Puerto Rico, had never instituted waiting lists before last year. So that's a recent thing that I think people are paying a lot of attention to. But this is a lot less in terms of number than we've seen in a long time.

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It's important to remember that waiting lists are just one measure of unmet need in a state. Some states have other levers that they are looking at. As you heard in the video, when South Carolina went to the decision of having a waiting list, I know that they went there and said, "Can we do anything else first?" And so that's what states grapple with. That's that delicate balance that I mentioned earlier. There are many other things that could make a program more expansive, more generous or more restrictive from a client's perspective. Some of the other things that states did, just in the recent fiscal year, two states reduced their formularies. Three restricted eligibility further. But we also heard about North Carolina, and we know of another one that increased eligibility. So it's a constantly moving thing. These are just some other measures to consider. And the report goes into these more in detail, as well as other things that states have done over time to manage this balance.

The budget: in fiscal year 2006, the ADAP budget from all sources—federal, state, et cetera—was at \$1.4 billion, with the earmark being the largest share, then followed by states, as I mentioned earlier. And in the report we go into the different components of the budget and what's driving the budget, with states being the biggest driver. This just looks at how these sources of the budget break down by states. All

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states, by definition, all ADAPs are getting earmark dollars, but not all ADAPs are getting funding from all these sources. So this breaks it down, and you can see again, states really are the biggest—the 40 states and drug rebates are the biggest other components of the budget. So, 40 states—I believe that's probably the most we ever documented—providing state support.

This looks at states that experienced budget decreases in any one of these sources; because the overall budget increased across the country, not every state experienced that. Twenty had decreases. And then some had decreases in specific areas.

Okay. I'm now going to turn this over to Murray, who's going to walk us through some trends and key issues that we wanted to highlight. And then we'll segue right into our panel discussion.

**MURRAY PENNER:** Thanks, Jen. I'm going to review some key trends over time and some important current issues and what they may tell us about ADAPs, as well as looking into the future.

This chart actually looks at trends in ADAP clients. And that would be the number of individuals receiving medications, as well as drug expenditures. I do want to note that this does not include the insurance coverage clients that Jen mentioned earlier. These are just those getting

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medications. And what we did here is looked at the one month snapshots over several different periods. And so you can see the trends. I'll go into that in a little bit more detail here in the next chart.

Client utilization: it increased significantly over time, but at a much slower rate as we progressed through the period. And one would expect that when you think about the early days of the heart [misspelled?] era, when we started. It was booming at that point, and really ramping up. And so client utilization has increased over time, but at a much slower rate, as have drug expenditures. Those have actually grown about twice the rate of client utilization over an entire period.

As Jen mentioned, for the first time we really saw a stabilization between the snapshots of June 2005 and 2006, relative to drug spending as well as client utilization. It's a one time shift, we really think. As Jen mentioned, May 15<sup>th</sup> was kind of a deadline, when HRSA mandated that states enroll Medicare Part D people into Medicare Part D, so that ADAPs actually saw a decrease in clients that were utilizing the program for a short period of time. Now, we know also that there are many ADAPs that have chosen to wrap around Medicare Part D. That means they have chosen to, in some cases, pay for expenditures for a Medicare Part D eligible clients when they

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reach certain points within their coverage, particularly the doughnut hole. You probably heard about the doughnut hole in the Medicare Part D coverage. That is probably occurring after June, when we looked at this snapshot.

So that's the reason why we think this is a one time kind of shift. It's something that we're going to be studying very closely as we move forward. We're really uncertain about what that's going to look like. It's complex, and, you know, certainly there are some other indicators that are also impacting this. We often looked at the June period of snapshot and said, "Maybe we should change that date. Maybe June is not the best, because we've got a Memorial Day holiday over here. We've got a Fourth of July holiday over here. And that may impact when clients pick up their medications, when expenditures are going out, et cetera. It's challenging to figure out when we're actually going to snapshot. So there are some other pieces involved as well as looking at those trends.

Turning to waiting lists, this chart looks at the waiting list trends. And we conducted these surveys now for approximately six years, every other month, so you really can kind of get an idea of what waiting lists are doing. Jen mentioned the president's ADAP initiative. You can see there in June 2004 when that was instituted at the peak of the waiting list numbers, and you saw it start to drop down as the

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PAI began. You saw it then end a couple of years later, and it started to spike up a little bit again. And then you can see the Part D enrollment deadline indicated there. And it drops off again. But now we're seeing, as Jen mentioned, the uptick. And we're going to be watching that really closely as we move forward. Twenty ADAPs had a waiting list at some point over this period of time, and usually over multiple periods within this trend.

ADAPs and Medicare Part D: This is, I mentioned earlier, the ability of ADAPs to make their own determinations about what they do in relation to Medicare Part D. We all know that the new benefit began in January of 2006. It's voluntary except for the dual eligibles. And as the payer of last resort, as I mentioned, HRSA required that all Medicare Part D eligible clients in ADAP are enrolled in Medicare Part D. Now, ADAP can coordinate—and this chart just shows various mechanisms that ADAPs use to actually wrap around Part D. You can see the breakdown there, but quite a few paid Part D premiums and deductibles and co-payments. And then some ADAPs chose to actually disenroll the clients that were—particularly dual eligibles, so those clients that were Medicaid and Medicare eligible and were getting a low income subsidy. Some ADAPs chose, about half of them chose to actually disenroll those clients. Thus, the reason why we saw the decrease in

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utilization as well, we believe. A lot of those clients were at that point disenrolled, and therefore drug expenditures were not occurring during June.

And then you can see the coverage gap. About half of the ADAPs actually pay for medications during the coverage gap, or the doughnut hole. And once clients reach the doughnut hole, we all know that ADAP expenditures do not count towards the true out-of-pocket expenditures. So once ADAPs start paying for that, for the rest of the year they'll continue to pay that.

Some trends about the ADAP national budget over time: you can see very clearly here that it's been growing, but again at a decreasing rate. You can really notice the bottom chart where the growth initially was very high, and it's dropped off and kind of stabilized over time. Now, this is the national ADAP budget overall. This is not the federal earmark. So, when you look at that, you would see something a little bit different. But certainly we've seen the growth continue over time with the other revenue sources that Jen indicated, the state funding as well as the important drug rebates.

This chart just shows the state growth. And you can see there's a little bit more fluctuation there. But particularly over the last year, as Jen indicated also, we've really seen the states step up, to the tune of about \$52

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million, I believe, has been added to state funding since last fiscal year. That was the largest driver of the growth in the national budget this last year. We know that the federal earmark was very low in comparison to the state funding.

Rebates are also an important piece, as was mentioned. It's not shown here, but it's the third largest budget component. And that's the result of state action to work with drug companies to get those rebates.

A couple of changes to occur in Ryan White: as we all have been hearing and know about, reauthorization is certainly impacted ADAPs. And one of the things that I think Jen mentioned also earlier about the reauthorization is the minimum formulary, where at least one antiretroviral in each of the classes—currently there are four approved—are required, or will be required as of July 1<sup>st</sup>, to be on ADAP formularies. Now, we don't see a lot of states that are going to need to be adding medications to make that at this particular point in time. I think it's either four or five states that are going to need to take care of that. But we also know that there are potentially some new classes of drugs that are coming online this year. So, as that happens, it's also going to be an implication for ADAPs to have to really look at their fiscal expenditures and figure out how they're going to add new drugs that are generally pretty expensive into their formularies.

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The ADAPs supplemental, the increase from 3-percent to 5-percent of the ADAP earmark, is a very important piece of reauthorization which we believe will help divert some resources to states in need. One of the most important pieces of that is not only the increase to 5-percent, but also the de-linking of the hold harmless. The hold harmless used to be funded out of the ADAP supplemental. And last year we saw that a good portion of the ADAP supplemental actually went to fund hold harmless, and there wasn't very much money available for the states that needed it through the ADAP supplemental. That is gone now, and so we will see more resources going to the states that actually need that supplemental funding.

There are some new requirements with matching. The matching requirements for ADAP supplemental can be waived in some instances, and some change in eligibility. And Doug may talk about that later, but HRSA is working on figuring out what the eligibility looks like for states.

Of course, the funding formula changed with the incorporation of living HIV cases into the formula, which was previously estimated living AIDS cases. Then it also because actual living AIDS cases, in addition to living HIV cases. So that's certainly impacted some of the shifts in funding.

And, of course, there are some other changes to the parts of Ryan White, the 75-percent requirement of core medical

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services, Part B base modifications, as well as, as Jen mentioned earlier, all territories now being eligible for ADAP.

All right. The outlook for ADAPs: certainly, we know, as the video showed us, that there is a growing population of people living with HIV and AIDS. And it's going to be more and more important for ADAP to fill that gap. We all know that. It's a very good thing that it's happening. But we also know that ADAPs are critical in making sure that all of the access and gateways into health care system are met.

The impact of Medicare Part D: we're going to be really looking at this next year, and really trying to figure out whether or not the trends that we've seen early on in this interaction between ADAP and Medicare Part D, whether or not that's going to continue the way it looks. We know that Medicare Part D benefits change every year, which will also impact the way ADAPs are picking up additional clients. It very well may be a time limited effect.

We're going to look at the Ryan White reauthorization impacts. That's going to be critical as we move forward, looking at the changes to formularies and potential new ARV classes and the funding shifts as a result.

We're going to continue to look at waiting lists over time. We hope that the trends continue and that less states have less individuals on waiting lists, because we certainly

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are working towards that. And we're glad to see that the numbers are down, but we're also concerned that they continue.

The states will remain—you know, legislatures are continuing to look at their role in providing HIV/AIDS medication in states. And we're happy to see that state legislatures are stepping in and saying, "Yes, we need to be a part of this solution." And so we'll continue to watch that.

And then finally, I think Julie mentioned this, the CDC's new recommendations for routine testing, and just trying to identify all those people that are not in care and don't know their status. That's going to have a huge impact on the care system; not just ADAP, but the care system in general. And we will continue to monitor that as we move forward as well. With that, I'm going to turn it back over to Jen.

**JENNIFER KATES, M.A., M.P.A.:** Okay. Now we're ready for the fun part. You know, in thinking about this year's findings and some of the bigger issues that we highlighted, compared to other years it's a little bit of a better picture than we've seen more recently, and I think that's a good thing. But one of the characteristics of this program, as the safety net below the safety net below the safety net, is that change is always part of this program. And one of the biggest changes that will occur are the Ryan White reauthorization changes. And we believe that those will offer some real opportunities to

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ADAPs and their clients, as well as potential challenges.

So we're very excited that Doug Morgan from HRSA is here, who can hopefully answer all these complicated questions about reauthorization. But I've asked him if he would just really focus us on a couple of the ones that are the bigger issues for ADAPs in particular. And when we get to the Q&A, let's try to keep the focus on ADAPs today, and give Doug a break, because he told me he hasn't slept for a long time as they've been trying at HRSA to figure out all the different changes in the legislation. Anyway, Doug, if we can start with you, and you can just give us some of the highlights about the changes that ADAPs are going to see.

**DOUG MORGAN:** Thank you, Jen. And I'd like to first start off by thanking our hosts for this event, and certainly thank the contributors to the report, because I think the report will be very helpful in many ways, both to inform the public. And I will say sometimes you used to beat us up on the head about why are we doing this.

But any event, a couple of things about reauthorization, because I do think it's important to understand some of the impacts that will be felt in ADAP program. As the report does highlight, some key changes in the language around the secretary identifying that all states must now have or cover all classes of antiretrovirals. There have

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been, I think, some disconnect in terms of information. I think a lot of people felt that we would be actually promulgating a list of drugs that every state had to cover. That's not the case.

What we have said, however, is that all states must cover all FDA approved antiretroviral classes. For some states, that means they will now have to cover on their ADAP formulary Fuzeon. And as the report notes, as we get into the future, as other classes of FDA approved antiretrovirals come online, states will be required to cover all classes. Now, does that mean they will cover every single drug in each class? No. And we recognize that for some resource states or some states that don't have as many resources as others, we will work with them within HRSA to try to assist those states at looking at how they can try to meet some of these requirements.

On the other side of this issue, I think the ADAP supplemental: the ADAP supplemental has increased from 3-percent to 5-percent of the earmark. That means some \$39 million are still waiting to go out to those eligible states. We are looking at the eligibility issue. We believe that rather than going through a whole new competitive guidance, we will simply request some additional information from those states that we believe are eligible and hopefully the entire \$39 million will be out the door sometime in early summer,

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around June, we hope. So I think that's important. And I will note the de-linking of the whole [inaudible] from the ADAP supplemental has been helpful, because that means almost all those dollars now will go out to ADAP programs for ADAP services.

Some other key language that I think is very important: there is some language in the bill that makes it clear that rebates that are generated through the participation of states in the 340B rebate program are to be used for the benefit of the program. That's been a little bit unclear in certain places. And we have seen some states where the dollars weren't always going back to the program. And we've actually intervened, or at least been on the phone with states, talking to them about this. I think the language in the statute makes it clear that it's the expectation that rebate dollars now do accrue to the benefit of the program, and states are to use those dollars for the Part B program.

On the budgetary side, you're right. Sometimes appropriations and reauthorization don't always go in sync. The president's '07 budget was already out there. We had the reauthorization bill come far after the president's budget was out there. In fact, we didn't have a budget until about February 15<sup>th</sup> of this year. The '08 budget does include a modest increase of \$25 million for the ADAP earmark, and we're

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very thankful for that.

I think, in all, there are some challenges for us in terms as we implement the new act. The 75-percent core medical service requirement we think will have some impact on states. This issue of consortia services not being considered as part of the core medical services may have some impact. We may see some shifting of dollars between the base and the ADAP grant. But I think it's clear that the intent of Congress was to make sure that ADAP and provision of antiretroviral medications was a key issue. It's almost the second or first core medical service that all Part A and Part B grantees are required to spend dollars on. So we're very happy with that requirement.

I think with that I'll stop. I'll allow my colleagues, my former colleagues—I am a former state AIDS director, but they are current AIDS directors—sort of get on and talk about some of the things they're facing. And hopefully they won't beat me up too much. Thank you.

**JENNIFER KATES, M.A., M.P.A.:** Thank you. I actually have two quick follow up questions, because there are probably a few people in the audience who aren't as familiar with ADAPs and Ryan White. So can you just give a couple of sentences about what the ADAP supplemental is intended for, why it's there? So that's one, so people understand the importance of any change there. And the second is: what kinds of things is

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HRSA doing with ADAPs and states on the minimum formulary issue? If a state says, "We know we need to do this, but we don't know how to do this," what kind of things are you putting in place to work with states?

**DOUG MORGAN:** Okay. On the ADAP supplemental piece, the ADAP supplemental was actually first introduced when the bill was reauthorized in 2000. And there was some very specific language around the eligibility for ADAP that looked at eligibility, it looked at the percent poverty that ADAP eligibility was set at, at a certain point in time, a minimum drug coverage, particularly around both ARVs and OIs. And I think those were the three major issues. Some of that language has been changed and modified. The requirement that the eligibility level be at a certain point in time has been removed. But there was some other language that was added, and we're looking at that now. We believe that we can address this, not through a separate competitive guidance, but by asking for additional information from all the states that actually applied for the ADAP supplemental way back in January, almost several weeks after the reauthorized bill was signed. So we're hoping to address that without having to go out with a new guidance.

In terms of the minimum formulary, I think this is where we will be working with states. We do know that some

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states have set up some preconditions or criteria that would sort of—I wouldn't say control access, but certainly it may control or limit access to a very high priced medication. This is not unlike what some Medicaid programs do when they institute preauthorization requirement. So, we realize that some states may determine that for people who are trying to access, for example, Fuzeon or other high cost drugs, they may look at have you gone on other types of antiretroviral therapies. If in fact you're on Fuzeon as a salvage therapy, what's your CD4 count? We can only do a certain number of slots. And we realize this is going to be very sensitive in some areas, and we will be working with states around some areas and technical assistance where we could help them out.

**JENNIFER KATES, M.A., M.P.A.:** Murray, do you want to add anything about [inaudible] NASTAD is doing around reauthorization and helping states understand it?

**MURRAY PENNER:** Certainly. I do think that we really are working hard on that, trying to make sure that states understand the requirements. The minimum formulary one is one I think that some states have been a little concerned about. They've been concerned about high priced medications coming online, particularly when we're looking at a couple of new classes coming on board.

I do also want to say that I know that ADAPs are

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committed to making sure that people have access to all the medications, the range of medications that are available to people, and certainly the wealth of treatments that we have available in this country versus other countries. And I'm going to diverge just a minute and speak personally, as a person living with HIV and AIDS, who has really relied on some end salvage therapies that have been very important in keeping my viral load down and my T cells up. It's been very important that I have access to those medications.

Now, I'm certainly not on ADAP. I'm fortunate and have my own private health insurance. I have been on an ADAP program before, and had I not had that available, I think it would have been challenging for me. And I think that we as a community need to be really mindful, to try to get those requirements met that are in place, that are in place for a good reason, but still stay fiscally solvent as far as the programs go, because that's the other challenge that ADAPs are faced with.

**JENNIFER KATES, M.A., M.P.A.:** Does anyone else from the states want—oops, sorry. I gave my instruction, which was, "Press this," and I've already failed at that. Anybody want to add, from your perspective, of what you're seeing in terms of reauthorization? Do you think these things are going to affect your state in a big way, wait and see? Yeah.

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**JAY ADAMS:** In West Virginia, we started shuffling very quickly when we saw the language of reauthorization. And part of the shuffle that we had to do was based on the 75/25. We used our base dollars to support some things for ADAP. For example, we don't have the infrastructure in our ADAP to pay Medicare Part D premiums. So instead we used our base dollars. And we did that through consortia. And we also paid some co-pays for medications for pharmacies that would not interact with our ADAP, because our ADAP is run through Medicaid, and we have some national mail order pharmacies that wouldn't interact with our particular Medicaid system.

So what we looked at with the new language was that these dollars, because they were being run through consortia, wouldn't even count towards the 75-percent. So we did some shuffling very quickly to get those out of consortium, because those dollars, for example, with the Medicare Part D, we were saving approximately \$300,000 a year for our ADAP by paying those premiums. And the new legislation said that those dollars used to pay the premiums wouldn't count towards the 75-percent. So we shuffled very quickly.

**ANDRE RAWLS:** In Illinois, we have been quite fortunate to have a state legislature that has backed our ADAP program probably as one of its primary factors. As your numbers show, and as is accurate, 30-percent of our dollars come from the

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state legislature. And as soon as we started seeing reauthorization, our legislators were asking us what would we need to make sure that we could sustain the programs and the drugs that we have on our formulary. So right now we have over 90 drugs, including the deep salvage drugs such as Fuzeon, available. So we're quite fortunate in that way.

**JENNIFER KATES, M.A., M.P.A.:** Okay. We'll just go out to our next – actually; I want to go to Part D. So that gives us, I think, a little sense of going forward, some questions maybe we all have, but it sounds like at least the states here are pretty clear on what reauthorization will mean for them; it sounds like some opportunities as well.

Part D: that was probably the biggest finding that we had this year. We knew that we would see some impact. We did not expect to see the impact that we did see. Again, what we saw, looking at the month snapshots, was a stabilization in terms of number of clients served for prescription medications in June 2006 compared to June 2005. We did still see an increase in the number of clients served through insurance coverage and purchasing.

We saw a decrease, though, in prescription drug expenditures between those two periods, first time ever in our report. We know that's the [inaudible] of Part D. What we don't know is what will continue, will that continue, what

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happens when clients reach the doughnut hole? Some states— actually, this is a relief for states. So some states are able to incorporate more clients, or get rid of a waiting list. I know all the three states here each have their own experiences with Part D, and the role it's played. I'm going to start with West Virginia, because I know the impact there has been pretty dramatic in what it's allowed your state to do, and it's a very different place than we were at last year when we were talking about this.

**JAY ADAMS:** It's really great to be able to look at the map on the slides and see that West Virginia is no longer one of those states with a waiting list. After 41 months of feeling like there was a dark tunnel that you were in, I really empathize with our colleagues who do have waiting lists now or who face them in the future.

But Medicare Part D was our saving grace. And it truly was something that we welcomed. And we didn't wait for May 15<sup>th</sup> to roll around to get people enrolled. We started January 1<sup>st</sup> to get folks into Medicare Part D, because we knew there was going to be a great impact for us.

In West Virginia, as we eliminated that waiting list, though, we still have fears of what's going to happen in future years. Our significant savings has been from those plans, those prescription drug plans that cover brand name drugs

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during the doughnut hole. And that's where we really see the big savings. And in 2006 there were three plans that offered [inaudible] coverage during the doughnut hole. In 2007, we have one. And our fear is that in 2008 there won't be any, and we'll only have those persons that are falling in and out of the Medicare Part D and ADAP and not have those persons who are off our program, unless we're paying co-pays for the entire year.

So, the uncertainty of the future with Medicare Part D is scary. And certainly the solution that I see is having ADAP count towards [inaudible]. And we would see a lot of relief then.

**JENNIFER KATES, M.A., M.P.A.:** I'm going to turn to Colorado.

**BETH DILLON:** We've had much the same experience as West Virginia has. I think we saved about \$300,000 or more the first year with Medicare Part D, which allowed us to actually expand our eligibility. And we had the same situation. We were fortunate that most of our ADAP clients who were eligible for Medicare Part D got on the plans without the doughnut hole. We had a few people who got on plans with doughnut holes.

But then we had to switch everybody, actually, to a new plan this year, the one remaining plan that doesn't have a doughnut hole. For that reason, we're fortunate again to have

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state funding. It actually got rid of our waiting list three years ago through a lot of activism among the AIDS service community and people living with HIV/AIDS. We had a waiting list of 300 people, and our state contributed almost \$3.5 million in state funds, which allowed us to eliminate the waiting list.

So, we found out recently that we could use state funds, because you can't use Ryan White funds, as you said, to cover that doughnut hole. So we're applying for an SPAP. Actually, we have to thank Montana for giving us some technical assistance in doing this. And this SPAP will allow us to cover that doughnut hole—

**JENNIFER KATES, M.A., M.P.A.:** Tell people what that is.

**BETH DILLON:** State—I can't remember.

**DOUG MORGAN:** State Pharmacy—

**BETH DILLON:** Pharmacy Assistance Program. Yeah. State Pharmacy Assistance Program. So, we're going to have this program so that people can stay on ADAP, so we're not in a position of taking them on and off ADAP every year. So, we're really excited about that. We think that will stabilize some of our Medicare Part D savings. If you're not able to do that, it's going to be a very difficult situation to manage.

**JENNIFER KATES, M.A., M.P.A.:** I'm going to turn it

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over to Andre in a minute, but just for those of you who are interested in Part D and broader Medicare coverage issues, we do have a lot of resources on our website about that. And we also have resources on SPAPs, and which states have them and what the populations are that are served by those, because not every state does have an SPAP, and some states that do have it limited for certain populations. So, states that can take advantage of either one that exists—and I believe that your state has created one as well—that's a definite benefit for the state and for clients, but there are some states that don't have that option. So, if you want to speak to that and also Part D.

**ANDRE RAWLS:** I think that when Medicare Part D started for Illinois, we were faced with actually coordinating all of the various programs that the state had available; to look at what was in the best interest of the client. So it was not always in the best interest of the client to keep them on ADAP. In some cases they needed to move, either to Illinois Cares Rx or some of the other programs that the governor had put in place to handle medication. We found ourselves in a position that we actually needed a benefits coordinator for each individual client, to look at what was the best case scenario for their medication, to look at Part D as well as Illinois Cares Rx, as well as some of the other programs that we had in

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the state, the Medicaid program as well.

So, as a result of that, we did hire a benefit coordinator, and we started looking at doing a decision tree for case managers, so that if they had a client come in, they would be able to guide them in the right direction. The initial impact of Medicare Part D was that we had about 280 off of the ADAP roles. But then as Medicare Part D matured, we saw some of them come back on.

What we're seeing now is sort of a stabilization. We think that at this point we've gotten the fluctuation, maybe March or April of last year, and it's pretty much over as the programs matured. So that's where I think Illinois is at this point.

**JENNIFER KATES, M.A., M.P.A.:** And about an SPAP? Did you one already in the state, and you were able to work with it?

**ANDRE RAWLS:** We had to coordinate with Senior Care, with Illinois Cares Rx, and several other programs to make sure that we wrapped around the patient. So yes, we did have a plan already in place.

**JENNIFER KATES, M.A., M.P.A.:** We're going to get to your questions in a minute. I wanted to see if Murray wanted to add anything about Part D and what you might be hearing from states now, and I think [inaudible] some additional monitoring

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of Part D.

**MURRAY PENNER:** Yeah. We are in the process of continuing to monitor Medicare Part D. And one of the things that the ADAP coordinators will love is another survey that's coming out very soon to actually start to put some quantification to that. We're going to do it on an aggregate basis, to kind of see what the impact has been. And hopefully, in conjunction with this project, we'll be able to really put some numbers to it and really start to look at the impact, and, you know, the changes, because we really do anticipate that particularly after 2007, we're going to start to see some more changes as Medicare matures in its programming. And as you've heard mentioned already, some of the plans are going away that have been advantageous. It will impact ADAPs.

**JENNIFER KATES, M.A., M.P.A.:** Before we go to your questions, I want to just bring up one more issue about waiting lists. And as we said, we've really seen a positive trend in waiting lists in terms of number of people and number of states going down over time, with the most recent few months maybe some troubling signs. We have two states here, Colorado and West Virginia, that have had waiting lists in the past and don't now for a variety of reasons, Part D, state support, et cetera. I don't think Illinois has ever had one. And so we have some variation there.

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But I wanted to actually ask Doug to talk a little bit about South Carolina and North Carolina. We were sort of thinking about it as a tale of two cities, or two states. You have these two states that are near each other, have some similarities. North Carolina—for those of you who have been following our report each year probably know that North Carolina had one of the longest standing waiting lists of any state, and had the highest number of people on that waiting list for many years, and as of last year got rid of the waiting list, which was a big challenge for the state. And they did it, and it has maintained no waiting list in that state. South Carolina never had a waiting list, and now it does. So I think it's a good illustration of the different things that can tip the balance for a state.

**DOUG MORGAN:** Well, I think you're right. We looked at that sort of situation as well at HRSA, because there are times that we said, "Well, look, what's South Carolina doing that makes them look so well here in this vein?" And we understood what some of the issues were with North Carolina. And actually, in the long term, North Carolina made a very strategic move, which was to switch from a rebate state to a direct purchase state. And in that regard, we did provide some technical assistance. It took I think almost a couple of years. I'm not sure if Steve Sherman or John Peoples or

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anybody else from North Carolina is here, but that did take them a while to do that. But once they made that switch, they began to see some immediate savings.

Now, I don't want people to walk out of the room thinking, "Okay, we do this and overnight we'll save money." Alaska has made that switch as well. They still have a very small waiting list. But nevertheless they have seen savings. And I was very enthused about some of the questions we had with one of the earlier sessions, talking about the prime vendor and other issues.

But I think one of the other things was that the state also began to recognize that it needed to put some more state dollars into the effort. I remember having discussions with Steve and others about how, over the years, the state legislature began to see the importance of [inaudible] more dollars into the ADAP program. So, I think a combination of factors there helped to change things around, and perhaps Medicare Part D as well has had an impact. We are very pleased. In fact, I remember Steve Sherman sending me an email saying, "We moved our FPL to 200-percent of poverty." And he said that with such joy. And we actually enjoyed sharing that joy, because I think that was a recognition on their part that they made some significant changes. They had convinced their policymakers that they had resources and could do this. And

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that was the change.

On the other hand, I think we are as perplexed as others are in the change in issue in South Carolina. They are very similar states. And it may just well be nothing more than increased demand on a state that maybe had not done as much outreach as it has done over the last several years and now is seeing the impact of that. I don't know. And I think we have worked with them. We know NASTAD provided some TA. And almost everything, all the other issues that they've looked at, they've been considering putting into place, and they still have a fairly substantial waiting list, which concerns us as well.

**MURRAY PENNER:** And I'll just add that if you've seen one ADAP, you've seen one ADAP. You cannot always compare, you know, North Carolina to South Carolina. I think certainly there are lessons that can be learned from looking at other programs, but there really are so many variables within a state that it's important to take a look at the entire picture that's happening in the state. South Carolina, for instance, could have changed their Medicaid program. And that impacts the way, you know, ADAP is required to pick things up. So there are so many variables that it's often very hard to compare.

**JENNIFER KATES, M.A., M.P.A.:** Okay. I think we are ready to take questions. If you want to direct them at

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somebody, please do.

**JAMES ALBINO:** Yes, I have a question.

**JENNIFER KATES, M.A., M.P.A.:** They might not answer,  
but—

**JAMES ALBINO:** I'm sorry. Excuse me, first of all.  
I'm nursing a cold, so I'm trying to—I have a question for Doug  
Morgan and for Murray Penner.

**JENNIFER KATES, M.A., M.P.A.:** Could you just say who  
you are and everything?

**JAMES ALBINO:** Yes. My name is James Albino with the  
National Minority AIDS Council. As of February, Puerto Rico  
accounted for 23-percent of the total number of patients on the  
ADAP waiting lists, nearly a quarter of the nation's total ADAP  
waiting list population. That real number, however, may be  
anywhere from 10 times higher to 25 times higher, given that  
the San Juan EMA who's currently under federal investigation  
for possible corruption turned over 1,200 patients from their  
coverage to the state program. Also, the state legislator put  
out a resolution indicating that there may be up to 3,400  
patients on the waiting list. And the Puerto Rico department  
of health, as cited by the Office of the Inspector General and  
the Puerto Rico Office of the Controller for Mismanagement of  
Data has no accurate data, no accurate current data.

The question for Doug is: what is HRSA prepared to do,

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other than to continue to offer more technical assistance, to accurately collect and evaluate data and take effective action to stem a national crisis?

The question for Murray is that NASTAD recently conducted an assessment of the Puerto Rico Department of Health on the ground. I think it was a couple of months ago. And I was wondering if you found any data that indicates that the findings of the OIG and the Office of the Controller that the Puerto Rico Department of Health has difficulty in the purchasing, ordering, inventorying, distribution of the ADAP medication that's there. Have you seen that? Weekly we get press reports of medication being rationed. And at the same time we're getting reports that medication is expiring on the shelf. In your observations or recommendation, did you have or will you consider a third party fiduciary agent to help the Puerto Rico Department of Health manage the accounts payable, receivable, ordering inventory and distribution of the [inaudible] ADAP medication?

**MURRAY PENNER:** I will attempt to speak to that very complex set of situations. I don't know if Doug will be able to comment or not. But I will say that NASTAD's role is not one of coming in and making an assessment of what is wrong, what is necessary. What we do is we will come in—in this particular case, in working with Puerto Rico, we've been asked

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by Puerto Rico Health Department to come in and help them insure that they are moving in the right direction towards fixing whatever kinds of situations they have. Our assessment was not one in which we went in and said, "What's wrong here? What kinds of things can we recommend?" Our role is to come in and really work with the health department in Puerto Rico to assess what they need to do to utilize our peer technical assistance network that we have among many programs that have experienced similar types of issues, to bring that technical assistance in and help Puerto Rico succeed. That's our role in this. Certainly the federal government has a different role in this. But our role is to really help Puerto Rico succeed.

**DOUG MORGAN:** I would add that our role with the Commonwealth of Puerto Rico is one of trying to work with them to provide as much technical assistance as we can to assist them, particularly around ADAP. They have made a formal request to us. We have indicated that we will work with the commonwealth to do that. In fact, I had a sidebar conversation with commonwealth representatives who are in attendance in this meeting. And we will work with them, through their governor's office, through any venue, to try to be sure that we address some of the concerns that we as an agency have and some of the concerns that we've been hearing about.

I think, to their credit, the Commonwealth of Puerto

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Rico wants technical assistance. This is not being forced upon them. They recognize that they have some issues that they want to address. And they've asked us for our help, and we're prepared to do that.

Your sort of earlier comments about another entity in the Commonwealth of Puerto Rico, I'm not going to address at all. I will simply say that we will work with the commonwealth, and we understand that the name of the game here is to actually provide medications to people in need. And that's our overall goal.

**CHRISTINE LUBINSKI:** Good afternoon. Thank you for an excellent presentation. Christine Lubinski, HIV Medicine Association. I have a question about the two new drugs that will potentially be approved this year, one of which may be approved by the end of this month, both of which, as reported at the retrovirus conference in February, are incredibly potent drugs. And as Murray and others indicated, there are already people who are dependant on these drugs and expanded access programs, and people in deep salvage who need these drugs today. And we're working with a number of groups, including NASTAD, and have advocated with CMS about these drugs, regarding the Medicare Part D formulary, because they will not be required to be on the Medicare Part D formulary for next year, because they're not approved by April 16<sup>th</sup> of this year.

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But again, the implications of a minimum formulary provision: I wonder whether it is HRSA. And I know you've had your hands full. But it seems to me it might be prudent to think about offering some guidance to states when these drugs are approved, especially states with limited resources that don't have formularies of 500 drugs, about, for example, I wasn't clear, Doug, about whether HRSA's interpreting legislation is permitting kinds of prior authorization policies or restrictions which may in fact be very appropriate with drugs in this class. And I know there are some good state models of prior authorization; for example, for Fuzeon. There are probably very credible clinical criteria that can be developed.

There is certainly the issue that we really highlighted in our own comments to CMS about Medicare Part D, about prioritizing access for people who are currently receiving these drugs on expanded access programs, programs that will end as soon as these programs are approved by the FDA. And certainly representing a bunch of clinicians, we'd be happy to work with you on clinical criteria. But I'm just wondering whether you've thought about that, since we could be looking at this very quickly.

**DOUG MORGAN:** I think in that respect, Christine, we actually have. And I think, if I didn't make myself clear,

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that's in fact what we want to do in working with states who are resource challenged, particularly as potentially two new classes of drug may become available. We realize that that's going to be a challenge. I mean, there are some good preauthorization models that do work. There is some sound clinical evidence that would suggest that not every person living with HIV should get this particular drug at this time. And I think, if people understand that and establish a system in place that sort of provides appropriate access when there needs to be, making sure that all the other opportunities and all the other medications that can be used are used, we will work with states to try to do that. Yes.

**BOB ROEHR:** That was one of my questions. Bob Roehr with the *Bay Area Reporter*. Probably from Jen and Murray here, could you give a sense as to what states are doing the best job in terms of their own funding, in terms of—I know some states are not contributing anything to the ADAP program. And what is the highest percentage state, or how do those sort of fall into categories?

**MURRAY PENNER:** Gosh, you're going to make me look in my packet and actually look at the state that has the highest percentage. But I think what I would say there is you've seen one ADAP you've seen one ADAP. You can look at state funding in a particular jurisdiction and say, "Wow, you know, this

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particular jurisdiction puts in 40-percent of their ADAP budget from state funding." And it can be very significant. And North Carolina was a good example of that several years ago. They were putting significant amounts of state funding into their ADAP program. And they still had a waiting list of over 800 individuals.

And so, I would hesitate to rank the states from highest to lowest and say that means that this state has got the best access to medications for those individuals, because it depends on a lot of things. It depends on the Medicaid system that's in the state, other programs that the state may have, state particularly programs like what Andre mentioned, to where a state may not be putting very much in. They may not need to. So it really does become a state decision as to what is necessary, and, of course, what the state is willing to do. And that sometimes takes advocacy on the part of the community in order to step up and say, "Wait a minute, you know, South Carolina legislature. Maybe we need some more money because we do have this demand growing over here."

So, I'm not answering your question specifically, but I'm saying it's very complicated, and I can't just say, "Oh, here's the best example of a state that's putting their funding in."

**MALE SPEAKER:** [Inaudible].

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**MURRAY PENNER:** Well, I think you have to look at access to care and individuals that are getting access, and not be critical of the states where you may not be getting exactly what you're getting if you live across the state line. I think it's very important to also recognize the fact that in South Carolina, when you looked at that video, and you saw that the majority of individuals in that state are still getting medications, the drug companies are an important partnership in this; that they've also stepped up to the table with NASTAD for negotiations with our ADAP crisis task force to increase rebates, increase discounts, so that more people have access to drugs. So there are efforts at various efforts. A state's efforts may or may not be reflected based on the money that they put into their program.

**JENNIFER KATES, M.A., M.P.A.:** I just want to add I think one of the big challenges to looking at a program like Ryan White, but there are others that are sort of the safety net below the safety net, is that figuring out where the pieces are and what pieces it's filling is always a challenge. And so, looking at one factor may tell you a lot. This state provides this much support. That state doesn't, looking at their formularies. But understanding the fuller picture is always the big challenge.

And I think, stepping back from ADAP a little bit, this

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is a broader challenge that HRSA faces with Ryan White. For example, with the 75-percent requirement now, jurisdictions can show, "Well, we are not needing to provide 75-percent to medical services because we have other programs available." That's a challenge for them to show, too, because again, Ryan White is helping to fill a patchwork. And measuring that patchwork is hard, and it varies by so many factors.

That is not to say that all of these things put together can help us understand what states are struggling with. A state that has no waiting list, for example, but a very low eligibility and a formulary that doesn't have a lot of medications on it, if we start looking more deeply and see, well, there's no SPAP in that state, there's no other program that's really available, well, then that might post some significant barriers. But it really has to be that fuller picture. I think it's a challenging picture to paint. I don't know if, Doug, if you want to add anything. I know that the federal agency struggles with trying to paint that fuller picture as well.

**DOUG MORGAN:** I would just ditto what Jen has said. I think you do have to look at each state individually. I mean, some states put in a fair amount of money. There are states that have the benefit of a Part A program, where the Part As do contribute to the state ADAP program. That has always been

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very helpful. There are states where you have a combination. I can only refer to my own former state, where we had a very good Medicaid program. We had an SPAP. We had a program for the disabled and elderly. And then we had ADAP. And taking all three in conjunction, persons could literally be covered from one program to another as they got sicker, or as they had less of an ability to earn income. And states have different revenue sources. You know, I think Murray's point is well taken. You look at one ADAP, you look at one program.

In terms of state circumstances, the same thing goes. So there may be certain things going on in the state that can work against, you. Actually, as another good example, one of our states actually has a risk insurance program where most of their ADAP dollars pay for health insurance that covers not only the ADAP benefit but the direct primary care. That's a great example, and one of the things that we have actually studied, that shows that you do get a larger benefit where that's available. That opportunity is not available universally across all 50 states, across the territories. But that's one state using an opportunity that exists there to make it happen.

**JENNIFER KATES, M.A., M.P.A.:** Actually, I want to just pick up on that. You mentioned earlier that one of the things that North Carolina did was move to being a rebate state to a

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direct purchase. That option—again, these are all creative options that states can explore, but it's not available to every state. So part of it is helping states, I think, figure out what options might be available, and then seeing which ones are going forward to pursue those options.

Time for maybe two more questions.

**ARNIE:** Hi. It's Arnie from Tibotec. Of course, I had to grab a microphone at this ADAP meeting, at least once.

**MURRAY PENNER:** Arnie's a former author of this report, by the way.

**ARNIE:** I just wanted to sort of second Christine's concern or the issues she raised. And I just wanted to add maybe more fuel to the fire. I think it's not only the drugs in new classes that are going to be coming out, which we're all looking forward to, but as drug development has gotten more sophisticated and targeted, there are new drugs out and in development in existing classes that are specifically targeted for people, for example, that have developed resistance to the existing drugs in those classes. And some of those drugs will need to be used with the new class drugs. And so they're just as important in terms of patient access. Now, with Part D, you at least have the six protected classes, and so there's some level of guarantee that there will be access eventually. With Medicaid a lot of times, there are carve outs for HIV drugs.

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And so people generally have access.

But I guess the potential issue I see with ADAP is that there is no sort of protection around the system like there is for Medicaid and to some degree Medicare Part D. So I'm wondering, thinking to the future, you know, what can we all do together to insure that there's going to be access to these new therapies. If you can answer that one, you get an award.

**JENNIFER KATES, M.A., M.P.A.:** I can't answer that, so I guess I won't get an award. But I would say that I think it's really important to remember what this program is designed to do. And it's designed to be that net below other nets. Structurally, the way it's been set up, is not necessarily to always be able to completely fill the gap. But I think you're raising a very big, big challenge for this program.

And again, I think it connects back to Bob's question. What else is available in a state for a person living with HIV? You mentioned Medicaid. Medicaid would cover all of those medications. So that becomes very critical to understand, and where there might be limits for a particular individual.

But I think it's a challenge that this program will continue to experience. One of the things we talked about amongst the panelists in advance of today was the challenge that they face in projecting need and projecting demand. And that is, I think, a really great example of how does a state,

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sitting where you are now, and West Virginia saying, "Well, we're actually in a better place than we've been in a long time." But what's going to happen in a year or two years? That's one of the reasons we do track the program every year, as Arnie knows quite well.

So, I don't think any of us has the award winning answer. But let's also remember what the program was designed to do, which is to just kind of fill in those gaps.

**MURRAY PENNER:** I'd like to add one thing there, too. I mentioned NASTAD's ADAP crisis task force earlier. But this task force is an amazing group of ADAP coordinators and AIDS directors that sit down with industry and have some really hard conversations about access to medications. And Arnie, your point's perfect, because one of the things that we really strive to do is make sure that we can do the best that we can to get the best price that we can, so that ADAPs can make a good decisions. They can look at all of their resources, and they can try to balance things so that there's some kind of access to those that are the most in need; kind of what Jen said, the safety net under the safety net.

And maybe it means that there needs to be some kind of criteria in place, prior authorization or whatever. Let's use the new class of drugs and CCR5s that are potentially coming down the road. About half the individuals living with HIV and

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AIDS will not even—it won't even work for them. So there are going to have to be some clinical things in place to make sure that ADAPs are making really good decisions. And we want to make sure that they have the best price possible so that we can get the most people getting those drugs as possible.

**JENNIFER KATES, M.A., M.P.A.:** Actually, on thing I want to add, and then I think we might have time for one more question. We have tracked in the past, and I know NASTAD continues to do that, how ADAPs make formulary decisions. And for the most part, all of them, or most of them, have clinicians very much intimately involved in these decisions. So, the decisions about what to put on a formulary and how to make decisions about prior auth is done in these kind of consultative ways. And I think that is, you know, just to emphasize the importance of that process to continue.

I think we have time for one more question, if anyone wants to get the last word in. Or, of course, we get the last word in. Okay.

Well, I would be remiss if I didn't once again remind you that we hope that you will access the video, either online or request it. We know it will have a life beyond today. But we want to thank everyone for coming and staying this entire time. And we really appreciate it. And thanks to everyone on the panel. [Applause]

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