

**Getting Medications to People with HIV/AIDS in the U.S.:
The AIDS Drug Assistance Program
March 30, 2006
The Kaiser Family Foundation and NASTAD,
Washington, D.C.**

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JENNIFER KATES: Good Afternoon. That's your cue to sit down. Welcome to The Kaiser Family Foundation. My name is Jennifer Kates, I'm the director of HIV policy here. And I'm looking around and thinking that the number of people that is here is really a sign of how critical ADAP's are and how much they are on our minds today and at this time. We didn't know that we would get a turnout like this. So I just want to let you know that think this is a really important and good sign. And the other thing that hasn't gone unnoticed is what we've tended to have events on global HIV/AIDS and we get a packed house. So it's really exciting to have something focused on the epidemic in The United States and also get a packed house.

Everyone should have gotten packets. All of the materials are there so you can look at those at your leisure. Separately from today we have everything posted online. Our state health facts site, that many of you are familiar with, has all the data. So there's no shortage of ways to access the information that we're going to talk about today. But the conversation today, will be more broadly about some of the issues.

Before I go in and briefly introduce all of the panelists that are here, I wanted to say two thank you's. The first is to the state, really. The state's AIDS directors and

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ADAP directors. Every year, we've been doing this project for over a decade, we rely on the states as sort of the main stakeholder for providing information and helping us understand what's happening with ADAP's. They take time to do it, they take time away from providing services. We try to make it a minimal amount of time. But we just really want to thank them for understanding the importance of this effort and, each year, really contributing in a big way.

And then secondly, I want to really thank our project partner, NASTAD. NASTAD and Kaiser have been working on this project together for well over a decade. We have an amazing partnership in trying to find ways to bring this information to you each year. Thank you, Julie. Under Julie's leadership throughout all this time, it's really grown. And I think we've all increased our sophistication of understanding about ADAP's.

And I also really want to thank Murray Penner, who takes the lead at NASTAD for this effort and has worked closely with me and his team. Beth Crutsinger-Perry and Natane Singleton who have really just--without that team, there would be no report. And finally, my staff, Alicia Carbough who jumped in recently with our team and now is an expert on ADAP. So if you have any questions, just ask her.

We'll just hear from Julie in a moment. But first, I just want to tell you who we have here today so that when we

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get to the questions, we can just get right to it. As you see Murray Penner who is the Deputy Executive Director of Domestic Programs at NASTAD and co-author of the report and will be presenting some of the findings. We're very happy to have two congressional staff here. Shana Christup, who is a professional staff member of the health committee for Senator Michael Enzi. And Connie Garner, the democratic policy director for disabilities and special needs populations with Senator Kennedy, also on the health committee.

We also have three ADAP or AIDS directors here representing the states. Jay Adams from West Virginia, Beth Scalco from Louisiana and Duane Haught from Texas. And last, but not least, we have Arnie Doyle who is here from Rosche pharmaceuticals and was a former NASTAD person who actually was the person who was working on this report for many years. So he has many perspectives to bear on this.

Before I go further, I am going to turn it over to Julie for some opening comments. And then we'll go right to the presentation. Thank you.

JULIE: Hello everyone. This is a great site to see. It's wonderful to see so many of you out here today. I really want to join Jen Kates in welcoming you to today's forum for the release of our 2006 National ADAP Monitoring Program Annual Report. We're really excited about the turnout. And we're really excited about the panel that we have today

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which, I think is part of the reason we have such a great turnout.

By way of background, as many of you know, NASTAD was founded in 1992 to represent the views and concerns of state and territorial AIDS directors. These are the folks in public health departments across the country who, back then were trying to manage a burgeoning HIV/AIDS epidemic. Our members are the folks in state and territorial who have programmatic responsibility for managing the continuum of HIV/AIDS care, prevention, surveillance, Ryan White Care Act, care and treatment and the AIDS drugs assistance programs. Increasingly they also have a responsibility for viral Hepatitis; Hepatitis C in particular. And many are often the STD directors as well. And as many of you know, NASTAD has programs in HIV prevention, care and treatment, viral Hepatitis, government relations and a global HIV/AIDS technical assistance program.

In addition to just taking a minute to welcome you all, I also want to give a round of thanks because a lot goes into this report. And this event really takes 12 months of the year and lots of folks that do lots of work to get us to this point. The ADAP coordinators and AIDS directors; you know, we survey our members constantly. And our members also have to reports to the Feds, constantly. And whenever I'm about to do a survey, I always remember the words of one AIDS

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director who said to me, "Garbage in, Garbage out." And you know, it's always—you know, we're so proud when we have this data. Because we don't think it's garbage. We think we're getting good, reliable data from almost all of the jurisdictions every year for over 10 years. And that's really notable. And that's because the AIDS directors and AIDS coordinators care so much about this report.

I really want to thank our industry partners who are here with us today. And I want to thank them, not only for the, you know, year-round support they give to NASTAD's ADAP technical assistance and monitoring program, but really for the partnership with our ADAP Crisis Task Force that has resulted in incredible savings to our programs over the last, I think it's three years. We're estimating that this year alone, that partnership resulted in savings of about \$145 Million. And all of us here in D.C. know that that's not chump change anymore. You know, that is a significant contribution to keeping the doors open of these programs across the country. And we think now in the three years of this partnership we might have saved these programs \$300 Million or so.

It's also really special this year that we have senate staff, Shana and Connie with us today. You know, these are the folks who have this tremendous responsibility in front of them of championing the re-authorization of the Ryan

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White Care Act and we really appreciate the time that they're taking away to be with us.

Have to thank again, the NASTAD and Kaiser staff. Beth Crutsinger-Perry; I keep saying I'm going to single her out and make her answer tough questions here. But really was leading the charge with Natane Singleton and Murray Penner and Larry Cross who is also here working with NASTAD. I want to thank Alicia and Jen as well.

This project, as Jen mentioned, is now over 10 years old. And the first time we did this report we did it with a partnership of PERSA [ph] and we really do need to acknowledge that PERSA has been a partner with us around the AIDS drug assistance programs since their inception. But again, Kaiser had the vision and the commitment to see that supporting this kind of a project and data collection for a report, year after year after year, would give us incredibly valuable information. And I really want to thank Jen and Kaiser for continuing that commitment.

This year's report really has taken on some heightened importance. And I think the reason so many of us are here today is that we're living in a time where we're paying special attention to what's happening with this program. I think, as many of us know, we are about to commemorate 25 years of the HIV/AIDS epidemic and 10 years of the highly active antiretroviral therapy. Treatment options

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continue to expand and improve. Those are notable pieces of the context in which we're working today.

Re-authorization of the Ryan White Care Act is underway and we know that it's going to have some significant implications for ADAP's. We're in the midst of implementation of Medicare Part D Prescription Drug Program, which will impact ADAP's in many different ways, in many different states. And we don't all know yet, how that is going to play out.

And last but not least, the President has proposed a domestic HIV/AIDS Budget Initiative this year which includes a \$70 Million increase for Title 2 programs, including ADAP's. This is coming in a year when we've also seen the lowest Federal increase in the ADAP earmarks since ADAP's began. So it's an incredible, critical time and I really want to thank you for being here. And I'm going to turn it over now to Murray Penner who is NASTAD's Deputy Executive Director, to get us launched into the report.

MURRAY PENNER: Thank you. I'd like to echo the longstanding partnership with Kaiser Family Foundation and thank everyone for being here today. This is truly exciting to see all of you out there and knowing that there is interest in this particular project as we move forward.

I'm going to kick off the initial findings of the actual report and then turn it over to Jen to conclude that.

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And then we'll continue with some panel discussion. I also have to thank the ADAP coordinators and the state's directors for their participation because it really is critical for us to move this project forward, to have accurate data. And believe me, they know that we're out there working on this project. And I'm sure they hear us calling and it's like, "Oh no! Don't take that call! I don't want to take that call!"

But, we had a really, really good turn out. This year, we, as always, surveyed 57 states. And we actually had 53 of them respond, so we get an excellent response rate. We have every year. And we're very thankful to the AIDS directors and the ADAP coordinators for providing us with this information.

The data for this report comes primarily from June 2005 and fiscal year 2005. But we do have supplemental data collection efforts where we collect eligibility and formulary data. That was from September 2005. We looked at Part D policies that states had in place in November of 2005. And then we looked at more current data for waiting lists and cost containment as of February 2006.

Real quick, what are ADAP's? We know what ADAP's are. They are the nation's prescription drug program for low income people living with HIV and AIDS that have little or no access to medications. Obviously, it's authorized under Title II of the Ryan White Care Act and delivered to states by

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formula. States administer and design their own programs including the eligibility criteria and their formulary composition. And they also are the payer of last resort and fill gaps that are in place in the larger healthcare system in each state. The smaller the gaps in the state, obviously, the less there is to fill. But because of these factors, there is significant variation across the country in AIDS drug assistance programs.

Moving to the ADAP clients that were served in June 2005. ADAP's are serving a significant portion of people living with HIV and AIDS in The United States with more than 134,000 enrollees. Which is about one-quarter of the people estimated to be living with HIV and AIDS. In June 2005 alone there were 96,000 individuals that received prescription drug coverage. Thousands more also received insurance coverage. ADAP's are allowed to purchase insurance, continue people's insurance, their co-pays, deductibles, et cetera. So thousands more received that.

Most of the clients were concentrated in 10 states which reflects the prevalence and the funding distribution states receive based on the prevalence of AIDS cases. This was a slight increase in the number of clients served, but it is a smaller increase than in prior years. So we've really seen the program leveling off fairly much so as opposed to early growth in the project.

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Who are our ADAP clients? Most are people of color. They are low income. Mostly male, uninsured and indications of advanced HIV disease, which you can see from this chart. Drug spending reached the highest level to date at about \$103 Million in monthly spending in June 2005. Now, the per capita drug spending is more than \$12,000 per client per year. Again, this is off of the June 2005 data. I do think it is important to note that this is not an annualized figure; that we're taking a snapshot in time. We've been doing that snapshot in time throughout the course of this project which does allow us to provide some trend data there.

Also, insurance coverage spending for the year is estimated to be at \$75 Million. And as with the client growth, drug spending is concentrated in 10 states and increased at a faster rate than client growth. But, consistently it has slowed down. This can also be seen in chart five. Showing trends in client utilization. You can see that the drug spending has increased at a faster rate than client growth. Which I think reflects the drug costs increasing in combination therapy and increasingly complex therapy; multiple scripts per client, et cetera. Both of these have slowed significantly over time. The growth, as I mentioned earlier, you can see the early growth very high and slowing down over time.

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Turning to the next chart. Drug spending and prescriptions filled. There are a couple of main points that I'd like to make here. First, antiretrovirals represent the bulk of both of the spending on drugs as well as the number of prescriptions that are filled. Particularly the NRTI's, you can see 46% in drug spending and 33% in the prescriptions filled. In each of the Antiretroviral classes do represent greater shares of the drug spending than the scripts filled in 2005. And this is a reflection of their higher costs as opposed the OI drugs; the Opportunistic Infection Drugs which, you'll see larger numbers of prescriptions filled there and smaller cost.

As stated earlier the income eligibility is determined at the state level. Excuse me, I've missed a slide here. Differences in drug spending per prescription can be seen more clearly here. Overall drug spending per script, if you take all of the prescriptions filled versus the cost of drugs in that particular month, it was \$272 per prescription. Now, again, you can look at the antiretrovirals being \$282 per prescription versus all the other drugs being \$85 per prescription.

Obviously, you see differences in the costs of different classes of drugs. It's important to note that the fusion inhibitors which are the large bar that you see at \$1412 per prescription, is more of a treatment experienced

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class of drugs. So it doesn't represent that high of a spending. But per prescription, the cost is higher.

As I stated earlier, income eligibility is determined at the state level. And it is based on several factors including the funding available, other programs in the particular state; including the Medicaid program and other state programs that may be in place. This map shows the eligibility and the variability from state-to-state. I think a main point to make here is, a significant proportion, approximately 20 of these states, set their eligibility at 300% of the FPL, the Federal Poverty Level, or above. But 15 are below 200%.

One of the things that I do think is important in this to note is that, because most of the individuals are very low income, under 200% as we saw earlier, a state may choose to cover up to 300% and it doesn't increase their cost very much. There's not very many clients that are at the higher income level. So there are several of the waiting list states, and Jen will go over the waiting list states in a moment here, but there are four of the nine states with waiting lists that do have eligibility levels above 300% of the poverty level. By eliminating that and lowering it to 200%, they might save a little bit of money. But there's trade-off decisions. And we'll go into some of those trade-

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off decisions the states have to make as to how to cover the most number of clients.

The next two slides show some formulary coverage. This first one is the coverage of approved antiretrovirals. Most states, in this case 35, cover all of the antiretroviral medications. But there are still some gaps. The other thing I can think that's really important to note here is, again, it's a snapshot in time. We're taking a picture as of September 2005. Some states may not have added new drugs to their formularies. So, just because a state doesn't have all of them on there doesn't mean they're in a position to do that and may not be doing it at this particular point in time.

Looking at the A1 drugs. And those are the highly recommended drugs for the treatment and prevention of opportunistic infections. We've added that this year. We used to look at the, I think the prevention of OI drugs only. There are now guidelines for treatment and prevention of OI's. So we have added all of the A1 drugs. Taking a look at that, there are 29 drugs that are highly recommended for the treatment and prevention of opportunistic infections. As of September 2005, you can see here that only three states cover all 29. And most states cover the bulk, if you look at the 16 to 28 range.

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Again, there are some trade-off decisions that states make. There may be some drugs in the 29 overall drugs that are recommended that may be more expensive. And so a state may cover a similar drug, but not a more expensive drug. So just because a state doesn't have all the drugs on their formulary doesn't mean individuals in that state can't access them. There are some states that have other programs that provide opportunistic infections. And that's why they don't have the full range on their formularies.

At this point I'm going to turn the podium over to Jen and let her finish up the report.

JENNIFER KATES: Thanks, Murray. And I'll be quick so we can get to conversation here. Sorry. He already moved it back. Okay. Waiting lists. The final section of the presentation really focuses on some of the issues and challenges that face ADAP's and I think will get us into discussion.

The first, obviously, is waiting lists. Waiting lists are always what we're really concerned about. Not because they're the only challenge ADAP's face, but because they're probably the most visible. To know that there are people with HIV who are eligible for their ADAP in their state and their not able to get the AIDS medications through ADAP is a very big challenge facing The United States. And it's just indicative of the way ADAP's are structured.

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And as you can see from the most recent data available, in February 2006 there were nine states that had waiting lists in place with almost 800 people on waiting lists. And one of the things about waiting lists that we've seen; we've been surveying the states on this project for over 10 years, and every single year there are states that have waiting lists. So waiting lists are almost—and we'll talk about this later, the question is, are they a permanent feature of ADAP's at this point, in terms of the way ADAP's are structured?

Obviously, waiting lists are just one measure that ADAP's have to grapple with that do limit access. There are other cost containment measures. And you can see here some of them. For example, as of February 2006, four states reported they had reduced their formularies to save costs. But that restricts access in some way. And there are other things going on, too.

So going back to waiting lists. In addition to finding that waiting lists have been in place throughout the course of this project, and we assume even before the earmark was introduced, which was when we started looking at ADAP's. You can see from the surveys that were able to be done for the last several years, waiting lists are in place in every survey period. They fluctuate. And this fluctuation is very critical because I think it's indicative of the fact that

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states themselves have trouble predicting what kinds of demands they're going to get and what kinds of resources are available. And so you see an up and down fluctuation over time. But consistently, several hundred people on a waiting list across the country at any point in time. The height being over 1,600. And that's, of course, when the President announced the ADAP initiative, because it was so high. And you can see that initiative has had an effect.

A couple of things to point out. That initiative is due to end soon. It was a time limited intervention that we know made a difference. But it is time limited, so it's not a permanent fix at this point. And in addition it was targeted to 10 states who were eligible at the time it was announced, and their clients, at the time it was announced. And we know since then, other states have developed waiting lists. Other clients in the same 10 states are ineligible. So it wasn't able to address the whole national issue, although it did alleviate waiting lists to some extent in those states.

Now going to the budget. The next few slides look at the budget. And just quickly what we see here just like, clients utilization has increased to its highest level in drug expenditures, the budget has increased and is at its highest level that we've seen. At one point, \$3 Billion. With the ADAP earmark making up the largest share, almost 60%. And that's very consistent.

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Two things we'll highlight here; the role of state contributions. Because states, as you know, are for the most part, not required to contribute. And most states do and do when they can. And you see, that's the second largest share, almost one-fifth. And then drug rebates, and hopefully we'll get into some discussion about drug rebates. And our drug rebates now representing the third largest share. And we see increasing at a significant rate. In fact, driving most of the budget in growth that we saw over the last year.

Is this really the role drug rebates should be playing in this program? They're critical, they're important, they're a partnership with industry to some extent. But are they really the main funding source, as they're becoming in a major way, that we see?

This just makes the point. This next slide, that there are many different funding sources that ADAP's are relying on. And most of them are not required other than the earmark. And so you can see tremendous variation by a number of states receiving these sources. So 20 are getting the supplemental. And that's because certain members are eligible for that. Funding source, 19 are Title II based. Which is a decision made at the state level, et cetera. And so, each state has a very different makeup in terms of its revenue sources and how those fluctuate over time.

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And, speaking of fluctuation, we looked at the last year to see, where were there decreases in the budget and by what funding source? And you can see that 12 states actually had an overall decrease in their budgets. And then by the different funding sources, you can see what probably drove that in these states. And all of these data are in the full report by state in all of the appendices.

Some important trends in the budget. Very much like clients and drug expenditures, we've seen a tremendous budget growth. But slowing over time. And interestingly, budget growth and drug expenditures almost mirror each other in almost every period. And this is another point that we've seen over the course of the project. ADAP's are roughly, when a budget increase occurs, are using that funding to provide more medications or insurance coverage to clients. We see almost 100% revenue coming in is being spent directly on medications or insurance coverage.

The next two slides spotlight two issues that we focused on this year that we think, while specific and to some extent unique, have tremendous importance and lessons broadly, to all ADAP's. And to reauthorization. The first is a spotlight on Hurricane Katrina. And we'll hear—we actually have two states here that were directly affected in different ways by Hurricane Katrina. We'll hear about that. But what we saw when we looked at this and this issue and what it taught

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us about ADAP's and ADAP clients, we saw two things over all. One thing is that ADAP's really served as a lifeline for people with HIV who were evacuated in a big way. And some heroic efforts that—I don't know if Beth wants to talk about all of those that they went to. And also in Texas on the receiving end. But also, the many challenges they faced in not having information. Really trying to figure out, what's the path to chart, the course to chart here. And some of the issues we've highlighted. One is just finding people in need. That's a big issue and not unique just to ADAP's.

The biggest issues that I think highlight the challenges facing ADAP's across the country have to do with portability of funding. Can funding follow people? Which, right now, it can't across states lines. But the comparability issues of benefits across states was another big issue that came up. And just the grappling with, whose responsibility is it to find people and get them what they need when they cross state lines? Is it a Federal responsibility? Is it the state responsibility? And as you'll hear, for the most part, it was the states that had to step in and address this.

The second big issue that we spotlighted is Medicare Part D, since that went into effect. These are the first data that we are aware of that are showing what ADAP's are choosing to do in preparation for Part D. And what's

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interesting here, as of November, so just recently, ADAP's actually had at least one policy in place related to the new benefit. The new benefit is sort of a moving target for ADAP's. It's not clear what the impact will be on ADAP's or ADAP clients. One thing that we do believe, very much like every other aspect of ADAP's, it will be very much variable across the country.

But some of the interesting things here you can see, ADAP's are choosing to help their clients make this transitions. So 20 to 22 are paying PART D premiums, 32 Part D co-pays, 29 will provide medications during the coverage gap. Medications that are on their formularies. What's significant about those first three bars to me is that none of those payments are going to accounts toward true out-of-pocket costs, which are necessary for clients to meet the catastrophic level and then get back into Medicare Part D.

So we don't know what that's going to mean. And I think there's two ways to look at it. And we might here a little bit about that from the state representatives. One is that, is that going to exacerbate budget pressures on ADAPs? So we're just going to continue to have to pay those costs that never count to a catastrophic level. The other thing is, actually, maybe it's more cost effective for them still to be able to do that and pick up those extra costs while their

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clients are getting covered. We don't know. And again, it's going to play out quite differently.

So just to wrap up and move us into discussion, some summary points and key issues. Some obvious ones that ADAPs are the nation's prescription drug safety net for low-income, uninsured people with HIV that wrap around all the other coverage sources, reaching a significant portion of those in care. And that they're spending almost all of their revenue on direct client services. I think that's a really important point.

Some key challenges and questions that we've seen over time and that are new ones. One is, what you get depends on where you live. This is not unique to ADAP, but it's very striking with ADAPs. The need for medications continues to outstrip their availability in the U.S. And this trade-off that we will always, I think this program has really struggled with and I think we'll hear about, should states serve more people with less benefits? Or serve less people with more benefits? Add a new drug to the formulary and not be able to add more people? Or add more people and not a new drug? What do you do when you have a limited pot? And that's a very big challenge.

As I mentioned earlier, are the cost containment measures, like waiting lists, are they permanent features of ADAPs at this point? Do we expect that they'll just be there?

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And what is the role of drug rebates, as I mentioned. And finally these two big spotlight issues. What are the big lessons from Hurricane Katrina and Part D for reauthorization? And just generally for considering the role for ADAPs in the larger healthcare system. And just wrapping up on, what are the implications here for reauthorization.

So now I'm going to take off the presenter's hat and become moderator and walk over there. And we will start on what will hopefully be the more interesting part, not listening to us present findings. But to real discussion, here. Is this on? Okay, it worked.

So, you've just seen all of the data. We're not going to necessarily go over all of that. What I thought would be more interesting is to hear some of the issues from the people that we have here that are on the front lines trying to grapple with the policy challenges and the challenges of serving people with HIV and to provide them with medications. And the first issue that I want to put out there and actually ask Beth Scalco from Louisiana about is, in some ways, Hurricane Katrina is a very unique and very dramatic event. It's not something that's really happened in this country before. And hopefully it won't happen at that level ever again. We don't know. But I think what's most telling about it, there's two things. One I mentioned earlier is what ADAPs actually did in response to the hurricane and really reaching

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out to find people with HIV in need. And trying to make sure that they didn't skip a beat in their medications. And second is, what did it tell us or teach us about ADAPs and the authorization and the challenges that might serve as guiding posts for moving forward? So Beth, would you let us know your experience there on the front lines, literally, looking at probably water coming towards your office? And what you did and what the status of things are today?

M. BETH SCALCO: That's a loaded question, Jen. Let me start a little bit with the evacuation experience because it's interesting. Some of the questions that I've received and some people's perception of how much time people had to prepare to leave their homes. And what their expectations were when they left their homes.

The Friday before Katrina in my office, which is located four blocks from the Superdome, we were still convinced that the hurricane was going to be hitting our friends in Florida. Not to aim that way again. But that, in fact, is what we were still hearing on the media. We saw a slight shift to the west. However, worst case scenario is maybe Alabama, but certainly not, you know, a dead hit. So, fortunately for us, when we left our office on Friday, we did not have many things that we would have liked to carry with us to really smooth the path for making sure that people who

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are on our ADAP program had access to medications as quickly as possible.

Prior to the hurricane, we had over 1,700 people who were living with HIV/AIDS accessing our ADAP program in the month of August. SO that was really our current monthly census prior to the hurricane. Really, what we saw is two types of evacuations. You saw by Saturday, people realized that, oh wait; it looks like the hurricane is maybe going to hit us instead. And people began to make preparations as best they can. Which meant that you had to make some pretty fast decisions about where you were going and what you were putting in your bag to go with you. And I will tell you that, the majority of people who chose to evacuate thought that they would be gone for two to three days. And that is what you had in your bag with you; what you needed for two to three days, and not anything more than that.

That was really the group that decided to leave Saturday and Sunday. And so I can imagine that some people who were HIV infected had in their bag their medications. Some people had their ADAP cards. However, as they were grappling with arranging for their relatives and boarding up their house and doing all the things you do in hurricane preparation, that might not have gotten into the bag.

The second group of people were the people who decided to stay. And there were a large number of people who

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decided to stay. And remember, when the hurricane hit on Monday, actually many people were okay immediately following the hit of the hurricane. Their houses were not destroyed and they were still living in their homes. What then happened is that the levee broke, or multiple levees broke, let me say. And as that happened, water came rushing into the city at a very, very rapid pace. Which meant that people all of a sudden saw water rising. And when it came into their house, it rose quickly.

Again, there would have been a decision as to, what do I grab and bring into the attic with me? Do I have my medications? Do I have my ADAP card? And then further, if I wound up on the roof of my house, did I actually manage to get those things up with me? So that's really the type of evacuation that happened in New Orleans.

I think to complicate things, our office was located in New Orleans. Our data on people who are on the ADAP program was in New Orleans. So as we were evacuating as well and had cell phones that no longer worked, we were then trying to figure out; not only how are we going to take care of ourselves and our families? But as, you know, Tuesday and Wednesday, how are we then going to make sure that the people we serve are okay?

You know, I think one of the unfortunate experiences is that there is not a back up plan in place if an ADAP

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program goes down. So there is not the federal government to step in say, "Okay, we're going to be getting coordinating services." Or, you know, "You're partnered with a state that's not in crisis. So they're going to begin trying to take up some of the issues that you're not able to perform as you're evacuating from your state."

One of the good things that happened during that week is that when we did realize that, oh wait; we're going to have to figure this out, is that we did have assistance from NASTAD. We had assistance from Kaiser to begin coordinating a conference call with other states so that we could make sure that other states would be willing to take care of our clients if they showed up in the state. And regardless of what's the states situation was, whether they had a waiting list, what their income eligibility requirements were, they were attempting to make sure that people that were in need of medications had access to them if they showed up.

The big problem was if they showed up. Because again, you had people in crisis. And whether or not their healthcare was going to be the top priority or worrying about where they're going to stay that night was a priority was a difficult one to call. The other thing is that, if you find yourself in a shelter and you're HIV infected, you're not necessarily going to go and tell somebody that. So if you're

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in that shelter with no medication because of your fears about the stigma—and it goes beyond shelters.

Depending on who took you in, you might have relatives that are not aware of your HIV status. And then to ask them to help arrange for you to get to a doctor to get a prescription, to get to the drugstore to get it filled becomes an overwhelming set of barriers prior to you getting your medication. And I think in the long run, the fact that ADAP is not portable is obviously a problem. Because as clients try to grapple with different situations, they might have been eligible in my state, but when they went over to another state, the income eligibility was different. Or the list of medications that they could get was different.

The other thing that client had problems with was the terminology. Many clients in my state had no idea that they were on the ADAP program. And we strive to make a seamless system of care. So in Louisiana we hooked the ADAP program up to wherever somebody is receiving primary medical care. They go from seeing the doctor with their prescription and they go to the pharmacist in that clinic and they get their medications filled. So when they showed up to Dwayne in Texas and Dwayne said, "Who pays for your medication?" they said, "Charity". And Dwayne said, "Well what charity?" And the bottom line was that they were getting their medications from what they call Charity Hospital in New Orleans or the medical

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center in Louisiana, which most people refer to as Charity Hospital. So there was in fact lots of difficulty in trying to figure out a new system of care versus one that they came from. And again, no ability to have a coordinating center. Our hotline was also based in New Orleans. So we did not have a phone system in New Orleans, so there was no way to even call in our own hotline to say, okay if you're in this state, go here. If you're in the northern part of our own state, go there. So I think it would have been helpful, again, if there had been some assistance from the outside to try to step in to try to really assist in an emergency situation when you know all the communications are down in that particular area that has been hit.

So with that, Jen, I'll stop and see if later you've got questions.

JENNIFER KATES: You could spend a whole day on that topic. Actually, you reminded me and I should really thank Beth and her staff for this. We, very soon after, called Beth and were in communication to see how we could help. But we also said we want to interview you and have you share your story. She was able to do that. And we subsequently went back and now we're doing interviews with people who were evacuated from New Orleans. And we included five individuals with HIV thanks to Beth and her staff who helped us find them. We'll be releasing those findings later this year.

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I want to turn to Dwayne because Texas and other states, but particularly Texas, was on the receiving end of most evacuees with HIV. And really I think it was sort of the lesson we all now look to. What do you do? And you can tell us a little bit about what you did and what some of the challenges were and where you are.

DWAYNE HAUGHT: I mean, it's kind of interesting. What I'd like to tell you first is, just last week we had two clients identify themselves as Katrina evacuees. So we are actually still enrolling clients—I don't know, how many months is it, Beth? Six months? Seven months after the hurricane, who are just coming out of the shock and saying look, okay, now I need my meds and are coming in. So, you know, we are still actually adding new evacuees each week.

I guess the other thing I want to say, and I don't want to take a whole lot of credit for what happened with the Texas ADAP. Actually, that Friday that Beth talked about, I got a call from a case manager at the Triangle AIDS Network in Beaumont. And she told me that they had a client coming to their AIDS service station who was a Louisiana ADAP client, and what were they to do? And I, like everybody else, was kind of watching the news and wasn't exactly sure what was going to happen. So the wheels started turning in my head. And I thought, well we really need to develop some plan. You

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know, New Orleans is really close. It makes sense that if something happens, people might come over.

Well, Monday, things really changed pretty dramatically. And I put a call in to Murray and Murray was out of town. And then I tried to call Michael Montgomery in California and I couldn't get him. So I thought, oh I'm going to be forced to do something here on my own. You know, so what I thought was, the Texas AIDS drug assistance program is kind of always teetering. We're kind of like the dog chasing his tail. Every year we need money. You know, we just get through the end of the year and it seems like we just make it. So I thought that, I'm a nurse, so I felt compelled to do something and to provide some type of service for those people coming over.

But, I also realized I live in a state, you know, that had an ADAP that was constantly needing money. So I thought whatever plan I put together, it would have to be as minimal in cost to the state because when I presented it them, I wanted them to have no options of saying no. So what I did was, I called the eight major drug manufacturers who manufacture antiretroviral medications. And I asked them if they might provide in-kind donations for whatever medication that we expended for Katrina evacuees for the months of September and October. And it took many of them just one day to get back and say yes.

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So what I could do within 48 hours was kind of present that plan to the state and say, "Look, the major drug manufacturers have agreed to replace anything that we use for evacuees." So, I'm going to take this minute and thank all those major drug manufacturers who did that because it really made a big difference. And it made us to be able to respond to the emergency immediately. So I presented that, and the state said yeah. And NASTAD, by that time, we were talking and they were involved in letting other states know what was going on.

So, you know, we were able to do that. But the other thing that we needed was a hoop-free kind of screening process. And our application now at the Texas ADAP is about 12 pages long. And you know, we want to know everything about everything. So I knew we couldn't do that. So what we did was we developed a one page, front only, kind of temporary application that covered the key information. You know, we wanted their name, obviously their original state address because, when we put that into our data system, we could track it. If you're a non-Texas resident, then we could track it. So we could track expenditures.

We wanted to know who their physician was, obviously. What their state ADAP was. And then also we had a clause in there of a release of information so when New Orleans or Mississippi got back up and running, we could actually send

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information back and forth about the client. So those were kind of the things that we did.

And then immediately, we were surprised that, like Jen said, I was surprised how ADAP kind of became the center for a lot of HIV services and a lot of meds. Because people who needed meds, whether they had ADAP or whether they had Medicaid somehow gravitated to the AIDS drug assistance program for medication. So we were doing a lot of information providing for people on how to access Medicaid in Texas and different things like that.

So I think we ended up with about initially about 328 clients who came onto the program. I did make a call to HERSA immediately that Monday morning and I spoke with Doug Morgan and asked if they had some ideas if we were able to participate and stuff like that. So, you know, at that point they couldn't tell me that we could or we couldn't. But you know, the one piece of information they gave me was they said, well you know, hopefully you have the same eligibility criteria. And we actually did. I think we had less than 200% of the federal poverty level. Our formulary was bit different. But still, the eligibility criteria was the same, so that simplified things.

So, just over the next two months, you know, we kept adding people. And again, I think I just want to stress what Beth said. I mean, as hoop-free as you can make it. You know,

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I know there was a lot of benevolence in the beginning and people were offering up all types of things. But even for clients to have to call a 1-800 number and register for a program was almost overwhelming. And the transportation piece, I mean, somebody would be in Fort Worth, and we'd arrange for them to pick up, you know, medications at one of our participating pharmacies in downtown Fort Worth.

And then, you know, we had to find someone to arrange transportation. And then, it was simple things like, well where are you? Well, I'm not sure, I'm in Fort Worth. I mean, you know, these people were displaced. They didn't know who they were with. I mean, one woman called me and she was in a house with 60 other people that had come over. So it was overwhelming. So you know, we wanted to make it as simple as possible.

Let's see. A couple of things that I think that we learned and what we're doing that we didn't do before this hurricane. And it didn't impact us. But monthly, what we're doing is, you know, we're sending a list of our clients and the medications that they're on to another state agency in El Paso, which is far away from us. And then each month, they shred that list. Because one of the difficulties, like Beth said, and we experience the same thing in Texas—wherever a client actually picks up their med, that's who they think is

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actually providing it. And if they pick it up at a clinic, they think they're getting it from that clinic.

So a lot of the clients didn't know what medications they were on. They didn't know whether they were actually an ADAP client or not. And to complicate things, there's a slight is a slightly different system. New Orleans has a system where they distribute AIDS medications. So we had asked some clients, well, where do you get your medications? And they'd say, "NO AIDS". And I'd go, you know, no AIDS? You know, if you don't have AIDS, why do you need AIDS medications? And they'd go, no, NO AIDS. So it meant New Orleans AIDS. So you know, that's where they got their meds. They didn't get it from ADAP. So we had a big learning curve, too.

But the ability to exchange information in a system, whether it be federally, you know, central or state central or somewhere else, was critical because we had many clients that didn't know what medications they were one. They knew they took a blue pill or a green pill or white pill. Or they took a pill three times a day. And I have to share with you, you will appreciate this. The first client that we had come in, and it was a big deal to get the first client on the program, and I wanted to be a success. So you know, this guy had called up and said that oh, you know, I have Louisiana

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ADAP, I have my ADAP card with me and stuff. I want to come in and enroll, they told me to come in.

So, he was a Tulane third year law student. He came in with a briefcase, he had his card, his meds were all written up. I thought, oh god, you know, this is really going to be easy. Well, that was it, you know? That was the only time someone came with their card and with a briefcase and with their meds written. But it was good to have the first one be successful. I was like, you know. I thought, ooh, this is going to be easy.

So those are really the things. I think the ability to have access to the client's name, birthdate, their social security number and you know, meds that they were on would have helped. And again, you know, if that can be, you know, centralized in the feds or another part of the state. And what we've started to do just because we've learned, because we weren't doing it. And we thought well, what if there's a disaster here? What are we going to do? So now, we're sending that once a month to a state agency in El Paso. And then they shred it and we send them a new one each month. That's about enough. I'll quit here.

JENNIFER KATES: Again, I think we could have actually had a panel on ADAP and Katrina. Both of the things you've said though I think seg-way nicely into some of the challenges for reauthorizing the care act. And what are we

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learning from this? And not that we necessarily have to have the answers, but we're very pleased to have both of you here. I know you're actively working. We're probably keeping you from working on it right now. And it's on everyone's mind that, you know, Senator Coburn actually dropped this first bill on this. Your process is working a bipartisan, bicameral processes you've been working on for many months with, probably, many of the people in this room. And I just would love to hear an update and I'm sure everyone else would, from Shana first on: What is the status, what are some of the big issues that you're grappling with specific to ADAP's? Or anything you want to share with us on this?

SHANA CHRISTUP: Well, I can just say that, as you talk about differences between ADAPs and what happened in that situation, when you start looking at the whole Ryan White Program, you see the differences happen across all titles. So we've been really grappling with some of those differences. Whether it's the access to services or access to drugs and how to make sure that we can make this as equitable for all those with HIV, all Americans. And in doing so, that raises a lot of challenges. And not only what you have with sort of the differences between the states or dealing with ADAPs and everything else. But you also have an epidemic that's changing. So the types of people you need to reach out

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to and how you do that, what mechanism do you use, is maybe different than what we've used before.

And we have to recognize that we have to fight the epidemic of today, not that of yesterday. And making sure that money follows a person the best it can. That is also recognizing, obviously that there is key healthcare infrastructure that we have been building and supporting for years. And we're not saying to undermine that completely right now. But we do also need to build new infrastructure in places where those new people are and make sure that we can actually respond to the changing epidemic.

So with all of that as a backdrop, it has been a very good discussion. We're constantly talking. We could not do it without our house colleagues and some of them are actually in the room. Sort of cheering us on. And we make them speak at some point. No, William? And it is true. I mean, we are meeting regularly to talk and sort of discuss that. And as soon as we have more information about where we are, we will definitely share it with all of you. But, to be honest, we're still in the throws of figuring out just the basics of the program and making sure that we can.

I think we all agree we want equitable treatment and we want to make sure that it all makes sense. It's just how you make that turn into legislative language can be a challenge.

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JENNIFER KATES: And Connie, your perspective on that. And also, I know one of the issues that you must both be grappling with is, to what extent do you focus on medications? And how do you also address the larger components of the care act? I mean, obviously people don't just need medications. So how do you grapple with those?

CONNIE GARNER: And I think—is that on now? I think, for me and particularly coming from Massachusetts, where, as you look at the sheets and look at the grids, you'll see we have a very strong both connected program in Massachusetts in terms of the Ryan White Title I and II. With the program, with the amount of state dollars that are put in, with the drug company. And we've kind of got a system that works fairly well up there.

And so, the concern I think for me, and it was interesting for me to come into this today because I'm a Nurse Practitioner by trade. And so when I looked at this bill originally I said to Shana, what a strangely written bill. I haven't really quite seen a healthcare take from a systems point of view the way this bill is written. And for me, that kind of began to sort out some of the challenges as Shana said that I think we have.

Drugs are drugs. And you needs to have drugs. And drugs, I think, have made the biggest difference in this disease and also in the co-occurring infections that happen

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when you have any kind of immunologic condition going on. One of the things we're concerned about in the drug portion of this and just ADAP and I think questions from a policy question point of view. That at least from our end we continue to mull around in is, what is the relationship, really? And what should it be? Between ADAP and Medicare Part D, considering the number of people that you have on D either for Medicare that now have a new drug benefit or folks who are on Medicaid who lost what they used to have now to a new system. And then the folks that are the dual eligibles that are in a hole of some sort. Which, we are, we've really done our homework. A hole, a gap of some kind that has kind of different interpretations.

But what are the relationships of those two programs, really? Because there's a lot of questions I think, that have to be looked at in terms of the relationship between Medicaid and Ryan White as a whole. And certainly Medicaid and the issues of ADAP. So that's one thing that we're still trying to work out in terms of resource and resource allocation. But sort of, what's the best use of that resource, as well.

The second thing is, when you look, as Shana says, the demographics have changed over a period of time since 1990, which all of you know. And for better or for worse, there have been medical infrastructures and support infrastructures that have been set up in this country that

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still do attend to what seems to be, via the numbers, the density of folks who are infected and living with this disease. There's a concern about tearing those infrastructures or doing anything that really begins to take those infrastructures away before you're really convinced that you have something to replace it with. And that's the question. If we were to redesign this totally, do we have what we need to take up the slack from that? And I can tell you, in Massachusetts, not sure. And that's a premier program and in a premier state in terms of the amount in investment that goes in and the utilization use of best resources.

So that's a question I think we have to think about. So, you know, when Shana talks about the fact that we have addressed the need in some areas for a while and now we have new need that arising, we may need to create new structures. I still haven't answered the question in my mind whether we really need to create new structures. But whether we, as a result of 15 years of change, need to reconfigure what we already have? And that's a question.

And those of you who say, you know, where's this bill? Why is it taking so long? If you want something that's done correctly, when you're talking about a piece of legislation that I am very concerned is driven about two principles and that's it. One is, power; who's in charge? And the other is who is going to lose money and gain money? And

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the right kinds of policy questions aren't asked, aren't analyzed, the data is not run. You're going to wind up with a mess if you don't have a bill that's thought about that correct way. Because there isn't one thing that I don't think on our bicameral group that we talked about is, that if you change, does it either have a domino effect to not just the ADAP program or Ryan White or Title I, II, III and IV; but to the rest of the healthcare system they articulate with. Whether it's state operated or whether it's a federal system.

So that's part of the reason everyone is frustrated. I know that we don't talk a lot. And that we don't have a product to put on the table. You don't want a product, I don't think, that's not through well. And we have the rationale as to why we're doing what we're doing. And right now, there's a lot of stuff in this plan as it stands currently based on where the disease and epidemiology of that has gone that doesn't make sense if you begin to think about it right now. Not back in 1990, right this minute.

And so that's why it's taking us a while to think about that. But I think that whole issue of infrastructure is huge. You know, what should it look like right now to be responsive to the needs now? But also to not jump from you know, for better or for once, from one system that's been reliable to a system that we're not sure about? Or, how do you move towards that in a reasonable way so that you don't

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have one fall down and the other one, you know, not ready to be there. So I think that's one of the biggest challenges that we have.

The other issue, and this is a very big issue for us, and you heard at least my boss talk about it at the hearing, is this issue of Medicaid. And does it or does it not meet the bottom line? Should it count as a resource allocation when looking at Ryan White? So, in other words, what we're very concerned about is, if you have a state, really, that state, for whatever those tax payers are worth, really put effort into what they want in their system. And maybe they wanted a good Medicaid system. Or maybe they wanted to put, as Wyoming does, 15% contribution into their drugs. And that's what they chose as tax payers. Do we have the right to take away or reduce what their resource allocation is from the federal government to try to support a state that may not have put that value? Not that they didn't have it. But that they didn't put that value into developing their systems. So there's a real deal here with the Medicaid system and Ryan White and what we do with that. So, that's important.

So, the other parts of Ryan White that we haven't spent a lot of time on but we need too. What do we do with dental schools? What do we do with all the populations that don't seem to be getting what they need? Native Americans, those folks. You know, we haven't dealt with that yet. I

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guess I just would make the case that I respect a lot in terms of what Shana has to say. And what her input from working at CDC and what her investment in Ryan White has been over the years. Our house people have really been good. We have very productive meetings. But we really don't want this bill to come out unless it's the right kind of bill with the right kind of under-paintings for why these policy decisions are made. So that's just so that you know why that you don't hear that much from us right now.

JENNIFER KATES: Thanks. Just a couple more questions for our panelists before we open it up for your questions. And actually, you reminded me that the bill is complex and has many different components that have come in at different times. So I'm actually going to turn to Murray. You have helped us understand one of those components that we're hearing more about which is the double hold-harmless and the relationship to supplemental and all of these things. Which I think is a very good example of, you do one thing here and what's the impact there?

MURRAY PENNER: Yeah. And I won't bore you with the intricacies of this double hold harmless. There are two hold harmless provisions within Title II. Hold harmless basically protects losses of funding from states from year to year. There is one portion within the ADAP supplemental grants

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which 20 states received last year. That requires that states get level funding over the previous year.

What's happening now in the current fiscal year, with a flat ADAP appropriation, no increase, states are seeing losses in their grant awards. And in order to make that up, ADAP supplement funding is back filled into the ADAP awards for every state. It's an unintended consequence, we believe. But the ADAP supplemental awards this year are going to be significantly less than they were previous years. What that means is the severe needs states that have the most need for ADAP funding to continue the access to drugs are going to be cut in their funding. So, it's an unintended consequence, it's a domino effect, exactly what Connie said. That is very complicated. And you make one change and something else occurs.

So, I think it is really important to be a very thoughtful process. It's very much like other discretionary grant programs where you've got things piled on top of other things. So, very complicated.

JENNIFER KATES: Thank you. Okay, I want to turn to Part D. And actually ask Jay a little bit about that. In West Virginia, the state on this panel that actually has a waiting list in place. That's another thing that maybe you can talk about. But Medicare Part D. Every ADAP is grappling with what does that mean? And trying to adjust. So can you tell us a

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little bit about your experience with policies related to Part D?

JAY ADAMS: In West Virginia, which is a low incidence state, anything that happens is a jolt. The news Murray just talked about. The fact that ADAP supplemental is going to go down is a jolt. A waiting list is a jolt. A present ADAP initiative ending is a jolt. And when I left West Virginia, the jolt from Medicare Part D still had the ground shaking for us.

It is a complex program for a low incidence state to implement. Our clients have one goal in mind. And that is to get their drugs. I'm always extremely interested to see the ADAP report that comes out from Kaiser and NASTAD. The information is always very informative and I use it throughout the year. But my clients just want their drugs. They're not interested in the data, they're not interested in programs, they're not interested in more co-pays, they're not interested in premiums. They just want their drugs. They've always got them for free and they still want them for free.

So we had to figure out how we were going to pay premiums with an ADAP system that doesn't pay premiums. Our claims are processed through Medicaid. And Medicaid said, we can only pay for drugs. We can't do premiums. So our other Title II dollars, which are a base award, are being used to

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pay the premiums. We are paying co-pays through the ADAP system.

And in some ways, it's very rewarding to be able to see a very expensive drug that I know my clients couldn't get before because it wasn't on my formulary, coming through our Title II base award, and we're paying \$5 for it. That's wonderful. It's disheartening to see patients going to the troop already where they really don't have the dollars. And we are going to be stuck with those patients for the rest of the year now. So we sell benefits for maybe just two months. And now we are offering the coverage.

West Virginia chose to cover the premiums through the base award and also pay the co-pays through the ADAP program because that's the way we've always done it. Our patients who are served and are eligible got their drugs for free. And when we first heard about Medicare PART D and people were told that they had to enroll, the first thing we heard from people is, I'm not going to do that. I don't have the money for the premium and I can't do that.

So we had to figure out a way to do that. Fortunately, when you're a low end state, you wear a lot of different hats. And as a person who wears that hat, the ones that base award program, the consortium and also in charge of the case managers who were able to go out there and educate our clients and help them find plans that would benefit them

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but also benefit our ADAP program. And that took a lot of time with each and every one of those clients. 115 of them.

And many of my case managers have case loads over 100 clients. So it was just an extra burden. And now that the folks are entering that coverage area where ADAP is going to be fully responsible again, it's certainly a burden again.

When you have a waiting list though, and when you accept those extra responsibilities such as Medicare Part D, and then you hear that ADAP supplemental is going to be cut, it's scary. Because you know for sure that again, you're looking at deficits. We have a couple drugs we have not been able to add to our formulary. We've had a waiting list since February 1st of 2003. And it continues. And each and every day as you look at these programs either ending, starting, or you adapt, you have to figure it out.

JENNIFER KATES: Thanks. And I hope maybe in questions we can get to some of the other Part D experiences that the other two states have had already. I want to actually turn to Arnie and hear a little bit about the industry's role broadly speaking, particularly related to the ADAP crisis task force. And then Murray might want to add something. And then I promise we're going right to questions.

Arnie Doyle: I thought I was going to get out of this. As Jen mentioned before I've sort of seen these story unfold from outside. I managed the District of Columbia's

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AIDS assistance program many a year ago. And that was around the time when combination therapy became the standard of care, in '95 and '96. Programs really hit their first crisis mode. And then I worked at NASTAD managing their care and treatment programs. Working with the states, working with industry collaboratively, too. And with members of congress collaboratively to help make this program serve as many patients as possible. And now I'm working at Rosche pharmaceuticals. So I've been on all sides of the table I guess you can say.

Just a couple of things that stand out. When I think of the years of working on ADAP issues and the role that industry has played in working with the programs I think first is the ongoing collaboration with both the states, the programs themselves, NASTAD, members of the community, efficacy groups. In actually working with policy makers on the hill in the administration to really discuss the importance of these programs to people living with HIV/AIDS and to really try and get the resources that these programs need to serve the ever-increasing number of people with the disease. So that's been an ongoing collaborative effort I think we can all be really, really proud of.

Sometimes it's a rocky relationship. It's not all—and not everyone is always happy with each other. But, we've maintained those relationships despite any of the bumps in

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the road. And I think we should all be very proud of that. I think, secondly, as certain events have occurred; Katrina being one example, and then also examples in other cases where a state has hit a particularly rough spot with their program. Where industry has been able to step in. I can remember, for example, Colorado completely running out of dollars even for their existing clients. And going to the manufacturers and saying, listen, we need help for our patients until we get the new federal money. And industry picking up all of their clients on their patient assistance programs until they got the new federal dollars.

So, when events like that occur, I think there's opportunity for collaboration. And I guess I'm proud to say that has also worked very well over the years. And you know, I get calls from Murray at NASTAD all the time as these issues arise. And also Annie Cross. I'm also welcome and willing to take the discussion.

In terms of the ADAP crisis task force, that has been a very interesting process. And I think it's astounding when I actually read a draft of the report that, over the last few years that we've been working with the task force that, it has saved the programs, I think now when you add in this past year, well over \$300 Million. I think that's an amazing thing. And, again, I know those discussions haven't always been easy within the state health departments and the AIDS

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directors that manage these programs. They have priorities and they're answerable to their higher ups for running a program that doesn't run over budget. You have people living with HIV that need access to these therapies and they're banging at the doors of the ADAPs. You have advocacy groups who are seeking to represent the best interests of their clients. And then you have industry, who are trying to balance the provision of medications to people living with HIV and other diseases. As well as being answerable to their share holders, et cetera. The chain of command.

And so, it's balancing and juggling a lot of different priorities. And I think it's worked really, really well. I know that when we walked in the room with the ADAP crisis task force some years ago, we did not go in with like, you know, what's going on here? Why do you want more, you know, more from us, per say? We went in knowing the programs. Knowing what they were up against. Knowing that the federal funding and in some cases state funding was not really able to cover the needs of the programs. And said, what can we do to help you out? And I think we've continued along that path for the last three years. So I think those are all examples of the importance of the collaboration. And I hope to see that continue throughout the next coming years as we work really, to find some more sustainable solutions for these

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programs. I'm sure our friends in congress are going to come up with the prefect reauthorized care act.

JENNIFER KATES: Thank you. Thanks to all of you for the amazing, rich discussion you've already started. We're going to turn to questions from the audience.

DAVID: Hello. I'm David with AIDS foundation, Chicago. I have a question for Jen and Murray. One, thank you for the support and your ongoing commitment to the project which is so important. And for looking at the wait list trend data over time. I was wondering if in your analysis you looked at mobility of people on the waiting list? I'm wondering whether, you know, there's a core group of people who have been a long time waiting on the waiting lists? Whether it paths off of waiting lists? And, if there are paths off of waiting lists, what those are?

MURRAY PENNER: We did not look at that, David. I think that it is something, as we move forward with this project. Every year we come up with new questions. And I think as the waiting lists have persisted, one of the things that we have wanted to do is look at that more. We'll certainly take that into account, I think, as we move forward. Sometimes, you know, we look at these states and the variability of their abilities to collect data. And you look at some states with very small infrastructure in place, and just data collection alone is very difficult. And so in some

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states, it might be easy to do that. In other states, it might be very difficult for the state to say, yes this is what we see happening with clients on our waiting list. We will continue to look at that and appreciate the suggestion there.

BILL MCCALL: Hi, I'm Bill McCall with AIDS Action Council. It was actually this study two years ago that convinced us that portability was a significant feature that needed to be addressed with the AIDS drug assistance program. And to us, it seems like the real questions at the bottom of portability are creating baseline eligibility requirements and a baseline formulary. I mean I think that where we've—I mean, we did put forward a proposal that would do that. It was an expensive proposal for \$720 Million. But, what we're trying to get out there was the idea that portability itself is a real question here. So I'm wondering without sort of saying that we shouldn't spend \$720 Million on this program, if there are ways to get down to these issues of portability, I note that Louisiana has an ADAP card of a sort already. Are there ways to get to this issue that might be cheaper or less expensive? That we can all start to come together as community around.

MURRAY PENNER: I think I'm going to throw that out to maybe, to Beth. And actually, I'd love to hear if Shana and Connie have any thoughts about that. Or Dwayne.

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M. BETH SCALCO: You know, I'm not sure that there's a way to do it any cheaper. I mean, depending on where you're going to set your financial eligibility and if you follow the public health standards on, you know, what is recommended as being available in medications, you're going to come out with a dollar amount that we don't have right now. So, you know, if we're going to go in that direction, one, we have to have the money behind it.

The second concern that comes up with that is that there are, in fact, states that are able to offer more. And the worrisome thing about saying, "here's the basic standard that we will offer" is that might relieve some states of their obligation and their commitment in providing additional funds to make that even higher than what you've set as the bottom standard. So, if you're already a state that has the ability to offer up to 500% of the poverty and a formulary that's, you know, over 100 drugs and all of a sudden, we've decided that it's going to be set at 300 with a formulary of 45 drugs, will that in fact be an incentive for states to reduce their contribution? To consider that they will only meet the minimum, rather than the maximum.

BILL MCCALL: [inaudible]

M. BETH SCALCO: Yes. And some states are better at that than others. So, you know, I would agree. It depends on how strong the activist is. But it also depends on what the

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state budget looks like. If I were to try something right now, I would not have good luck.

SID STEWART: Hi, My name is Sid Stewart. I'm with Monogram Biosciences. I have a questions for you. First, excellent report. But the question is, I don't see anything related to resistance testing and the importance thereof as it relates to resistance testing. And as you know, the DHE just guidelines indicate that they should be used as the standard of care. And it's sort of like in the world of oncology, now medications are available that help you genetically utilize the drug that will work the most effective. Is there anything being done along those lines? Thank you.

MURRAY PENNER: I can take a stab at that one. And my colleagues at the state might chip in as well. We do collect some data about what states are doing around resistance testing. One of the complicating factors is, in many cases the ADAP programs themselves are not doing the resistance testing. It may be done in the Title II program or the Title I program. There is a lot that's happening. Our particular survey focuses on ADAPs and we do not go beyond ADAPs as far as data collection. And so, we do have a little bit of data about what some states are doing that. We didn't publish it because it's not complete because of the fact that we do not

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go out to other funding sources within the Ryan White Care Act system. But we could provide some of that for you.

DWAYNE HAUGHT: Right. And I just want to concur with what Murray said. ADAPs are eligible to pay for resistance testing. But in Texas, resistance is paid for by Ryan White Title I and Title II funding. And it's usually because it happens at the point where the client is getting service, where they're seeing the physician and stuff like that. So, our resistance tests in Texas are paid from Title I and Title II.

JULIE MARSTON: Hi, I'm Julie Marston from Community Research Initiative of New England and the Masters of ADAP. And I have a deep appreciation for the complexity of ADAP programs across the country. Health insurance programs are better. But I was struck by your data point that suggests that per capita expenditure on people in the ADAP programs is about \$12,000 which is about twice the cost in the very expensive states, such as Massachusetts for example, for health insurance. And is there any incentivizing in terms of the way you're thinking about future legislation to begin to look at that? And over twice as many people [inaudible]

CONNIE GARNER: I've been fighting with that point with Wyoming here for a couple of hours.

SHANA CHRISTUP: WE were sort of discussing some of the information on some of the per capita expenditure

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information before. And one of the caveats that we learned from talking to Kaiser Family Foundation and NASTAD is that that per capita drug expenditure does not include Medicaid rebates. And so if you're a Medicaid rebate state, obviously that's not going to be calculated as a part of that. So it's going to be a lot higher than you would expect. Connie was sort of going on to the fact that Wyoming does actually do a 50% state match. We're still at 200% of the poverty level. And yet we spend about two or three times as much money per capita as Massachusetts does. She says we should get better bargaining. But some of that may be caught up in-

CONNIE GARNER: We do a better job at this pharmaceutical companies to my right, I think.

SHANA CHRISTUP: Because you actually have some in your state.

CONNIE GARNER: That's true. It's a problem.

SHANA CHRISTUP: If we get a pharmaceutical company in Wyoming, I bet we could negotiate with them pretty well.

CONNIE GARNER: This is what goes on all day.

SHANA CHRISTUP: But we are looking in, obviously, lots of different ways to make sure that as much as we can, we can really look at drug pricing as a part of this. And also look at other incentives to make sure that we provide care as efficiently as possible. Whether it's drugs or

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healthcare services or whatever else. But it was duly noted, at least, in our conversations already.

CONNIE GARNER: I would just add that we actually have seen over the course of the project a real increase in the number of states that are using insurance coverage as their mechanism of coverage. In the states that have insurance market laws that allow them to do that. Not every state does. And it is more cost effective than I think—I don't know if any of the states want to talk about that. You can pass on it. But I think it is a mechanism that more and more states are turning to when they can.

SHANA CHRISTUP: Yeah, we actually use in our insurance, we will pay for peoples premiums if they have access to insurance. Our big problem is that we have a huge group of people who are uninsured when they first come to us. And at the point they have an HIV diagnosis is not the time when you can find an insurance company who will accept them.

Now we do use our states high risk insurance pool. They, however, have a limited number of slots that are available to us. And when I say limited, we're 10 to 15 slots a year that we can use for clients who are HIV infected. So the bigger issue for us is having the insurance in the first place.

ANNIE PAULSON: Hi, I'm Annie Paulson from the Whitman Walk-In Clinic. The report is extremely useful in

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terms of what's happening to the ADAP. But I was wondering, in terms of the impact, on average, how long do people stay on the ADAP before moving, transitioning to another service, for instance Medicaid or something? Whether this is collected by the states or by NASTAD, or whether it be at all?

DWAYNE HAUGHT: I'll address that. In Texas one of the big cost drivers, we were actually going back and looking at data and seeing what was really pushing our costs up. And one of the issues that we saw that really jumped out at us is something that we called an 'intensity of client usage'. And one of the issues about intensity was that—what we saw were people were staying on the program for much longer periods than previously. And it seemed as though we always had a core group of clients who stayed on the program. And we were their insurance for life. And the majority of those were people who had Medicare prior to any prescription coverage.

But then, we always had a second group of clients that came on the program, were on the program for a short while, and got off for whatever reason. But, what we're seeing when we compare recent data with previous data is that people are not leaving the program. They're staying on the program. I don't know the reasons, but there's not the change in on and off that there was previously, at least in Texas.

MURRAY PENNER: And I would just like to add that it varies from state to state depending on the Medicaid system,

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for instance. You'll see some variability where some states will have clients move back and forth from Medicaid to—well, depending on whether they're Medicare eligible now—but Medicaid back and forth to ADAP, depending on what Medicaid provides. And so you've got a lot of variation from state to state. And I would like to make this point very clear that, even things like what we were talking about earlier, a lot depends on a Medicaid program in a state as well. So, it's a huge interaction.

JAY ADAMS: In West Virginia, we have folks who've been on the ADAP program 10+ years. And part of it is a testament to the fact that the drugs are working. And if a person continues to work, they're not on social security, not eligible for Medicare and also not eligible for Medicaid. So ADAP is that safety net, and they'll be on there for a long time. And it's a testament to the fact that our program is working for them.

CAPPY HIRES: Hi. Cappy Hires from AIDS Alabama and the Southern AIDS Coalition. I'd like to thank Shana and Connie for, I know, the countless hours you've put into this. And I totally hear your point, Connie, about not disincetivizing contributions from states. So, coming from the state with the longest, oldest waiting list and a terrible Medicaid program—although we do match the Ryan White dollars at about a 50% level. My question to you is, are you

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guys running numbers to look at the impact on how we could fix just Ryan White? You know, to make it fair within Ryan White, setting aside Medicaid. Because we don't expect Medicaid to—you know, Ryan White as a safety net will never solve our Medicaid problem.

SHANA CHRISTUP: We're saying off the record, yes.

JENNIFER KATES: So, you're not solving all of the other problems in the healthcare system with this? Okay. I think we have time for maybe one other question. Maybe two.

ERIN BURNS: Hi, my name is Erin Burns and I'm with the Student Global AIDS Campaign. I had a question for Mr. Doyle. Just given the urgency of the domestic AIDS crisis, how can pharmaceutical companies justify spending about twice as much on marketing as research and development, as well as the manufacture of generic drugs? Thank you.

ARNIE DOYLE: Geez, that's a loaded one. Actually, I would probably prefer to discuss that outside the context of this discussion because this is focused on domestic AIDS programs. And I think that's a larger discussion that we could have an entire forum about. So I'll be willing to talk to you afterwards and maybe go deeper into that. If that's all right.

JILL MORRISON: I'm Jill Morrison. I'm with the National Women's Law Center. Several of you commented on the demographic shift of HIV and AIDS. And I was wondering, do

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you see an actual potential explosion of the ADAP program, given that the face of AIDS is becoming more and more female and you already have a disproportionate number of women in Medicaid? So I see the program is kind of being more seamless if you have women who are being tested for HIV within the Medicaid program and moving very quickly to, potentially, other resources than ADAP. And has this been bandied about in any of the funding decisions as to whether or not, you know, the sustained funding or the flat funding is going to actually serve the nation's needs?

SHANA CHRISTUP: We have. We've had a lot of conversations, not just about, you know, migration yes, migration no issues. But also, the fact that women, women of color and kids for that matter; adolescents into the 25 to 30 year old timeframe, are really on the rise. Where before, you know, generally it was men. So we have had that conversation. The issue that you're bringing up is really an interesting one because it's the issue, again, that keeps rising up. Where are we in terms of parallelness with Medicaid? Maybe population. Maybe poverty level. Maybe drugs now. Now the issue of women brings it even closer together because as you know, single men are not in Medicaid. Men are not in Medicaid. So it brings up that issue. And that is an issue that we continue to keep talking about in terms of one

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system? Parallel systems? You know, what are we really doing here?

Where it begins to get complicated, however, is the one issue that we never talked about here today. And that is the importance of—now that this disease, a number of people, you know, are able to live 20-30 years. And so, what was a response to a public health emergency when this first came about? When all of a sudden sarcoma—I remember when I first got out of nursing school. You know, the same picture was sarcoma. And then it turned into, you know, another name. Same disease, just more identified.

But now that you're getting into issues—and I don't say this to say this is a chronic disease. Because I don't believe it's a chronic disease. But it has issues of chronicity built into it. And so the question is, we can put tons of money into drugs, I could argue. But we can't forget nutrition. Because if you can't absorb the drugs, you're wasting your money. And if you're keeping people alive for 20 to 30 years, what are the support services they need to have some quality of life?

I do a lot of the disability work for the democrats. And it's the same issue we deal with all the time. If we're keeping everybody alive, if we're saying there's a value to having a disability; which people with HIV/AIDS, I will argue, do have, then we have to care about the quality of

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life that those people have. Or we have to ask them questions, you know, why we're doing what we're doing.

So, when we get into some of this stuff where it's like, almost medical, real medical, not even health. Medical debates versus the other kinds of support services one needs to have some quality for what those 20-30 years look like. That's when you see our conversations go to programs, one part- you know, what do you really do? And it's very hard to sort out because you begin to wonder why you're doing what you're doing half the time.

So, long answer to your question, are we looking at that? We are. Particularly around women.

JENNIFER KATES: I actually think we are going to wrap up because we are ten minutes over. Many of us will be here for a little while after. And I just want to first, thank our panelists for taking the time and really just having this discussion be so rich. And thanks to everybody for coming.

[END RECORDING]

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