NATIONAL ADAP MONITORING PROJECT
2004 ANNUAL REPORT
CONFERENCE CALL DISCUSSION
ON WEDNESDAY, MAY 19, 2004
AT 12:30 PM EASTERN TIME

OPERATOR: This is a recording of the teleconference scheduled for May 19, 2004, Wednesday, 11:30 a.m. Central time, 12:30 Eastern time, for Rob Graham, the Henry J. Kaiser family.

Excuse me, everyone. We now have Jennifer Kates in conference. Please be aware that each of your lines is in a listen-only no mode. At the conclusion of Ms. Kates' presentation, we will open the floor for questions. At that time, instructions will be given if you would like to ask a question. I would now like to turn the conference over to Ms. Kates.

JEN KATES: Good afternoon, everyone. This is Jen Kates from the Kaiser Family Foundation. I'm very pleased that you can all join us here today for the release of the eighth National ADAP Monitoring report, which is based on our most recent survey.

This is a project that we have been doing in partnership with the National Alliance of State Territorial AIDS Directors and AIDS Treatment Data Network since 1996. It's a very important project to all of our organizations, to the foundation, in particular because ADAPs (AIDS Drug Assistance Programs) serve so many low income, uninsured people with HIV/AIDS, and they have grown in importance over time as more people have been living with HIV/AIDS; as drug costs have increased, their importance has increased, and because some of the issues and challenges that I think we'll hear today served as reminders and markers of some of the larger challenges of the healthcare system that face people with HIV/AIDS.

Before we go into the presentation, I just want to acknowledge a few people here who we work closely with comment without whom the reports that, hopefully, you are all viewing online, would not be possible.

First, from NASTAD, especially Danielle Davis, Chris Aldridge, and Murray Penner, who really do the lion's share of work on this report every year, and also, from AIDS Treatment Data Network Lei Chou, and Daniel Kubert. So thank you to all of them for all of the work that they have done, and also just a special thank you to all of the state ADAP directors who really take the time out of running very busy programs to respond and provide the information. It's very critical, it serves a very important function, and we really appreciate the time that they take, and how seriously they take this project.

So, today, this presentation will go like this. Because ADAP is a complex program, we've assembled a group of discussions to represent different perspectives. I'm going to briefly [indiscernible] here, and then Murray Penner and myself from NASTAD will present the findings from the report. We will have the discussants say some comments, and we'll open it up to all of your questions.

So today, we have with us the following discussants, and we thank them for traveling from different places around the country, or from not too far away, but still far away in other ways. We first have Doug Morgan, the Director of the Division Service Systems at the HIV/AIDS Bureau, at the Health Resources and Services Administration.

We also have Ron Weinstein, the ADAP Coordinator of the state of New Jersey, Lisa Daniel, the AIDS Director of the state of Kentucky, Robert Cooke, Jr., who is an ADAP client in

Washington, DC, and Bobby Spencer, who is waiting to get onto the ADAP in Colorado, and is currently on a waiting list. I particularly want to thank Robert and Bobby for coming today, and taking the time to tell us how the program is or is not working for them at this time.
With that, I'm going to turn this over to Murray, who will present the findings, and I will pick up from there.

MURRAY PENNER: Thank you, Jen. It's great to have all of you with us on the call today, and we appreciate everyone's interest in our report. The National ADAP Monitoring Project was first commissioned in 1996, in response to some very rapid changing environments occurring in the ADAP field. This project provides timely information on the current status of ADAP, trends over time, and key issues that are affecting client access.

The national ADAP survey, conducted each year in June, serves as the basis for the project's annual report, which we are going to present to you today. Other data that are collected from NASTAD, throughout the period of each year, is used to supplement these findings.

This is the eighth annual report that is being released by this project, and in this year's report, we're highlighting data from 54 of the 57 state and territorial ADAPs which respond to our survey in June of 2003. Except where noted, data is from June of 2003, and in some cases, the fiscal year 2003 associated with the ADAP programs.

Now, ADAPs are very dynamic programs, and during the course of a given year, there are many changes that occur in the ADAP programs, and so, some of the data that we're providing to you today may have changed throughout the course of the year, and we want to be sure that that is

noted up front. The data that we collect provide a snapshot of what's happening related to the ADAP programs, during June of 2003, and during the fiscal year of 2003.

In this report, national and state level trends in ADAP utilization, expenditures, funding, and other measures over time will be presented, and those have been collected since 1996, when the project began. We will also provide some updates on ADAP drug formularies, and cost-containment measures that are in place in these programs.

Moving on to the findings of this year's report, ADAP client utilization in the month of June 2003: ADAPs served 85,825 clients in June 2003, and this was about two thirds, or 67%, of the total clients that were enrolled in that month. 10 states accounted for three fourths of the June 2003 clients served. The number of clients served in the program ranged from one, in a jurisdiction that is new to the ADAP scene, to over 16,000 in the month of June 2003.

The rate of client utilization continues to increase, but it is increasing at a slower rate than it did in the early years of our monitoring project. Part of that is due to the fact that in 1996, there was the advent of polyanthil retroviral active therapy, and that was a significant turning point in the course of ADAPs, and we saw a lot of early utilization growth that has since leveled off substantially.

Turning to the clients that are served, in June 2003, the race ethnicity of the clients served in ADAPs programs nationwide were approximately 60% among minority individuals. 33% were African-American, 25% Hispanic, Native Americans, Alaskan natives, native Hawaiians, Pacific islanders, and Asians accounted for approximately 4%, and white individuals were 38%.

Other client demographics from June 2003: Mostly male individuals served were primarily younger adults from the ages of 25 and 44. Most were very low income. In fact, half of the clients utilizing services in June 2003 had income levels below 100% of the federal poverty level. Most of those served have no other form of insurance coverage, and indications of advanced HIV disease, which would be CD4 counts of under 350, accounted for about half of the clients served.

Turning to ADAP drug expenditures in the month of June 2003, total expenditures in that month nationwide totaled $77.4 million, and annualized, this represents approximately $929 million, or 97% of the entire ADAP national budget, and I think that's important for the simple fact that it does show that the majority of the expenditures are going to provide drugs in this program. Again, 10 states accounted for approximately three fourths of the expenditures in the month of June 2003, and expenditures ranged from $620 in one jurisdiction, to over $16.3 million. Also, similarly to client utilization, we continue to see increases, but the increases are at a slower rate.

Turning to ADAP drug expenditures by class during June 2003, antiretrovirals account for the bulk of the expenditures. In the month of June, 86% of the expenditures were among antiretroviral medications. Opportunistic infection and other drugs make up only 10% of drug spending, including 4% spent on the 14 A-1 drugs recommended by the public health service, the IDSA guidelines. This was also very similar to last year's breakdown of the expenditures.

Moving to per capita drug expenditures in June 2003, in that month, approximately $902 was spent per client, and this was an increase from $838 in the month of June 2002. If you annualized that figure, it accounts for approximately $11,000, just under $11,000 per person per

year. Per capita expenditures ranged in the national program from $319 in one state to $1402 at the top of the range.

Moving to the ADAP prescriptions that were filled by class: ADAPs filled over 300,000 prescriptions in June 2003. Antiretrovirals represented 61% of that total, and this is opposed to the 86% of expenditures, and I think that that is an indication about the relative costs of these medications.

Opportunistic infection drugs, and other drugs, represented 37% of the prescriptions filled, as opposed to the 10% of expenditures among that class of drugs. This is also very similar to last year's breakdown.

Something new this year in our report is a breakdown by class of the expenditures for the various drugs. Antiretrovirals are the most expensive drugs, if you take a look at the cost of all antiretrovirals, it represents about $357 per prescription. Protease inhibitors of those represent about $439, and opportunistic infection and other drugs represent $94. Overall, the total cost per prescription was $258.

Moving on with ADAP drugs to the formularies: The formularies in the various states ranged from 18 drugs in one state to 474 drugs in another state. There were four jurisdictions among all of the respondents that reported having open formularies, which means that they cover all of the FDA-approved antiretrovirals.

16 states did not cover all of the approved antiretroviral drugs at the time of the survey, and this is one of those instances where it's important to note that that could have changed since the

time that we did the survey. At the very time that we were doing the survey, there were several new drugs that came out, and so it could be a matter of timing why those states did not cover those drugs.

17 states offer all of the 14 IDSA Public Health Service guideline drugs for the prevention of opportunistic infections, and this is up from 15 states last year. 39 states cover 10 or more of those drugs, which was the same as in June of 2002, and two states don't cover any of those drugs at all. That's down from three states the previous year. 33 states provide Fuzeon, which is the first drug in a new class of drugs called fusion inhibitors. Many of those states have medical criteria associated with access to Fuzeon. 20 states reported coverage of hepatitis C treatments, and 22 states offer hepatitis A and B vaccines through their ADAP formularies.

I'm going to move now to the national ADAP budget, because I think it's a very important look at what happens with ADAPs, as we look at the national picture. The federal earmark of the ADAP budget represents 72%, or about $693 million of the national budget. State contributions account for approximately 18%, or about $172 million. There are some other funding sources, including Title II base funding, Title I funding, ADAP supplemental, and other federal incomes, such as carryover from previous grant years, etc. Those fluctuate significantly from state to state. The federal earmark is the constant in all of the programs.

The fiscal year 2003 budget grew to $961.5 million. This is an increase of $83 million over the previous year. The federal earmark, as I said earlier, is the largest component of that budget, 72%, with the state general revenue accounting for 18%.

The Title II base funding actually decreased by 23% from the previous year, dropping to just over $22 million, and Title I contributions to ADAP also decreased by 11% from the previous year, dropping to $17.5 million.

At this point, I'm going to turn the program back over to Jen, who is going to talk about key themes and trends.

JEN KATES: Thank you, Murray. Just picking up from that, and I want to first provide just one bit of contextual information, for those of you wanting to get a better understanding of what role ADAPs are playing in the larger care delivery system for people with HIV in the United States, and using data from HERSA, the estimated number of clients served over a year period by ADAPs, and some data collected that also corroborates how many clients are served in a year. It's about 136,000. People are receiving their medications through ADAPs each year. Using data from the CDC, how many people are estimated to be living with HIV, and the care system, that indiKates that about 30% of those people are getting medications through ADAPs. So around 30% of people who are living with HIV/AIDS, who are getting care in the United States are getting their care, the medications portion of their care, through ADAPs. That's a relatively significant number, and it's just important to provide an overall context.

So moving to some trends and things that we think are important things in looking over the course of the project, and looking this year, I know this was mentioned earlier. It's important to emphasize the trends and clients served, and drug expenditures, which we have been seeing increases each year, but increasing at a slower rate, and in fact, potentially a leveling in the increase rate. Still going up, but at the same rate. The biggest increases were early on, at least

in the status of the course of our project, in 1996-1997, right after the introduction of CART, and the federal ADAP earmark that was established to respond to that.

It's important to note that national trends may mask what may be happening across the state, or within states. For example, between just June 2002 and June 2003, in terms of client services, 41 ADAPs, the most, had an increase, but 11 had decreases. In terms of expenditures, 35 had increases in what they were able to spend on drugs, and 18 had decreases, and both of these things, clients and drug expenditures, are mostly a function of available dollars in the budget.

These next few slides just show this in pictures, "Trends in ADAP Client Utilization". You can see that between 1996 and 1997, there was a much greater increase than in the more recent years. Between 2002 and 2003, there was a 10% increase. Same with the next slide, and for those of you on the call, this is slide 21. This is in ADAP drug expenditures, similar pattern, with the biggest increase between 1996 and 1997, and a much smaller increase in more recent years, 9% over the last year. And this almost completely mirrors what happened with the budget, particularly on the drug expenditure side, where you see a 97% in the overall budget, from all sources between 1986 and 1997, and a 9% increase in the last year. So ADAPs have been able to increase and expand to the extent that the budget has as well.

Now, I think it's important to look at the budget, and look at the components from the perspective of what's happening to states. Other than the ADAP earmark, as Murray mentioned, which all of the ADAPs get, through a formula -- it's a federal earmark, so all 57 jurisdictions are receiving it -- the other funding sources are highly variable, and they aren't available to all ADAPs. They are dependent on local decisions, and the availability of resources, so if you look across the jurisdictions, the 57 all receive the earmark. 39 also receive state funding. 24 receive

Title II base funding, so that's dollars from their Title II portion of the Care Act going to states, which is a state-level decision, and 12 receive funding from Title I, that they have in their jurisdiction. 12 of those Title Is also provided funding to their ADAPs, and 17 received ADAP supplementals.

So it just shows you that the funding sources that comprise the budget are highly variable, and impact the program each year. And actually, if you look at -- even though the overall national budget from all sources did increase between fiscal year 2002 and 2003, several states, five, actually saw decreases in their total budget. Why was that? It's because they all got an increase in the earmark. The reason was these other funding sources, so there were decreases for a number of states in other funding sources, and two of the biggest ones that I think have biggest impact, 12 experienced decreases in state funding, and 17 experienced decreases in Title II based funding, and there were a lot of reasons for those decreases, most of which are due to state fiscal pressures, but those all affect the total dollars that ADAPs are getting, and have led to the situation where several have actual cuts.

And so all of this means that for this program historically -- and we always continue to see this, and see this this year -- that what people are able to get completely depends on where they live, and if you look at some of the key measures of that, income eligibility, for example, ranges from 125% of SPL to 500% of SPL in different states.

Formularies, as Murray pointed out earlier -- there's a highly variable number of drugs offered, and a variable type of drug. You can get all of your antiretrovirals and everything in one state; you can maybe only get a subset of antiretrovirals in another, and this variation is a result of several factors that primarily is the availability of resources, and how big the gap is that ADAPs

have to fill in their jurisdiction. What other programs are available to people with HIV? If there are not a lot of other programs available, or there are limitations to those programs, the gap may be bigger.

In addition, states have discretion over how to set the income eligibility, their formularies, and a lot of other variables, so both of those things play a role. And just to emphasize something that Murray mentioned earlier, there's not just variation across the country. The program changes within a given state may happen over the course of a year. Waiting lists may go up and down. Formularies may change. That makes his programs incredibly dynamic and complex.

Looking at the most recent period where NASTAD was able to survey all of the ADAPs and find out what cost-containment measures were in place, April of 2004, you can see the number of states, and these are not mutually exclusive. Some of the states actually have to use more than one measure, have measures in place, some of which may limit client access. So 11 had closed enrollment. Two had reduced formularies. Three had annual or mostly per capita spending limits, and one had increased cost sharing.

As you see, a visual of where these are, the next couple of slides look at maps of the country. You can get a sense of where waiting lists are in place, and on slide 27, it's a map of all of the waiting lists that were in place; as of April 2004, there were nine ADAPs that had waiting lists, with over 1,200 or 1,300 people on those waiting lists.

I think it's very important to note that waiting lists are only one measure of limited access. Not everyone has counted who is waiting for services. Not everyone has access to a primary

physician, to get a prescription for medication. So waiting lists are one marker of unmet meets, but an important one.

The next slide looks at ADAPs' current and planned cost-containing measures. You can see that several other states have measures in place, or anticipate having to implement new measures, due to resource constraints.

So looking forward, and taking stock of where ADAPs are, and some of the things that Murray and I both, and NASTAD and other organizations have identified as important issues on the horizon, and to think about, and just to emphasize the importance of ADAPs, and the role that they're really playing, providing medications to a significant number of people in United States, particularly those who are low income, and uninsured, and their importance has been growing over time. They have been trying to respond to challenges in the fiscal and the treatment environment.

One of the challenges that we believe faces ADAPs is that even though there are tremendous health benefits from ADAPs, because people are getting their medication, living longer because of it, living healthier lives, and there are fiscal benefits, because if people are able to stay in the workforce longer, because people are able to not become disabled, and not qualify for Medicaid and other programs, there are fiscal benefits to those other programs, but those health and fiscal benefits do not accrue directly to ADAPs. It's not a savings that ADAP programs can absorb. They accrue to other programs, and it makes it challenging to truly understand the positive impacts of the program.

Looking forward to key issues on the horizon, the challenge that states are facing in terms of fiscal pressures, and their Medicaid programs, will continue. Over the last couple of years especially, many states, most states, have made various cuts in their Medicaid programs, in terms of -- or they have limits to their Medicaid programs, particularly if people have prescription drugs, to respond to fiscal pressures, and types of those measures may continue, particularly as the end of federal fiscal relief this next month goes into effect.

In terms of the Medicare description drug law recently passed at the end of last year, there are a lot of questions about what that will mean for people with HIV, and what that love will mean for ADAPs. Will it increase demand on ADAPs? Will it relieve ADAPs? There are a lot of unanswered questions there.

And then, on another very important and recent development as of last week, with the release of a new Institute of Medicine report, that specifically looked at some of questions that we know are big challenges from studying ADAP programs, specifically the challenge of the variation in access to services across the country, and that report has some very important recommendations, and some of them have implications for ADAPs and Ryan's Way.

And I'm going to stop there, and let Murray provide some thoughts on other key issues, and then we're going to open it up to our discussants.

MURRAY PENNER: Thank you, Jen. I do think that the IOM report, and the recommendations associated with that to elevate this discussion relative to the difference is that we find in ADAPs, particularly the fact that it proposes a 100% federally funded state-administered entitlement program for people living with HIV and AIDS, who have a federal poverty level income of below

250%, so we do think that's a significant recommendation, and it does point out the importance of providing care to people living with HIV and AIDS.

Another issue that is on the horizon for ADAPs is the reauthorization of the Ryan White Care Act, which is scheduled for fiscal year 2005. September 30, 2005, is when the current authorization expires. Certainly, there are many efforts, and many discussions going on in the community relative to the entire Care Act, but in particular, to the ADAP situation, and the challenges that many ADAPs face, and so there will be some issues that will be discussed as we move towards reauthorization of the Care Act, I think in particular, the fact that many people do not have access to these drugs, and that the access varies so much, it's going to be an important issue as we look at reauthorization.

Then, finally, NASTAD has convened an ADAP crisis task force, which is partnering with the pharmaceutical industry to try to address some of the short-term issues relative to construction drug costs, and is really working hard at trying to make whatever differences can be made to help provide access to additional individuals who need access to HIV medications, and so, those are some other issues that I think are on the horizon, or are on the horizon for ADAPs as we move forward. Jen?

JEN KATES: Thank you. Now, I'm going to turn to Doug Morgan, from HERSA, who is going to provide some brief comments from the federal perspective, on ADAPs.

DOUG MORGAN: Thank you, Jen. I wanted to thank the sponsors of today's event for their invitation to say a few words. As many of you know, the Health Resources and Services Administration, or HERSA, administers the AIDS, or the assistance programs to ADAPs under

the Title II of the Ryan White Care Act. In fiscal 2004, HERSA provided $1.30 billion to the 50 states, Washington DC, Guam, Puerto Rico, the US Virgin Islands, and five jurisdictions in the Pacific under the Title II of the Care Act. The ADAP awards totaled over $748 million.

Back in 1996, when the ADAP appropriation was established as an earmark at $52 million, the appropriation has risen dramatically. This growth has been spurred in part by the introduction of new, highly effective, antiretroviral medications, including protease inhibitors, to fight HIV infection. In fact, the president's proposed budget calls for an increase of $35 million, to $783.8 million for ADAPs in fiscal year 2005. Even with the proposed growth of ADAP appropriations, we are still continuing to hear from jurisdictions as to this project, that they are facing problems in meeting growing demands for ADAP services which exceed their available resources. In fact, as of Monday, May 3, 2004, 10 states have indicated to us that they have a total of 1,472 people on waiting lists for ADAP services.

The national ADAP monitoring report, from our perspective, helps to highlight the needs of territories in regard to ADAP services, and complements our efforts at HERSA to work with grantees to provide technical assistance to our grantees, the system, in response to growing demand for services. On behalf of HERSA, I want to thank the Kaiser Family Foundation, the National Alliance of Territorial AIDS Directors, and the AIDS Treatment Network for their work, and we look forward to working with you, and this group, in the future.

JEN KATES: Thank you, Doug. Okay, so, I'm going to start, and ask a few questions of our discussants, and we are on schedule, and by 1:35, we will turn it over to those of you on the call for your questions, and I'm going to start with Ron Weinstein, the ADAP Coordinator in the state of New Jersey, and Ron, let's start with New Jersey -- where New Jersey is today. I'm looking at

our report, and the data we have from the state. New Jersey has had a relatively generous ADAP program, and that is measured by eligibility level, relatively high, an open formulary, and other measures that indicate if you are in New Jersey, you have access to a broad range of services.

Is this current picture stable? Is this what you have looking forward to the next year, or are there new challenges on the horizon?

RON WEINSTEIN: Well, Jen, this year is going to be a challenge in New Jersey. In New Jersey, ADAP has always said as a goal providing a comprehensive formulary of medications with as many clients as is financially feasible. In New Jersey, ADAP is currently only one of four states that provide an open formulary, which covers basically all of the FDA-approved medications. Income criteria in New Jersey are also quite liberal, and are currently set at 500% of the federal poverty level. I think that's the top of the range.

The major challenge for New Jersey ADAPs' fiscal year will be to secure the financial resources necessary to maintain the high level of current services. It is clear the current level of services are just simply not sustainable without tapping into new revenue streams. We are currently looking to three revenue resources to close the projected budget deficit.

First, we would like to knowledge the AIDS Crisis Task Force for their hard work in securing supplemental rebates. The supplemental rebates that were negotiated by that Task Force have had a real impact. We are really seeing a difference. Second, we will be looking to New Jersey's five Title I EMAs to provide a proportionate share of support. We will request that the Title I EMAs recognize ADAPs as a high priority, and provide support for line items in their budgets.

Now, the Title I EMAs in New Jersey have come from the past, and we're looking for them to step up to the plate once again.

Finally, as we seek advocate groups and pharmaceutical industry representatives, we are laying the groundwork for a state of appropriations, and we recognize that the additional revenue sources generated may not be enough to close the budget gap, but we preferred focus on the revenue side of the budgetary equation, and see what we can bring in, in terms of supplemental revenue.

However, we do have a contingency plan, and this plan was developed in collaboration with the ad hoc ADAP Advisory Committee. The contingency plan includes scenarios of formulary and/or income restrictions needed in order to balance the budget. While the days of an open formulary in New Jersey may soon be limited, we are met covering all FDA-approved antiretroviral medications, as well as the pH recommended OI medications, and as a last resort, we would even consider redirecting state and federal AIDS dollars to ADAPs.

But to summarize, after several years of a surplus, New Jersey is facing difficult times, to say the least, and we're hoping that the additional efforts to generate revenue will be successful, but we may be forced to make some difficult decisions.

JEN KATES: Thanks, Ron. I think that what you've described really illustrates what was one of the things that we've seen over time, in that states have a limited array of options when facing resource constraints, and even in relatively generous states, there are certain things you can try, and you can look at, and ultimately, ADAP directors are facing really tough choices,

because all of them -- all of those choices could affect clients, and ultimately, that's clearly not what one would want to do.

Turning to Lisa Daniels, who is the AIDS Director in the state of Kentucky. Kentucky has a very different situation. Kentucky's in the South. There have been a lot of reports for the last couple of years about the South and HIV, and resources, and Kentucky as a state gets very little state dollars. Kentucky has rural and urban areas, and Kentucky has a waiting list, and it's had a tight resource situation for several years, so it's in a very different position than New Jersey. Could you describe a little bit what's going on in Kentucky now, and particularly with your waiting lists? How does the state manage that list, and is there any hope of bringing people off of it, and how would you do so?

LISA DANIELS: Thanks, Jen. As you said, Kentucky has had a waiting list for quite some time, and in fact, it was implemented in February of 2000, and it remains in effect. Applicants are enrolled into the program on first come, first-served basis, as funding permits. That is reviewed monthly. The state of Kentucky contributes $90,000 annually to the Kentucky AIDS Drug Assistance Program, also known as KADAP. Although this only provides about 10 days of medication each year, the program is grateful for the continued funding. The state continues to experience budget shortfalls, and other state programs have suffered significant budget reductions in an effort to balance the budget.

KADAP covers 52 products, including all the antiretrovirals except Fuzeon. In order to cover Fuzeon, KADAP would have to reduce the number of clients currently being served, and this was not recommended by the KADAP formulary advisory committee. Because the program covers so few products, it is a challenge to ensure that clients enrolled in the program receive

products we do not cover. Further, it is a challenge to ensure that clients on waiting lists obtain medications until they are enrolled on KADAP.

Kentucky is a rural state in the South, as you mentioned, and we face issues surrounding transportation, and clients who are moving back to their home states to be near family and friends. Over the years, we have addressed some of those challenges, and have been successful at doing so. Because Kentucky meets the definition of a needy state, KADAP receives just over $480,000 in additional funding from the HERSA supplemental treatment drug grant. This allows the program to serve an additional 50 clients each year. I would also like to give special thanks to the ADAP Crisis Task Force for their work, as it has benefited Kentucky by allowing us to serve an additional 16 clients.

In fall 2000, KADAP conducted an efficiency study, and determined that approximately 30,000 clients were potentially eligible for medical benefits through the Veterans Administration. KADAP continues to screen for VA eligibility, and has transferred or referred approximately 50 clients to VA for services.

The Kentucky HIV Care Coordinator Program is funded with state and Ryan White Title II base money, to provide case management services across Kentucky. The program is divided into six regions, and a total of 30 case managers assist more than 1,600 clients annually, and almost 50% of those clients are enrolled in KADAP, or are on the KADAP waiting list. To assist KADAP clients in obtaining medication through alternate sources, such as patron assistance programs, KADAP clients and waiting list clients are required to enroll in their regional care coordinator program, and maintained a relationship with their assigned case managers.

KADAP contracts with the University of Louisville hospital pharmacy as a single source provider, to supply medications to all KADAP clients. Most descriptions are shipped to clients via mail order, reducing the transportation barrier, so we have been able to address some of those challenges, but many others remain, particularly, the fiscal crises.

JEN KATES: One quick question about the potential clients who are on a waiting list, who you are able to work with through the care coordinators, and try to get them on patient assistance programs, pharmaceutical assistance programs. How faithful is that for them? Is that something they can rely on? Is it more of a month-to-month?

LISA DANIELS: We do find that if the client will work with their care coordinator, it is more stable than if the client chooses to do it on their own. However, having said that, we do run into problems were clients will run out of medication prior to receiving an additional supply of those medications, and in that instance, the regional care coordinator program tries to provide a five or ten day short supply, until those medications can be received. We do run into problems where a physician will prescribe a regimen to a client, and the client, for whatever reason, does not qualify for a manufactured patient assistance program, because their income is too high, or what have you, and then that is a problem, because the client then cannot get the medication that been prescribed to them.

JEN KATES: I know we'll hear a little bit more about this from Bobby Gutierrez, but the pharmaceutical manufacturers' assistance programs, which are very important, do require applications per drug to the company, and that those applications often need to be put in every month, so it's a complicated process as well.

I wanted to pick up on something you said, which I think is innovative idea that some states have used, which is mail-order pharmacy delivery of medications, so that you can minimize transportation barriers, and other kind of access barriers. Ron, can you talk a little bit about how New Jersey distributes medication? You've probably got some of the same barriers in New Jersey as in another system.

RON WEINSTEIN: Sure. We take advantage of the existing Medicaid infrastructure for a number of functions. First, we use the existing Medicaid infrastructure to distribute medications through the more than 2,000 Medicaid pharmacies statewide. We also use Medicaid to pay claims through their data processing intermediary, Unisys, and claims are paid at the point-of-sale to pharmacy. You can just go on a computer screen, submit the claim, and get paid electronically.

We use -- and this has started recently -- we use Medicaid pharmacies at the point-of-sale to collect TPL. If there's third-party liability for clients who have partial insurance, that would show up on a computer screen, and the pharmacist would be forced to bill that insurance first, with any remaining balance being billed to the ADAP program, so that has saved us a lot of money.

We use Medicaid on contracted vendors to do all of our prior authorization on such drugs, such as Fuzeon and Micron. Medicaid has their own fraud abuse investigative unit. We take advantage of that as well. And finally, we use Medicaid to bill and collect drug company rebates on our behalf.

Now, this arrangement is formalized through a memorandum of agreement, in which we pay an annual lump sum of $100,000. The Department of [indiscernible] processes all ADAP

applications and determines eligibility, and we also retain authority over all possible key decisions, such formulary coverage, and income guidelines.

JEN KATES: Thanks. I'm going to switch gears a little bit. We've just heard a lot of information about the data from the program, from our survey. We've heard a lot about how the administrators and managers of these programs are making decisions in a tough environment, some innovative decisions, and some real challenging ones.

We are now going to turn to more of a client perspective, and what these programs really mean for people living with HIV? I mean, what are some of the opportunities and barriers? And first, we have with us Robert Cooke, Jr., who is an ADAP client living in Washington DC, and Robert, can you just tell us a little bit about how long you have been on the ADAP in DC, how has been working for you, and what would you do without ADAP? Where would you go?

ROBERT COOKE: Thank you. I've lived -- excuse me, I have laryngitis. I'm getting nervous. I moved here three years ago from Virginia, but I have been on VA ADAP program since I've been diagnosed. When I was diagnosed, I had PCP pneumonia. That's the only symptom that I had, and it only lasted three or four days, but if it hadn't been for the medications, I would not be alive today. With the ADAP program, there's some barriers, because with the medications, even though they do help to put things in perspective with your HIV, you also tend to get high blood pressure; some clients can get diabetes. In my case, I did, over a time, become with high blood pressure, so they have you on high blood pressure medicine. Also, my cholesterol is very high, and if I'm not on medication, I would have a 99.9% available to have a stroke. That's where I'm coming from right now.

JEN KATES: And with the DC ADAP, are you able to get those medications for the complications related to HIV? Through the ADAP, or do you have to go somewhere else?

ROBERT COOKE: I can get them through the clinic, but I have to pay for them. I get the generic form, which makes it a little cheaper.

JEN KATES: I think that illustrates that in some states, were all of the other medications are offered, and they can be obtained through ADAP, there are places where they're not all covered, and the clients have to find other means to access them. If you weren't able to be eligible for ADAP, you know there's another program that you'd be able to get your medications from, or would you -- what would happen?

ROBERT COOKE: There would not be another program. I don't think. I mean, luckily, when I was placed on -- I am on full disability, but luckily, I was at a very good job, that my disability is just right to make me comfortable living by myself, but there's no way possible that I can afford the drugs, and pay rent, and all your other life. You know, shop, you know, groceries.

JEN KATES: Okay. Now, let me turn to you, Bobby. Bobby Spencer lives in Colorado, is from Colorado, and is on a waiting list, an ADAP waiting list. Bobby, how long have you been living with HIV, and how long have you been needing to be on medications, and how long have you been on a waiting list in Colorado?

BOBBY SPENCER: I've been HIV positive for 15 years. I've been on medications continuously for the past eight to nine years. Before that, I was on medications off and on for about five years.

JEN KATES: And so, you've been on the waiting list for how long?

BOBBY SPENCER: I've been on the waiting list for about a year now.

JEN KATES: Can you talk a little bit about that? Why is there a waiting list in Colorado? You've been on the waiting list for a year. How much longer do you think you'll be on the waiting list?

BOBBY SPENCER: Basically, Colorado has one of the more severe funding shortfalls in the country. We have, at last count, 297 folks on the waiting list in Colorado as of last Friday, and basically, the waiting list is not even moving in Colorado. There is no funding to take people off the list. The governor only recently released some money to bring 40 people off the waiting list, but it's a one-time funding situation, and other than that, no one has moved off the waiting list for the past year.

JEN KATES: So what do you do? You can't get onto the program --

BOBBY SPENCER: Right.

JEN KATES: -- and just so that we understand, you are -- the reason you would need to -- I understand you were working, but you had to leave the workforce. Can you talk a little bit about that? What put you in the situation of needing to go to ADAP in the first place?

BOBBY SPENCER: Sure. Okay. About three years ago, I was on a good, stable regimen. Because of life circumstances, I wound up becoming noncompliant, and that regimen quit

working for me. My health declined, I wound up going on disability, primarily for long-term fatigue; after fighting the virus for 15 years, my body is just fatigued. I'll get up, and not be up for two or three hours, and lay down to take a nap, and wake up four hours later. My body is tired of fighting.

The way I'm getting my medications right now, and have for the last year, I'm getting them from the drug companies through compassionate use programs. Those were initially intended for folks -- most of them are set up to go either three or six months, and they're not intended to be indefinite -- as an indefinite alternative to ADAP. The pharmaceutical companies obviously are making the medications to make a profit, and that isn't consistent with having people on their compassionate programs indefinitely.

I've had to basically periodically -- I have a great pharmacist who is very good about filing the paperwork and staying on top of it for me. She calls me anytime we need to make an update, or whatever. The first two or three months, while I was waiting to get on the program, the hospital actually paid for my medications out of some other funding. I don't know -- you know, where you get that funding, because it is a publicly funded hospital, and once I got on the medication, the compassionate use programs, I've been on those for nine or ten months.

It's been fairly good. Every couple of months, I have to make an update. The pharmacist calls me, we have to make an update of information, a photocopy, copies of my social security checks, whatever, or if I need copies of leases, or whatever, and I have had one problem with one particular drug. That company was not sending the medications, because they want to send the medication to a pharmacy, and that pharmacy sent it to our pharmacy in the hospital, and

then that pharmacy dispersed it to the HIV pharmacy. All the other companies actually send it straight to the HIV pharmacy, and let me purchase it.

The problem with getting to the point -- I went in every month to try and get the medication, and I'd go in to pick it up. I'd call in two weeks ahead, because that's what I was supposed to do. They would call in my order, and I would show up two weeks later, and the medication wasn't there. They would have to scrounge around, and find me a couple of days' worth of medication somehow. Well then, the drug company would say, "Okay, here's your month of medication." Well, in the meantime, the next month, when it came time to fill it, because we had about medicine from other suppliers that needs to be repaid, and I've run out, and they say, "Wait, you're getting it filled too soon, and that's not fair." So it's created a lot of problems, and long story short, I finally dropped that drug from a list, and actually had to switch to a different medication, just because it was too hard to get it, and I couldn't rely on it.

JEN KATES: Now, if the situation in Colorado work to change, and there were some new resources that became available, and the state was able to bring people off the waiting list, do you know how they would make those decisions?

BOBBY SPENCER: My understanding is that right now, they are -- or at least with the last bit of funding from the company, in the budget, they actually took people with the lowest income. Because they are -- the wait list isn't really moving, I'm not sure how they're really prioritizing at this point. When I went on the list last summer, they were upfront with me, and said, "You're not going to get off the waiting list for the next fiscal year. We're just -- we don't even have enough money for people that are on the program." So I don't know. The rules are going to -- they're

going to look at that for the next fiscal year for this summer, and look at how they're going to do the waiting list for next year, if they're going to change the way they take people off and such.

JEN KATES: That's in contrast to what Kentucky is doing, which is first come, first-served, if money were to become available to bring people off that waiting list.

BOBBY SPENCER: And I thought that was the way that -- in Colorado, when I was going to work, but I think with the governor's money, they -- because it was from a different funding source, they actually took lower income people off first. That was a change, but other than that, to my knowledge, no one has moved off that waiting list the entire fiscal year in Colorado.

JEN KATES: Okay, there are plenty more questions that I think we have here among us that we want to now take this opportunity to open up the call to -- take your questions, if you have questions.

OPERATOR: At this time, we will open the floor for questions. If you would like to ask a question, please press star key, followed by the one key on your touchtone phone. Questions will be taken in the order in which they are received. If it anytime you would like to remove yourself from the question queue, please press star, two.

Our first question comes from Sabin Russell, from the *San Francisco Chronicle*.

SABIN RUSSELL: Yes, can you hear me?

JEN KATES: Yes.

SABIN RUSSELL: Yes, just a question regarding the health consequences of these waiting lists. There've been sort of anecdotal reports that people have died on waiting lists. Have you looked into this issue at all, of whether in fact people are dying waiting on these lists, or in any way have you measured the health consequences?

JEN KATES: We -- as part of the project -- this is Jen Kates from the Kaiser Family Foundation and NASTAD. We've -- NASTAD especially has always kept in touch with all of the states when that situation has arisen. There are several reports from at least two states where this seems to have occurred over the last year, and maybe -- I don't know if you'll be able to -- but I think Lisa might be able to talk a little bit about it, but I think one of the challenges, say, from looking at this question, is those individuals on a waiting list are often not -- they're not in the system, and so be able to understand all of the things that are happening with them is just very challenging, and I don't know, Murray, if you want to add anything specifically, or Lisa.

MURRAY PENNER: I think the important thing to note is that certainly, there are unmet needs associated -- not only as Jen said earlier, with waiting lists, but other individuals that may not even be on the waiting lists, and certainly, we don't have all the information relative to the health status of folks that are obviously not in our care. I also know that many programs, including the states where the reported deaths occurred, have done what they can to help people get the care that they need, and it's not indicative of a lacking program as much as it is some of the resource constraints in order for people have the care that they need.

SABIN RUSSELL: Can I just have a follow-up?

JEN KATES: Yes.

SABIN RUSSELL: A question, I guess, for Mr. Morgan. I was wondering if you could repeat what the increase in federal funding proposed for ADAP is, and why that particular figure was reached, and why people seeking close to 10 times that figure in discussions?

DOUG MORGAN: The FYI 2005 budget put forth by the President has a $35 million increase for ADAP. It would bring that earmark up to $783.8 million. I can only comment at this is the President's budget, but we have to live with the Executive Branch, and that's the figure that we were given in this year's, 2005, request.

SABIN RUSSELL: But if there's a rationale for that particular figure, is it that there simply isn't any money, or that perhaps this money is being wasted? I mean, why $35 million, when clearly, we are caring for people waiting for medicine?

DOUG MORGAN: I clearly cannot -- don't have any comments on that particular question.

SABIN RUSSELL: Okay. Thank you.

OPERATOR: Our next question comes from Ceci Connolly from the *Washington Post*.

CECI CONNOLLY: Hi, thank you. I wanted to actually follow up on that first question. Maybe, Mr. Penner, can you tell us which states had deaths in the past year? How many deaths are we talking about? Can you give us a little better sense of the details there?

MURRAY PENNER: I don't necessarily have the details surrounding each particular case, but we do know that there were two deaths in the state of West Virginia, and five deaths in the state of Kentucky.

CECI CONNOLLY: Well, perhaps the -- Lisa from Kentucky can shed some light on their facts?

LISA DANIELS: What I can tell you is that we were able to confirm that all five individuals passed away from issues, or illnesses other than those specifically related to their HIV. We also were able to confirm that a -- some of those individuals were receiving medications through the patron assistance program

JEN KATES: This is Jen Kates. I'll add that -- this is a real big issue, and concern, for us looking at the program nationally, trying to accept what's happening, what's happening to everyone on waiting lists, particularly in states with very large waiting lists. A state that maybe has 500 people on a waiting list, or a state that has -- like Colorado, that has close to 300 people, and actually, I should say that I asked Bobby earlier if he is in regular contact with the Colorado ADAP, and he's not, not because he hasn't -- it's not that he doesn't want to, it's just that the program itself has resource constraints, and cannot always be working with potential clients, so I think there are some real issues here over what happens to clients, to people who are on waiting lists. Some are getting medication, some are getting sick, and it's not always clear as to what is causing their illness. Is it related to their not getting medication, or other things?

CECI CONNOLLY: Okay, thank you.

OPERATOR: Our next question comes from Murray Jacobs, from *News Hour*.

MURRAY JACOB: Hi, thank you. I was wondering if one of you could talk a little bit about how the waiting list increase, and these other measures that are being taken -- how that compares to the last couple of years, with the recession, with the budget, if this is definitely something that is on the upswing, or is more or less keeping pace, or is it declining a little bit? And also, if you could talk a little bit more about how the Ryan White Care reauthorization fits into all of this.

MURRAY PENNER: This is Murray Penner with NASTAD. A couple of things. I think that we have generally seen an increase in the number of people on waiting lists, and programs that are having to implement a couple of containment measures. I don't know that I can say specifically that it's continued to go up every time we've done the surveys of these programs, but I will say generally, it's gone up as a -- seems to be a correlation between state funding and Medicaid cutbacks that are occurring. I also want to point out again that there is wide variation and wide fluctuation based on varying levels of funding, and in some jurisdictions, when a state, in particular, were to reduce its state funding, it could cause some pretty serious shortfalls, and therefore is, some additional people on waiting lists. However, we've also seen it go the other direction, when a state legislature has come forward, for instance, with some additional money, and been actually able to people off of waiting lists, so I think we would have to look at a state-by-state basis; over time, over a national trend, we are probably seeing increases, however.

Secondly, relevant to the Ryan White Care Act reauthorization, I know that one of the things that we continue to look at our the needs of these particular states, that are especially implementing cost containment measures, and waiting lists, etc., and I think that one of the things that would be important for us as we move through reauthorization would be to be able to direct some

funding to particular states that are in severe need states, and that maybe something that requires some changes in distribution methods, of, for instance, the ADAP supplemental awards, the eligibility for some of those programs, and so, I think those are the kinds of issues that we would be looking for as we move through reauthorization, to make sure that we address some of the areas that are in severe need and crisis.

JEN KATES: This is Jen Kates. I want to add a little bit to that about the waiting list numbers. We heard from Doug Morgan earlier that in their very recent contact with states, even since the time that we were in contact with them about their waiting lists, the number having waiting lists went up by one state, and it sounds like there are even more people, so it is something that seems to be increasing, even though it can fluctuate, and one other thing that I think relates to, or puts ADAP in a broader context of the Ryan White Care Act is that everyone coming to get medications through ADAP has to get a prescription from a doctor, from a physician, so if that interaction cannot take place, if there are limitations on the front end, they're not even getting their prescriptions to get in the door, and this provides more information on the President's proposed budget. Other than for the proposed increase to ADAP, there's not an increase to some of the other components of the Care Act, so there could be challenges around getting those primary care visits, and have those connect up to ADAP, so it's a big picture, challenge, I think, and ADAPs are part of that.

MURRAY JACOB: Thank you.

OPERATOR: Our next question comes from Brenda Wilson, for National Public Radio.

BRENDA WILSON: Thank you. I am sort of not understanding how the waiting lists work, since no one seems to know, you know, whether there's a connection between deaths in the status of the individual. Once a name is on the list, is it possible for a person to then go somewhere else, and is served? Does the state monitor them? Two different states handle these lists differently, once -- is it just a number? And so therefore, if you get 40 served, then, the number goes down? It's just not clear to me, and then, I guess my second question is, has anybody been kind of watching trends of HIV and AIDS, and making any "connections", say, for example in southern states, where they've been seeing these rates of increases of HIV in poorer populations, has the funding process -- is the funding problem connected to the epidemic in that regard, you know, since some time has passed?

JEN KATES: This is Jen Kates, and Lisa will actually talk about the waiting lists in Kentucky, but from our discussions with states, each state handles the waiting lists quite differently. In Bobby's case, in Colorado, he's had very little contact with the ADAP. I don't know if you want to say anything about that, but they're not monitoring you, per se. Lisa can talk about what they do in Kentucky. It varies from state to state, based on the resources that the state has available to monitor people, to help put them through case management into other programs. In some states, they're not monitored. In other states, they are. Lisa, what is the situation in Kentucky with people on your waiting list?

LISA DANIELS: In Kentucky, we monitor the waiting lists monthly, and in addition to monitoring our expenditures. It expenditures are being low, where our monthly Is, then, we at folks from the waiting list to the program, and again, like I said, that's done on, we basis. It varies by state. In terms of how clients on the waiting lists receive medication, for clients to be able to receive monetary assistance through our care funding program, they are required to have a case

manager within that program, and maintain regular contact with them. One of the benefits of doing that is the case manager assigned to that individual will assist them in completing all the necessary paperwork for patients assistance programs, and help in obtaining their medications, and can have them specific to the manager's office. Then, the case manager will make arrangements to have those medications given to the clients.

BRENDA WILSON: And the other question? Has anybody seen any connection, for example, in some states, in relationship to the increases in demand due to changes in the epidemic?

MURRAY PENNER: I think there have been some reports in -- that you've probably seeing coming out of the southern states relative to budgeting HIV epidemic, and new infections in some of those particular states, that may have some reflection of the demand in those particular jurisdictions, relative to non-increasing federal funding, state funding, etc. I also need to note that the formulary distributions that the Ryan White Care Act is especially entitled to, awards are based on, is on living AIDS cases, an estimated living AIDS case formula. It does not take into account HIV infections, and for jurisdictions that are experiencing increasing numbers of HIV infection that would not have progressed to AIDS yet, the demand for services may be higher, and therefore, the funding may not be exactly following the epidemics. That doesn't specifically answer your question, but there could very well be that correlation.

LISA DANIELS: Let me just -- this is Lisa Daniels, the State AIDS Director for the state of Kentucky. Let me just follow up briefly. Kentucky produces an HIV/AIDS semiannual report. In this report that I'm looking at was our year end report for December 31, 2003. Compared to other states, Kentucky ranks 31st in the number of AIDS cases reported in the year 2002. A dramatic decline in the AIDS incidence rate in Kentucky, based on year-end diagnosis, was

observed from 1995 to 2000. However, in the year 2001, an increase in the AIDS incidence rate was observed in Kentucky, and continued with a slight increase, also observed in the year 2002. Previous [indiscernible] observed difficulties in adhering to complex treatment regimens, and late diagnoses of HIV, which delayed initiation of treatment, and could be among several factors responsible for the lack of continued progress in reducing new AIDS diagnoses.

BRENDA WILSON: And did you see an increase in clients, people wanting ADAP services? A relatively stable number? Increases in your waiting list?

LISA DANIELS: We did. Our highest waiting list numbers came in March of 2001, at 265, so we had seen an increase in the number of clients. Again, we have almost doubled the size of our ADAP program from 2000, to the current 2004 fiscal year.

JEN KATES: Next question?

OPERATOR: Our next question comes from Barbara Isaacs of the *Lexington Herald-Leader*.

BARBARA ISAACS: Hi. This question is for Lisa Daniels. I guess I'm just wondering, the five people who died, do you have any sense of exactly how many of them were being treated or were on medication, and also, the waiting list in general. Do you have a ballpark idea of, like, what percentage of people are being served in some way, if not by the program itself?

LISA DANIELS: Let me just address your first question. All five of those individuals had the opportunity to access medications through the patron assistance program. It is my understanding that not all five of them took that advantage, but all of them had the opportunity to

access medication. They were all eligible to take part in the program, or could receive medication through another payer source. If you could please repeat your second question

BARBARA ISAACS: What percentage of the people who are on the waiting list now would you estimate getting medication or not?

LISA DANIELS: I'm sorry, I can't answer that question. We do not track it to that --

BARBARA ISAACS: Okay. One of the other things I was wondering is, what is your sense of -- do you get a sense of, like, interest from the state as far as increasing funding for this? I mean, what is your sense of what the future looks like for you? I mean, do you think there's any chance that you are going to be able to reduce this wait, or --?

LISA DANIELS: Unfortunately, I'm not able to address that question.

BARBARA ISAACS: Who is actually in charge -- I mean, who would decide? Is that legislative, or who gets to say if you all get more money?

LISA DANIELS: It is legislatively appropriated.

BARBARA ISAACS: What's the [indiscernible] budget for the typical state? The situation in the state?

LISA DANIELS: Right, well, as I said my presentation, while we receive $90,000 in state funding, which provides about 10 days' worth of medication for our clients, we have not taken a

cut in funding. We have remained state funding. We have remained level funded for a number of years, but Kentucky being in a fiscal crisis, other than -- other programs who provide human resource type services to Kentucky residents have taking cuts, so we are grateful that we have not had to take a cut in our funding.

MURRAY PENNER: This is Murray Penner with the National Alliance of State and Territorial AIDS Directors. Another thing that I would like to add related to the funding and some of these reported deaths on waiting lists -- over the last three years, there has been insufficient federal earmark funding to meet the growing demands of this program. There's approximately 40,000 new infections every year, and with these medications, people are living much longer. The pool of individuals that are HIV-positive continues to grow substantially, and a lot more of these individuals are seeking services, and the increases in the federal funding, and in many cases, the state funding as well, has not kept up with the demand for services. Therefore, we have a large number of individuals who are not even necessarily seeking services, and there certainly probably are other areas of need, people dying that are not on waiting lists, that it's basically an access issue related to the program, and the clients not being able to access programs

JEN KATES: Next question?

OPERATOR: Our next question comes from Joel Finkelstein, of *American Medical News*.

JOEL FINKELSTEIN: Hi, yes. My question goes to the Medicaid program. How does the problems or situation that ADAPs find themselves in differ from the situation that states are having with the Medicaid program, and funding that? Also, I'd like to understand better the relationship or interaction between ADAPs and Medicaid.

RON WEINSTEIN: Well, in New Jersey, there is a high degree of interaction or collaboration between the Medicaid program and the ADAP program, but again, we're only utilizing the Medicaid infrastructure. We are a completely independent in and of ourselves. We have different guiding boards. We make our own policy decisions. We simply use the Medicaid program because they have the systems up to distribute medication, and to pay claims. You know, Medicaid has their own problems to deal with, and I can't really speak to how Medicaid deals with them, but in New Jersey, there's a high level of collaboration between the two programs, but it's only to the extent to which we can facilitate the ease of distribution of medication, payment of claims, and things like that.

JEN KATES: This is Jen Kates. I'll just add that there is a fundamental difference between Medicaid and ADAP, ADAPs being part of Ryan White, and that is that Medicaid, while not immune, obviously, from fiscal challenges, and we know that from -- all of the states have problems in their Medicaid programs -- but Medicaid is an entitlement program, and therefore, all individuals who are eligible and enroll are entitled to Medicaid services, and the funding for Medicaid in general is made available to that need, and that growing cost. That is not the case in a program like Ryan White and AIDS, which is part of it, which is a discretionary grant funded program through annual federal appropriations, so the dollars do not necessarily match the need and demand for services [indiscernible].

That is a big difference between the programs. Having said that, ADAP and Ryan White were designed to wrap around and be -- to catch what Medicaid could not cover, to the extent that all the states really have experienced real challenges with their Medicaid programs, and almost all have looked at or made some kind of limitation, particularly around prescription drug benefits.

That's going to affect ADAP, because ADAPs will then be asked to pick up that slack. The other thing that we want to emphasize too is that to the extent that ADAPs are providing medication for people with HIV, who are living longer, and are doing well, and are not becoming disabled. They may be low income, but they're not becoming disabled. They aren't qualifying for Medicaid. It's a savings to the Medicaid program, but it's not a savings that goes directly into the ADAP pot, so it's a challenge, but these programs do play off each other, work together in different ways, and the gaps in one affect the gaps in the other. Next question?

OPERATOR: Our next question comes from Sabin Russell, from the *San Francisco Chronicle*.

SABIN RUSSELL: Oh, okay. I have a question, again, perhaps for Mr. Morgan, or perhaps from the state, from the ADAP directors. The federal government, the Bush administration, has recently signaled a different policy regarding AIDS drugs overseas that would expedite FDA approval for some of the AIDS drugs that the President's emergency program might consider providing overseas. Given that there is a limited amount of federal dollars for AIDS medicine in the United States, and that people are dying while waiting on waiting lists, is there anything that would stop the ADAPs programs from obtaining these FDA-approved -- presumably FDA-approved drugs -- at extremely low cost, to supplement what the program can't cover now?

DOUG MORGAN: I appreciate your question. I would suggest that you may want to talk with the FDA about their new policy, because I clearly can't comment on that, and as far as I get programs, ADAP programs are allowed to purchase FDA-approved drugs. If those are made available, that's what ADAP programs can do.

SABIN RUSSELL: So you're saying that if they are FDA-approved, ADAPs could presumably purchase them?

DOUG MORGAN: I really thought I covered that question. ADAP drugs -- ADAPs are allowed to purchase FDA-approved medications.

SABIN RUSSELL: Thank you.

OPERATOR: Our next question comes from Brenda Wilson, National Public Radio.

BRENDA WILSON: Yes, this may be a very obvious question, but I just thought I'd ask it anyway, and that is, I assumed that once people are on the program, they're pretty much safe, or have states actually cut? Because I know just in Oregon, at one point, people were on the program at one point, and then lost their eligibility. How many states to that happen in?

RON WEINSTEIN: This is Ron Weinstein from New Jersey. I think in some states, policies can vary. Some states may grandfather in certain clients, and exclude them from any subsequent program restrictions. In any event, if a client were forced to have less access, or not get as many medications, the state would work with the client and their case manager to navigate the complex network of services available, including patient assistance programs, and things like that.

JEN KATES: Bobby?

BOBBY SPENCER: This is Bobby Spencer from Colorado. I just wanted to add that in Colorado, actually, that's becoming a big concern this year, because of the state budget

constraints with Tabor, which is [indiscernible] bill of rights. The taxes this year are not going to be able to be raised to support a lot of those nonmandated state fundings this year, and they are actually looking at the possibility that the state contribution to ADAP may be cut drastically if not altogether this year, which is going to force some choices to be made about, our We no longer going to fund all 13 or 14 antiretroviral drugs, are we going to take people off the program that are on it already? It's definitely looking like Colorado is going to not take people off the waiting list again.

MURRAY PENNER: This is Murray Penner. I think, Brenda, to also answer your question, I don't necessarily think it means that just because you're on a program, you're safe. Again, if this was an entitlement program, it would be different, but because it's -- first of all, it's dependent on discretionary funding. If funding levels decrease such that individuals can't have the services that they need, it's possible that programs would have to do like Ron suggested, and try to find, you know, compassionate care programs, or other programs to get individuals that are currently in a program onto drugs.

JEN KATES: Next question?

OPERATOR: Our next question comes from Steven Kusarski, from Group Health Cooperative.

STEVEN KUSARSKI: Yeah, hi. I've got a question around cost-containment, and some strategies that states may be employing, in order to stretch their dollars a little more. In the state of Washington, for example, we've instituted co-pays for patients, and I'm wondering, across the country, what systems are currently using strategies like co-pays, and what strategies they are using to contain costs?

MURRAY PENNER: This is Murray Penner, again I do know that there are a few other states that are considering co-pays as well as -- like what you're stating in Washington. Some other common methods of cost-containment are to reduce formularies, and to implement expenditure caps, whether they be monthly, or whether they be annual expenditure caps. Another really cost-effective cost-containment measure is to purchase health insurance, or continue the health insurance of individuals, such that they may be going onto a COBRA plan, for instance, when they're losing their employment, and there are some jurisdictions, 22 states, that report that they use ADAP funding for insurance purchasing, and that is certainly a cost-effective method of cost-containment as well.

In our report, we do, on chart 21, if you have that available, we do talk about the states that report approximately 7,100 clients that actually -- took -- were able to have their health insurance continued via this mechanism.

STEVEN KUSARSKI: But as far as you know, is Washington the only state you know that's doing co-pays?

MURRAY PENNER: I do believe there are some others that have had it in place. I think it's four states that do. I also have heard reports lately that there's at least one other state that is considering it in the near short term.

OPERATOR: Our next question comes from Marianne Green, AIDS Institute.

MARIANNE GREEN: Hello, I guess our agency -- I mean, hearing everything we've heard today, and knowing what we know, our agency just really wants to know, what recommendations does the panel have for solving the problem that there are people in this country who need medications that are ADAP-eligible, but they're not getting those medications? And this goes beyond asking Congress for more funds over the coming years, because we know it in the past, that hasn't solved the problem. Does this panel have any recommendations?

JEN KATES: Anyone want to --? And just to repeat the question, because not everyone was able to hear, our recommendation separate from increased funding? Is that what your question was?

MARIANNE GREEN: Right. Beyond asking Congress for more funds, are there any other recommendations to address the fact that we know that we have individuals who are eligible for ADAP, and who need HIV medications, but are not receiving them.

JEN KATES: This is just to speak for the Kaiser Family Foundation. In the report, we actually don't provide recommendations, but there are several people here who are actively working in various coalitions, and that I think are looking at that question around it, and it is cost-containment measures, and other things.

MURRAY PENNER: I do think that one of the issues that we mentioned earlier in our presentation -- this is Murray Penner again -- was the recommendations from the Institute of Medicine, related to the national entitlement program. Obviously, that panel, that academic panel, looked at a lot of different options, as far as financing HIV care in this country, and that

the option that they landed on was a national entitlement program for people living with HIV and AIDS who had income below levels of 250% of the poverty level, and so, that is the actual kind of thing that would provide some stability to people living with HIV and AIDS, with the standard benefits package, formulary, etc.

JEN KATES: Next question?

OPERATOR: Our next question comes from Murray Jacobson, *News Hour*.

MURRAY JACOBSON: Yes, hi, this question is for Lisa Daniels, just to follow up one last time on the Kentucky situation. In the cases of those five who died, you said they had had the opportunity to access the medications through other assistance programs, but chose not to. The extent to which you looked into that and investigated that, is there anything you can tell from that -- by having to go an extra step -- is there anything about having to do it this way that made them less likely to do it?

LISA DANIELS: I'm sorry. I am not able to address that question in any great detail. The only thing I can reiterate is that all of those individuals did have the opportunity to obtain medication through other sources while they were on the waiting list.

JEN KATES: Next question?

OPERATOR: Our next question comes from Gary Clark, We Care, Minnesota.

GARY CLARK: Thank you. I'm glad to get on here. I'm the first person in Minnesota that is HIV-positive and has AIDS who is on the formulary committee, and because of my work in understanding it, I've gotten a point to the advisory committee. The things you are talking about now are allegedly what the formulary committee and the advisory committee are supposed to be dealing with, and that's when they can't make a decision, or there's a tie, and we get to vote. However, recently, our government, our state legislature, adjourned without appropriating any money, so there are $2.4 million that we didn't get, and the decisions on how we're going to do that were made in the back room of the Department of Human Services, and not in public, like it was supposed to be, so we are now implementing co-pays, $1.00 for generic, and $2.00 for non-generic, and we are having to pay our own health insurance at $55 a month, and keep going on this thing, we are all going to be poor, because most of us are below the federal poverty level, and even if you owe 100%, so it's a challenge in this state.

We don't know what we're going to do, but we are going to have a problem we have to deal with, and I hope we can do it can do it with a little bit of compassion. I don't want to see people pushed out of the system, and they can't get their drugs. I do know that people get -- if they go off their drugs -- I heard this from my physician -- if they come back on them after a while, they might not even work, and if they get to a different regimen, it may be very much more expensive, but I don't want to see that happen, and we don't have enough money right now. So the only way I can suggest is we lobby our congressmen and senators and see what we can do -- I don't think that will work, though. It's not -- you know, they're spending billions and billions of dollars on a war. How do they get just a few million to us? I guess they could, but we don't get that.

JEN KATES: Thanks. Thank you. I think -- your -- this illustrated a lot at stake, and for the public health, and health care for people that we are talking about. We have time for probably one more question.

OPERATOR: Our final question comes from Tony Collins, National Association of People Living with AIDS in Indiana.

TONY COLLINS: Good afternoon, or whatever time of the evening that it is. I'm honored to be able to be able to address these issues, and the gentleman who just spoke before me about all the millions that we're spending on war, I'm thinking that the costs that the government is spending on three or four of those smart bombs could pay for a bunch of people and their medication.

JEN KATES: Do you have a question? Just because we are running out of time.

TONY COLLINS: Is there anything that the states can do on individual or collective level in order to bolster the funds to help with the ADAP program assistance? Is there something we can do collectively, or does each state have to fend for themselves?

JEN KATES: Murray Penner from NASTAD?

MP: This is relative to what states are already doing. I know the state AIDS directors and ADAP coordinators came together to form, as I mentioned earlier, the ADAP Crisis Task Force, have been working on behalf of all the states in the country relative to trying to get additional price concessions, and discounts of drugs. Now, that's one level of involvement that can happen at

this state level. Another one that I think is a real important one is the advocacy efforts of communities in which you live, and I think there are lots of advocacy opportunities for people living with HIV and AIDS, who can help get their state legislators to appropriate additional funding, as well as their federal legislators, so I think involvement in your local processes are important as well.

TONY COLLINS: Thank you very much.

JEN KATES: Thank you. This is Jen Kates. I really want to think, in particular, our discussants: Doug Morgan from HERSA, Ron Weinstein from New Jersey, Lisa Daniels from Kentucky, Robert Cooke from Washington, and Bobby Spencer from Colorado, and thanks to NASTAD, our partners, and the AIDS Treatment Data Network, and thanks to all of you for your questions today. We appreciate your time. All of the materials that you heard about today have been posted on our web site, www.kff.org, and please read them, and if you have other questions, feel free to contact us. Thank you.