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Implementation of the ACA for People with HIV
Kaiser Family Foundation
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JEN KATES: Good morning everyone. It's so nice to be greeted in the morning. Welcome to the Kaiser Family Foundation, I'm Jen Kates. We're very, very happy to have you here and to have this event today. As probably a good portion of you know, we tried to have this event in January and it was a victim of a snowstorm.

We were able to reschedule and I'm happy to say that all of our original panelists were able to be here with us. Thanks so much to them for being willing to make the trip after that.

The purpose of today's event is to examine how the ACA has affected coverage and access for people with HIV as well as implications for the Ryan White HIV/AIDS Program. For those of us working on this, we know it is critically important to understand who has gained new coverage and who has been left out. It is critically important to understand the implications of state Medicaid expansion decisions and it's critically important to understand the barriers that still exist. I think one of the challenges that a lot of us have had is that it's hard to get a lot of information and data on what is happening.

I'm happy to say that about two years into the full

Dr. Laura Cheever was a co-author on, I would encourage everyone to look at those articles, but they really show the role of the Ryan White Program and changes in coverage. We're beginning to get information that I think is telling us what's happening with HIV and what coverage does do as well as what's still missing.

We at the Kaiser Family Foundation have been working to monitor the experiences of people with HIV as well as the providers that serve them by doing fieldwork to understand, in their voices and from their experience, what it meant for them. We've released several research papers from focus group analysis, from one-on-one interviews, we have some video profiles. We've also done some quantitative research looking at other things like the importance of fully assessing the cost of a health plan before signing up for a health plan and how important that is for someone with HIV.

What we want to do today is provide you with some background data on a new report that's going to be coming out and then we'll have more of a discussion about the experiences of the ACA. The flow will be as follows. First, my colleague Lindsey Dawson who many of you know, and is an expert on these issues, will present the findings from our new research being

snippet from one of them, and the star is actually here as well. Then we'll go to a panel discussion with our panelists, to have a dialogue and then go to your questions.

That's the flow. I'm looking forward to hearing your thoughts and everyone's and I'll introduce the panelists when get up to that portion of the agenda. Now I'm going to the podium over to Lindsey. Lindsey is our Senior Policy Analyst for HIV Policy and she has really led this work and her other efforts on the ACA, including many of the reports that I mentioned. She is really the lead author on this and I'll let her share the findings with you. Thank you.

LINDSEY DAWSON: Good morning, thank you Jen and thanks to everybody for being here. We do really appreciate that you were willing to come in both January and May. As Jen mentioned, I'll be presenting findings from our new brief, and it's in your packets and it's available on our website now.

It's research that we conducted with PerryUndem Research and Communications and that really identifies the key findings from focus groups that we did with people with HIV in five states. This second round of research that we did was conducted in February and it explores the impact of the ACA on

It's a complement to a report that we released in 2014 with focus groups in the same states and the focus groups were similarly structured and asking questions about access to care and access to HIV care. What's different in the second round is that in 2014, coverage opportunities were new, so folks were really entering into these new coverage expansions for the first time. They were supported by people who were also experiencing these expansions for the first time and many had not started using their coverage yet.

In this 2016 group, we've gone through three open enrollment periods and folks have had two years to really engage with insurance coverage. The groups were set in California, Florida, Georgia, New York, and Texas, and these five states were chosen for two reasons. One, the five states together represent about 50% of the share of the US epidemic, and secondly, the states have taken different approaches to the ACA implementation.

While California and New York are states that have expanded their Medicaid program and have created their own state exchanges; Florida, Georgia, and Texas have not expanded their Medicaid program and rely on the federal marketplace.

Launching right into key findings, we did note that in

expansion and the penalty. Overall, many still lacked basic insurance literacy, and this makes making really informed purchasing decisions and plan comparisons difficult.

Individuals were also not always really clear on what they were eligible for. We met a number of individuals who appeared that they might be eligible for Medicaid through a disability pathway but hadn't really pursued that. Not really understanding your insurance coverage, or what your coverage, might look like or costs might look like affects people in really profound ways.

We met a man in Georgia who was paying two to three thousand dollars a month out-of-pocket for his non-HIV meds. Nobody really sat him down and said, hey, look, even if you don't qualify for a subsidy you can probably enroll in a pretty comprehensive marketplace coverage, have insurance, and be out-of-pocket to a lesser degree, every single month.

One area that we did find more understanding was that people seemed really aware that there's differences in how they can access care across the country. Those in Florida, Georgia, and Texas actually pointed to individuals in the other two states—New York and California-and said, hey, we know people in these states and they have Medicaid expansion or their ADAP is

greatly valued the access to coverage they had. We met one man in New York who had just gained Medicaid, he had moved up from the state of Georgia, because he didn't have health insurance. He didn't know anybody in New York, he didn't have any other reason to move to the state except to gain health coverage and he was really grateful to do so. This is despite being eligible for a subsidy in Georgia's marketplace.
He just said at $200 a month, marketplace coverage would not have been affordable to him.

The individuals we met had a wide variety of reasons for enrolling. For many they wanted the security that could be gained from coverage but more often than in 2014, individuals cited the coverage mandate or the desire to avoid the penalty. This makes sense because we know the penalty is being phased in, so it did show some awareness that that message is getting through.

As in 2014, case managers continue to play a really important role in helping individuals navigate coverage opportunities. Individuals remained confused about the process and overwhelmed by plan selection. When it came time for plan selection, individuals often looked at cost- primarily at premiums- but they also considered the provider networks and

for instance, one individual said that he had a prior relationship with the insurer and he wanted to stay with that insurer. Another individual in New York's Medicaid program said that he based his decision to enroll based primarily on the ratings on the marketplace.

Most of those who were uninsured did look for ACA coverage at some point. What we learned was they generally looked just once and they were quite quickly deterred from enrolling. Somebody might see it's too expensive or be told they're not eligible. A couple of individuals asked questions and never really had those questions answered and so just put the brakes on the enrolment process. What we learned is that you really might need a significant push to engage individuals a second time around to consider insurance coverage.

Of those that we met, only a few had changed coverage over the course of the three open enrollment periods. One man in California had initially enrolled in platinum coverage and he felt like his premiums were too high. Hoping to reduce his costs, he switched to a Gold Plan but was met with higher out-of-pocket costs. As a result, he is now putting off follow-up care.

We met a participant in New York's Medicaid who had

in a new plan with his clinic's help but has yet to engage with coverage in that new plan.

The third person we met, has really been an example of somebody who's churning through coverage. He left college where he had college-based insurance, his family encouraged him to enroll in Medicaid, which he did. He found a job and enrolled in the marketplace and got subsidies. He got premium support and then lost his job and enrolled into New York's basic health plan.

This individual was really able to navigate this on his own. He was certainly somebody with a lot of initiative, but he did fall out of coverage for one month, when the enrollment into the basic health plan hadn't really gone through yet.

For those who gained coverage, the participants that we met in New York and California, like in 2014, those with Medicaid and marketplace coverage generally are very grateful for having insurance. They feel more secure but both Medicaid and marketplace enrollees are quite worried about maintaining coverage. For marketplace enrollees, that's really based on out-of-pocket cost, whereas, for Medicaid enrollees they have a lot of anxiety around recertification and being able to maintain coverage from year to year.

me is that they really don't consider Ryan White to be a safety net that's available to them once they've gained insurance. They've forgotten that the program is there to serve as a safety net for somebody without coverage and without access.

Overall, those who gained coverage did feel like their healthcare was easier to manage and that the health systems were easier to navigate. This contrasted quite sharply with those in Florida, Georgia, and Texas, who were the participants in the focus groups who remained uninsured.

Little has changed since we met with uninsured individuals in 2014. All are meeting their HIV care needs through Ryan White, but they suffer from significant health problems unrelated to HIV, and those are typically going unaddressed. Many didn't know about their state's decision not to expand Medicaid but when it was explained to them, they said they were dismayed by their state's decision but they weren't surprised. They said that they would enroll if they could. If fact several individuals had past experience with Medicaid, which they had when they were pregnant or when their children were younger living at home, and they have a really positive view of the program.

Despite feeling like living without insurance is scary

they're living with family and friends, some are struggling with substance abuse, transportation needs, lack food security, or have debt often because of medical bills as a result of being uninsured, sometimes in tens of thousands of dollars.

For all that we met, the Ryan White program has continued to play a really important role in the lives of the participants, and the insured in particular deeply value the program.

Again and again, the uninsured that we met said that they would be dead without the program. The main challenge for most who are engaged with Ryan White is recertification, where just as with the Medicaid program, individuals say it's burdensome and confusing, and it's a stressful period for them.

Most of those who have gained coverage are now less sure about the role Ryan White is playing in their lives. This is despite using services like case management, which are support services offered by the Ryan White Program and likely funded by Ryan White.

This contrasted quite sharply from 2014 when individuals had just gained coverage, and were really bridging out of Ryan White and into private insurance for their HIV care.

to Ryan White and it seems that a lot of that is about maintaining relationships with their providers.

All who we met, both in the Medicaid and marketplace and who only have Ryan White for their HIV care needs, have a positive view of their providers. They describe deeply personal roles and say their doctors know everything about them and particularly like that their doctors are HIV specialists and note how important it is that their providers are aware of the changing science and of the new medications coming to market. Maintaining this act of engagement with providers is really important for them during coverage transitions and is a concern for those who think about moving out of Ryan White and into insurance.

One of the most divergent responses we had to focus group questions was what kind of pharmacy needs do you have? It really points to the fact that individuals that we met with really see having different types of access to pharmacies as critical to staying engaged with their HIV treatment.

While some prefer a specialty pharmacy or mail order access, others prefer a mainstream pharmacy, saying that it's important to them to have greater discretion, or like a brick and mortar store where they have a personal relationship with

with HIV but that's not happening evenly across the population. Those in non-expansion states have limited access, access to and knowledge about ADAP and other Ryan White support for engagement with private coverage truly varies.

Enrollment in affordable health coverage is very variable and is individualized. It's based on individual income and it's based on the plan selection that an individual might make. Of course, others are going to remain uninsured and less impacted by these coverage changes. I'm thinking about being undocumented or those with just complicated life circumstances that make it really difficult to engage with insurance.

For all that we met, Ryan White is continuing to play an important role, especially in the lives of those who remain uninsured, but in providing support services for those who have found coverage.

As we look forward and continue to think about how the ACA is impacting the lives of people with HIV, it'll be really important to continue to improve insurance and coverage literacy so that individuals know what they're eligible for and can engage in coverage that truly meets their needs.

In addition, it's important, as Jen mentioned, to

people living with HIV, and under the ACA era, and to inform the future of the Ryan White Program.

Thank you very much, I'm happy to take questions and answers toward the end of the event, when we do an overall Q&A, but I'm going to share with you one of the short videos that Jen mentioned.

In 2014, we did our first round of focus groups, and after we did those we met with 12 of those individuals and pulled out personal stories and created the profiles report that Jen mentioned. Of those, we found three individuals that we really wanted to highlight their stories to a higher degree and let them tell their stories in their own words.

One of the people we met with is Shandora. She's here with us today from Atlanta, and she'll join the panel in just a minute. This video was created by Francis Ying and Melissa Majerol in our office and this is Shandora's story.

[Video playing]

SHANDORA LANE: My name is Shandora, I have been HIV-positive for 26 years, since 1989. My son and I have been at this program that house women and children living with HIV and AIDS. This program residents people that are homeless or on the verge of being homeless. I'm a server at a diner, I've been employed

I went to a case manager, where I receive my treatment at Grady, and she told me that I did not meet the requirements. I make too much for Medicaid and I make too less for subsidies for the Affordable Care Act in the state of Georgia. I'm very disappointed in the state of Georgia, and this is just my opinion, because there are other states that offer a lot.

I have a history of drug abuse. During my history of drug abuse I was receiving HIV care on and off for a lot of years, up until 2009. I started receiving consistent care through the Ryan White Program here in Atlanta, Georgia.

When I came here I was on 20 pills a day. The last two years of my treatment from my wonderful doctor, she has gotten me down to two pills a day, once a day. Besides me being HIV positive at this point, I have meniscus in my leg. It's not good because I stay on my feet a lot as a server; I work six days a week and the pain is unbearable.

I've had several falls on my job. I'm not covered with the insurance and I can't afford out-of-pocket, at this point, to pay with the procedures that I need to be done.

Even if I was to get health insurance, my HIV medications is very expensive, it's very expensive. So I just try to hold onto the Ryan White, I've got to hold onto that, to

part of my life, because I could stop all the pain that's going on with me.

[End of Video]

JEN KATES: Thanks Lindsey, that was a really great overview for us, and thank you again. I'm going to start with you, but first of all, I'll do introductions. We can start with Laura if we need to, but I'll just briefly introduce everyone, and maybe I will go to Laura first.

As you met Shandora Lane from Atlanta, Georgia, and a little bit of her story, we just are very grateful that she's shared with it us and with you. We know that that is hard to do, but so important because we who work in policy in DC know that those voices are really ultimately what make a difference, and also what we're trying to meet those needs, so thank you.

We also are really excited to have Dr. Laura Cheever here today, who's the Associate Administrator and Chief Medical Officer of the HIV/AIDS Bureau at HRSA, she oversees the Ryan White HIV/AIDS Program, which as we have heard is a lifeline for so many people with HIV, more than half of all those living in the USA today.

She'll be able to talk to us about its ongoing role and importance. We're also really excited to have Tim Westmoreland

who might not know him he's somebody who's made a huge difference in the lives of people with HIV, including when he worked for Congressman Waxman in the 80s, working with the Congressman to convene the first hearings ever on HIV in the Congress, in the early '80s, not something that was that easy to do.

Also more recently, through work with the House, helping to draft the ACA. He's a Medicaid expert. He actually ran the Medicaid program for a few years in the Clinton Administration.

Then last but not least, we have Dr. John Carlo with us, who's the CEO of AIDS Arms in Dallas, Texas. AIDS Arms is an AIDS service organization. I'll let him tell you more about it. What was really interesting to me when I was looking back at the history of it—it was formed in 1985. For those of you who might know this history about the precursor of the Ryan White Program, there were several community-based AIDS Service Organizations that were funded first by RWJ as models of community based care that eventually became Ryan White that really were the demonstrations that showed and made the case to the Congress, to the Administration, that we can have a program like Ryan White and it can make a difference. And it's still

ongoing project looking at the impact on providers of the ACA, so what is happening with providers.

Why don't we start with Dr. Cheever. We'll give you another minute. Just broadly speaking, a lot has been happening with Ryan White, obviously, it is a lifeline. What are some of the broad strokes—changes that are happening with it? Or what do people need to know? We heard some things from our findings that some are still not aware of it, that it's available to them.

LAURA CHEEVER: I did bring a couple of slides just because I thought it would be useful for us to talk about our client level data. You've talked about the importance of having data. In the Ryan White Program, we do collect data from the individuals that we serve at the provider level and we have now done an analysis. We can compare what's going on in 2014, which was early in implementation. I'm going to compare this data with 2012. We can put that information up there.

The first thing to note is that in 2014, if you look at the blue slice of the pie, this is the type of health coverage by clients that are followed by the Ryan White Program. I should say overall our program serves half a million people, so

This is actually not a huge change. I'm going to use 2012 as a comparison because '13-'14 looked very similar. In 2012, about 28-percent of all clients were uninsured, so 25-percent of all clients in Ryan White remain uninsured. The flipside of that story, and why it's important that people that have coverage understand the role of the Ryan White Program, is because 75-percent of people are insured. In prior, it was around that same number.

So most people served by the Ryan White Program, even prior to ACA, have some form of coverage. The Ryan White Program has played a very, very important role for those people in terms of health outcomes and continues to play a role. We've been able to document that both through our data and looking at the Medical Monitoring Project, MMP, looking at people that have Ryan White coverage and people who don't.

The other thing about the Ryan White program is that we take care of poor people. This program was really set up to take care of people that didn't have means to get care on their own. Overall, in 2014, two thirds of the people were living below 100-percent of federal poverty, and three quarters were living below 138-percent of federal poverty.

For those people living in states where Medicaid was

is that if you look at the yellow, which is Medicare, the purple, which is Medicaid—above that is Medicare and Medicaid combined—that among all clients, about 51-percent are covered by a combination of those two programs—most by Medicaid.

As you can see as we go from less than 100-precent of federal poverty to less than 138-percent to 139 to 250, that that proportion relatively decreases, which I think is what you'd expect to see but important to remember that most of our clients are going to be less than 138-percent poverty. Over that, over half are going to be covered by either Medicaid and or Medicare.

When we look at outcomes, we know that according to looking at CDC surveillance data, only about 30-percent of all people living with HIV in this country are virally suppressed, looking at surveillance data. When we look at our data, which are specifically people that have walked into care at least once in the year, so that is a different slice of people, we see that overall the national average in orange is that 81-percent of all people that walk into the Ryan White Program are virally suppressed, which is really amazing. I just told you that most of those people are very, very poor and have a lot of those structural barriers that create health disparities.

You just saw from this study that Kaiser did that people really feel personally connected to their provider, that their provider really knows a lot about them and is in deep with them in terms of this journey. Many of us with private insurance probably can't tell that story about our medical providers.

If we look starting on the far left that people are completely uninsured, relying just on Ryan White they have about a 77-percent viral suppression rate and people with Medicaid and other public insurance have about a 79-percent rate. Having insurance does in fact look like it makes improvements, so people with insurance have improved health outcomes.

Now some of this is confounded by things like poverty. We did a study together with the Medical Monitoring Project that was published in *JAMA Internal Medicine* last year that showed that if people are in care, in places that received Ryan White funding, they're much more likely to have a lot of the support services that we think are important to try to address some of those structural barriers to good access to care. Things like intensive case management, transportation services, linguistic services, much more likely to occur in the setting

federal poverty, that the viral suppression rate, if they did not have the Ryan White services, was at 67-percent and was about 73-percent if Ryan White services were available. For the poorest people, having Ryan White made a big difference and it is, I think, because of that full package that we have.

The other thing—another study we did working with people from CDC and the Medical Monitoring Project was also published last year. It looked at people that just had Medicaid coverage at their provider's office, versus people that had Medicaid plus Ryan White. They found that if they were on a Medicaid only site, their viral suppression rate, which was at 71-percent, and Medicaid plus Ryan White in that setting, was about 76-percent.

Once again, that having Ryan White in addition to Medicaid made a difference for people. If you're poor, you're going to do better if you have Ryan White services enabling you. If you just have Medicaid, actually even a private insurance plus Ryan White, you're going to do better, so an important part of the story.

The last thing I'll say, just in terms of some of the data that we have since you were talking about trying to insert data into this discussion, is we were fortunate last year—or

clinic and they just have Medicaid, Medicaid will be billed by Ryan White.

With payer of last resort, Medicaid will be billed. Those people walking in who have Medicaid are going to get a lot of other services funded by Ryan White, during that medical visit. The study we did with Abt was able to really quantify is that typically, when you walk into a clinician's office for a follow up visit, your visit's going to be 15 minutes long, typically. In the context of Ryan White, your visit's going to be 45 minutes long. What's going to happen during that visit is, they're going to do things like discuss things like adherence, discuss risk reduction, discuss those issues around housing and connections to care and what are your barriers to care.

All those other things that we think are so important to really get people that are significantly underserved engaged in care and retained in care. They did demonstrate that at least in terms time and content, that is happening. Even though a patient now has Medicaid, and they're like, “what am I going to do, I just have Medicaid now?” Most places they are going to get care, they're getting Medicaid plus Ryan White, because there are extra nurses, there are pharmacists there,

of Medicaid is being billed for that medical visit and for their medication and labs, Ryan White is paying for a lot of the other services that they're getting that's really significantly enhancing their care and improving outcomes.

Maybe it's longer than two minutes, but I just got started there. Final slide, this is just a final set of data here: when you look at a Medicaid expansion state versus non-Medicaid expansion states, because this is the issue when you look at our data overall, you see a wash but if you look at Medicaid expansion on the left, the purple are people that have Medicaid or other public insurance, and that grew significantly from 2012 to 2014, 38-percent to 43-percent. That is what we would expect to see. I think what we saw in that study that was published yesterday in CID.

From 2012, to 2014, you also saw a decrease in uninsured from 23-percent to 17-percent. We are not exactly; no one who is insured. People remain uninsured despite aggressive case management, aggressive payer of last resort kind of requirements in Ryan White. People remain uninsured in places that have expended Medicaid, and I think we'd expect that. Any large new program that comes into existence, it takes some while to get traction.

big change in the uninsured, from 33-percent to 34.5-percent but the people covered under Medicaid and other forms of public insurance actually decreased from 28-percent and 25-percent and I can't well explain that.

I don't think we understand all the issues behind that, I think we could postulate several but that is the difference we saw. I'll end right there.

JEN KATES: Thank you, I actually really commend you and your team. For those of who work on data, we know that 2014 data, which actually came out a few months ago, is really recent, so thank you for really pushing and working to get information out quickly. I know more is coming out, we've talked about it.

It makes a huge difference, that last slide is incredibly telling. Is there anything from yesterday's article that you wanted to highlight or is it really more about that last slide?

LAURA CHEEVER: I think it's more about the last slide, we looked in places like New York that went to expansion of Medicaid earlier, you see that change earlier, and for other

JEN KATES: Really important data, thank you. Shandora? Again, thank you. I guess you've already shared in the video, your experience. If you just want to talk a little bit more about trying to get health insurance, what that's meant or what might have changed since we talked to you in that video. Really, I'll leave it to you to update us or share with us.

SHANDORA LANE: Good morning. You know, Jen nothing has actually changed. As a matter of fact, I'm meeting with a navigator next Tuesday, to go through the health care coverage once again. As I explained in my video, when I first started looking for healthcare coverage, it was the part where I didn't make enough, you know, I was in that coverage gap.

The premiums that they presented to me—it was, what they wanted the premium a month—this was something I couldn't afford. I look at my Ryan White, Ryan White is like a vault. I know I've got that—it's lock and key as long as I'm doing what I'm supposed to do to keep my Ryan White insurance available. When I spoke with my provider, well you know don't—she didn't say don't worry about it, but it was like, well you know, you got Ryan White. I guess in my mind, it wasn't so

to me, as I expressed, that's why you see me here today and I strongly believe that.

I'm so afraid to diligently seek because if I get my healthcare coverage—I'm a server, being a server, you don't know what might happen, you know? I'm so afraid of losing Ryan White, because how about if I can't keep my premium. When my Ryan White drops, it takes a process to get it back, and to get it back started again.

JEN KATES: The recertification.

SHANDORA LANE: Yes, recertification. I'll give you an example, my fault, but I was so used to Grady telling me, you know it's time to recertify, and they didn't. I went to pick up my medicine on Tuesday and I couldn't get my medicine. I panicked. First time in seven years. I panicked.

I ran to my doctor, I ran to my PA. Calm down Shandora. "No, no calm down? I don't have no medicine, what you mean calm down?" When they finally got me calm, we looked, you were supposed to be here in March, but let's say I got complacent with them reminding me, my fault. See, this is one of my fears you know, with the process. Luckily, I got my

Like I said in the video, with my health insurance, it would cover a lot of my other needs that I need to be met. You know, I do have an insurance through Grady that gives me limited service, but every time I go to my mailbox, I got a bill.

We're talking about—Lindsey was mentioning the medical bills that the debt that you incur. I don’t go to the mailbox everyday no more, you know, because I know what I'm going to get out of it. It is what it is. I'm so grateful for Ryan White and I am going to continue to look in the marketplace for coverage and, hopefully, one day at a time, it will be available where I am fully secured with my Ryan White and my other needs being met.

JEN KATES: One of the things you talked about in the video that we heard from everybody we talked to is that non-HIV needs are really a big problem, that it's just without coverage, I mean those are not being able to be met. People are going without care for really—problems that don't have to get significant, but can be quite significant. You've had that experience?

SHANDORA LANES: Yes, like I said, I have a torn meniscus, I fell in so many times on my job, get right back up

gave me, they don't help. I went and had the injections about seven months ago.

As I said, I got a medical bill that followed behind that, because you know, they didn't cover everything. It's time for me to have the injections again, but I'm just not equipped to go and have another bill on top of that. I want to take care of this one first. I have to endure a lot of pain because I'm not insured.

JEN KATES: One of the reasons we went to Georgia, as Lindsey mentioned, was because it is one of the states that hasn't expanded Medicaid and Shandora and many others are in this coverage gap, which was not the intention originally of what the ACA was to do.

That brings me to Medicaid, and to our Medicaid expert Tim, who I hope will provide us with a longer view sense of what Medicaid has meant for people with HIV, and kind of what was supposed to happen with the ACA, and where we are today.

TIM WESTMORELAND: I think as the resident old guy that I can hark back to some of this, because I was working on the AIDS epidemic and before there was Ryan White, and before—and it's important to remind people before there was the Americans with Disabilities Act, also. In the early days of the AIDS

Now this is on top of all the people who had AIDS who didn’t have health insurance to begin with. And so, we had this catch 22 that at the time the people most needed health care, they were least likely to be able to have a third party source paying for that healthcare, and Medicaid stepped in.

In the early days of the AIDS epidemic, Medicaid was flexible enough that by—and Jen, I think you could correct me, but by 1990 that half of all people with AIDs ended up as Medicaid beneficiaries. It was the prime payer for people with AIDS to get health care services.

But it's not just—I have to say along the way that it's not just with with AIDS, that Medicaid is so incredibly flexible in meeting urgent national needs. It wasn’t long after that, that Medicaid stepped in and became the important payer for the 9/11 health care needs afterwards.

And then after that, Katrina, and then after that, Sandy, and even today, brand new work on Medicaid and Flint as way of helping to solve every different healthcare crisis that comes up. It's just such a flexible program to step in and do that.

And I assume that we're going to be watching Medicaid and Zika very soon too, since it's going to be such—that

even before the ADA protected the people from losing their jobs. Then the second thing I want to say which was prompted by your story, and by your data is that a Ryan White, even in the days—in the era of Medicaid expansion, continues to do so many things to help Medicaid be better.

It's a back and forth symbiotic relationship between Ryan White and Medicaid, that Ryan White is the safety net, in those places under—in those states that don't do Medicaid expansion. It continues to be there even if the state legislature and the governors have said, hell no, we're not doing Medicaid.

It's always there for people who are immigrants and the ACA and Medicaid aren't going to be there for them. It’s the safety net under all insurance to make—as you were saying to make insurance better. That it helps with those situations in which there are strict limits in Medicaid or health insurance that Ryan White will be able to pay for some of the traditional services that insurance and Medicaid just were out of line on.

On top of that, it will pay for services that insurance and Medicaid never would have paid for, but that are really helpful and, in fact, essential for people with AIDS and people with HIV.

history together and they're going to have a long future together.

JEN KATES: It's an interesting perspective to hear you talk about Medicaid as flexible, since one of the big challenges with Medicaid was the eligibility barrier in a sense, prior to the ACA, which was eliminated by the ACA, but given that we all know where we are and the 19 states are still not—have not expanded, what do you see looking forward based on—we won't to hold you to this, but based on prior—I mean we know with Part D, for example, there was some resistance beginning, but even Medicaid, when Medicaid the program was first created, it took a while for all states to come on board. What do you think is likely to happen?

Tim Westmoreland: I think as with the Medicaid program at the beginning of Medicaid, with CHIP at the beginning of the CHIP, it takes states a while to being but sooner or later they all arrive there. There's just so much need and on top of that, so much money on the table from the federal government that I think ultimately, I pray ultimately, all states will get there. It took a long time for all states to get there with Medicaid. It took a little less time for CHIP, but I think sooner or later they're all going to expand and start to meet the needs that are

JEN KATES: Thank you. John, turning to you, can you tell us a little bit more about AIDS Arms and what your role is, the population you're serving, or anything you want to share but the history, too, would be great.

JOHN CARLO: Sure, thank you for having me and thank you for having this program. I think it's really, really critical given in the time where we are around the ACA and the implementation. Before I start, I just want to say I am in strong support of the ACA, so I'm going to make some comments that might appear to be critical, because I think we do have challenges and we have been seeing quite a few in Texas, but I want to start off by saying, I do support the program itself.

Our organization is celebrating its 30th anniversary this year. We started as a case management organization with a staff of three. Today, we are just over 105 employees, provide medical care at two sites, we have five physicians and three mid-levels, and we are seeing just over 2000 patients, all living with HIV and AIDS.

You know, the growth, of course, was really around the notion of Ryan White itself and the comprehensive care and the approach, which I believe is incredibly important to addressing the HIV crisis as a community but also, to address the

Just a little bit about—I'll focus on three areas because it's interesting our view and our approach, because I look at this as three different domains. First, we're an employer and we have over 100 employees. Since the ACA has implemented, our premiums the first year it was implemented went up by 56-percent.

The next year, by 28-percent and we had to redo our program to go from a PPO, which was a good insurance to a high deductible plan which basically doesn't cover anything up until $6300. We’re still even with that, still paying about $7000 a year per employee and, in fact, we would have been subject to the Cadillac tax even with that plan, had that not been repealed.

We really struggled, and it was really, really hard for me to have employees come in, in tears and saying I can't afford my healthcare and I've had to discontinue my care. For the organization of what we do, that really, really hurt, but we just simply could not afford the benefits that we used to be able to offer employees.

As an organization, you know, we are a medical provider, unfortunately at the beginning of this enrollment period last year, we could not get into a single exchange

We say, hey, we're an essential community provider, by law you have to provide that. They say, no, we don't even know what that is, but if we do know what that is, we've already got that covered, thank you very much.

Thankfully, we've been able to get into two plans but I'll tell you we filed complaints with our Texas Department of Insurance, we filed an Office of Civil Rights complaint on one plan that basically had no infectious diseases providers in the entire county of Dallas, despite 18,000 people living with HIV. In my opinion that is wrong.

Even the health plans, they freely admit that their networks are being narrow to cover their bases and they're also freely admitting by the way, that their provider directories are incorrect. We had physicians who we know have died that remain in network, we know the information some of the provider's prior addresses remain in the provider directories. We see a lot of challenges around the implementation around the ACA, particularly with the health plans.

Our last piece is what it's done for our patients, you know, we've had patients with us for five to 10 years. They do the right thing, they get on the ACA and we have to tell them, you're going to have to find another provider, if you're going

a relationship with the doctor that they trust and really their care and we're having to make those hard decisions for patients.

We've even just yesterday had somebody call us and say, I can't find a single ID doctor that's in the exchange plan that I've chosen, will you see me? We're struggling with that. I mean, do we take somebody who is an out of network knowing that there's some risk there? We're really concerned about how that impact is going to be.

The last thing I want to mention is on the Medicaid expansion just because I think it's another piece of this. Those of you familiar with Texas politics, we are not going to be expanding Medicaid anytime soon, and unfortunately, there's a very politicized process right now, that basically is implemented, that’s just basically holding us back.

I will say though, that there is a greater problem in that access does not equal coverage. In Texas, the way the Medicaid system is run now, just as an example, an office visit at our clinic, we get about $35 for that visit. There was parity originally, but our legislature actually voted to not have Medicare or Medicaid parity.

We're going to be back at the $35 rate. I don't know how we would stay in business if we had to transition all of our

We're looking at that, how we can do that but that's a real concern for us. The last thing I'll mention, though, is providers' Medicaid acceptance in Texas is very, very low. About 19-percent of primary care doctors even take new Medicaid patients. We even have hospitals, nonprofit hospitals, that don't take Medicaid, at least the managed care plans for Medicaid, and I think that's really wrong.

I mean, I really am concerned when we have patients that can't get procedures done and they have to go to places like UTMB in Galveston, 400 miles away, because none of the hospitals in our area will accept the plans.

I think we support the ACA but, again, I really want us to recognize that there is particular challenges that we're experiencing, particularly in a state that's not expanding Medicaid.

Our ultimate goal, of course, is to keep people in care provide the best care that we can, and I really hope that we really use the experiences of Ryan White, and understanding of how to do this right, so that we continue to inform how to move forward in the best direction.

JEN KATES: Thank you for that sobering reality. One follow-up question, you mentioned patients are moving into a

JOHN CARLO: Right, and the other concern, of course, you know, insurance assistance for Ryan White would really, I don't believe, would cover out of network subsidies for support. You're kind of an additional loss, I think if you're—in that it could be derived in our own area, but there has to be decisions about co-pay coverage and costs like that and generally we don't—we see avoidance of out-of-network coverage costs as something that wouldn't be covered under assistance programs.

JEN KATE: Do you have anything that people should know about that, or is it really—and I think it points to an issue that it's very locally determined.

LAURA CHEEVER: It is very locally determined, certainly in the context of Ryan White if someone has insurance, there are a lot of place that—some places that has not expanded Medicaid, the Ryan White program or the ADAP program has still entered heavily into purchasing insurance for people.

In those settings, Ryan White does pay for a lot of out-of-pocket cost, including depending on why someone is going out of network, and sort of what the rationale is, helping out across the board.

JEN KATES: Shandora, one other question for you, you've mentioned that you started—you again are in care with Ryan

got that diagnosed and started seeking treatment, and they did cover. Like I said, my history of substance abuse would not allow me to continue staying with the Medicaid.
So my fault of my own, but seven years ago consistently with Ryan White, it is the best thing. It's absolutely heavenly for Shandora, in all sense of the word.

I don't idol any Gods or anything, I believe in God, but, I'm just dead without Ryan White, I know it, because I couldn't afford my HIV medications. That's a big part of my life, staying alive at this point. I have a 17-year-old that I have to watch over right now, you know and that's all I have and I'm just so grateful, I'm eternally grateful for Ryan White.

JEN KATES: One of the perspectives we don’t have represented up here, and it's something that we're actually going to be doing more work on, is when we did these focus groups and interviews, we also included New York and California, and no one from New York and California is here.

We heard a very different story and as Lindsey was telling you, and if you go back to our reports one of the of the things that we ascertained after talking to folks, because both of those states already had fairly generous Medicaid programs prior to be ACA, and fairly generous benefits in general, a lot

There was a shift in payer and that often presented a challenge for them, in terms of certification, recertification, maybe changing networks. In terms of getting things that couldn't before that was much less of change, and I think it was very telling.

What we're wanting to do in our next look at some of this in the next look at the field is to go to states where that wasn't the case. States that have expanded Medicaid, but prior to the ACA really had very limited Medicaid coverage. An individual who is poor but not yet disabled, and met the income qualification but was like an adult without dependent children, for example, would not be eligible.

A state like that, where people are effectively shut out of Medicaid and then all of a sudden were eligible. We're going to try to get that experience, because I think we'll hear some different things that we haven't heard before, people having Medicaid coverage for the first time, we're going back into Medicaid and see what that meant, and also the ongoing role of Ryan White.

I think we're now up to the point where we're going to get to turn to folks in the audience, and first, actually I'm really pleased today that we have Dr. Amy Lansky with us, who is

grateful that she came and has been here the whole time and is staying we us.

We know that you're very busy, one of the things that you're doing and you worked with your predecessor Douglas Brooks to launch and update on the National AIDS Strategy. That was very innovative and visionary and looking forward and now you're in the rest of the Obama administration working to implement as much as you can, so we appreciate you taking some time to talk to us. We’re just hoping you could share some words about the strategy and what you're trying to do, and then anything related to what we've heard today. Thank you. You can come up.

AMY LANSKY: Good morning, and it's nice to see you all here, it kind of brings me back to the blizzard and I'm glad we're having nicer weather. I also wanted to say thanks to Jen and the team here at Kaiser Family Foundation for hosting this event, and also for their commitment to issues around the Affordable Care Act and the Ryan White Program and really making sure that all of us understand both of these, I think kind of complicated topics, so thank you for being our educators.

I did want to take a couple of minutes to talk about the strategy. We have made a lot of progress over the past eight years, in terms of policy, in terms of science and our

As Jen said last summer, we released the strategy and it has really guided our work over the past year. It will serve as a road map through 2020, and allow for- I think- a seamless transition across administrations because it's very clear what needs to be done. I think it can transcend some of the politics, she said hopefully.

One of my important roles is to do this, which is to talk about the strategy and what we're doing, and I think the strategy makes it really clear that people living with HIV and people at risk for HIV need healthcare coverage. Really taking together the provisions of the Affordable Care Act and the Ryan White Program are really a powerful cornerstone of our response.

One of the things in the strategy that calls for seamless systems to link people into care, and this requires continuity of coverage, including through the Ryan White Program with, as we've talked about today, assistance with enrolling in coverage and also premium payments. Certainly the retention in care with provisions under the Affordable Care Act and the safety net of Ryan White are really critical for reaching this goal.

One of our other goals in this strategy is around reducing disparities. I think clearly access to coverage and

The role for the Ryan White Program, I mean, I think Shandora is our greatest advocate to talk about that, but her enthusiasm is also reflected through Congress and the administration.

There's really been strong support for the Ryan White Program. I think that as we continue to see and document its successes, that that will continue that. We're working on four priorities this year in the Office of National AIDS Policy and it's related to some of the things that have been talked about today.

We're promoting testing and linkage to care and linkage to prevention services, for those who test negative. Certainly the implementation of the Affordable Care Act, and continued provision of services through Ryan White are critical to these efforts. We're focusing our resources where the burden of HIV is greatest. I think that the way some of the Ryan White funds are distributed is a really great example of that, and how we need to be sure that we have adequate resources and are putting our money where that burden is highest.

We're developing three additional indicators, to help monitor the strategy. These include uptake of PrEP, HIV stigma and HIV among transgender persons. These reflect important

Lastly, we're doing our part to address the opioid epidemic in the United States and doing our part means preventing HIV outbreaks and addressing some of the increases in viral hepatitis transmission.

I think that linkages within the Ryan White Program to substance use disorder treatment, treatment for hepatitis C and co-infected people, are going to be important aspects of achieving these goals. Lastly, what I want to do is just urge all of you here today, those of you on the panel, those of you in the audience really think about what can help us fully implement the Affordable Care Act to maximize the benefits of the Ryan White Program. It's really going to take all of us working together with our resources and our policies and our programs to help achieve the goals of the strategy, so thank you.

JEN KATES: I actually want to add just one thought about the strategy and we also have Jeff Crowley here who is the original architect of the strategy as the first ONAP Director under President Obama.

For those of us who work also on issues outside the US, on global HIV, there's been strategies in the global sphere for a while. Some of them don't always work, but there's always

It was really a challenge that we hadn't had that in this country. Starting to get that in 2010 and to now have it carry through and as you said, it can hopefully transcend a change in administrations, because it really is something that while we might not achieve everything in it, having that normative framework and that structure is really important for ending an epidemic, so thank you. I take to heart what you said about figuring out what we all need to do.

Now it's time for all of your questions, what we'll do is we'll take three at a time. If you have a question for specific panelist please let us know, if not, we'll turn it over after the three, and just identify yourself. Thank you. Carl?

Carl Schmid: Hi, Carl Schmid, so Shandora, I wish we could bring you to the Hill, to our Georgia delegation talk about the importance of Medicaid expansion and the importance of the Ryan White Program, but I guess my question is really for Laura. Shandora talked about her reliance on Ryan White, and she doesn't have health insurance, but you know, the Ryan White Program as you said can pay for premiums for health insurance.

I was just wondering how is Georgia doing that, and she also talked about her other needs and your study did this as well, you know the co-pays for other medications, or for other

MARNIE: Hi, my name is Marni, and I'm an attorney and I used to work in rural Mississippi doing legal services for folks who had HIV and AIDS and faced employment and housing discrimination, access to medical care. I partnered with doctors, so I formed a medical legal partnership with doctors who served low-income patients who were my low-income clients, and we worked together.

I'm hoping the folks on the ground are working together with attorneys and doctors, I want but that plug in. Second is, I also worked in Botswana as a Peace Corps volunteer in the PEPFAR program helping folks with HIV/AIDS in rural Botswana. I was able to get people on HIV/AIDS medication better and easier in my village - there was no electricity and no water in Botswana - than it was in Mississippi.

Most of it is because in rural areas, the treatment focused in rural Botswana was getting doctors to villages. They'd have mobile clinics. We'd all sit under a tree and we knew what day to come, and we'd have 15 people there, and they all got their medication. In Mississippi, the hospitals, which, as you know, in rural areas are closing, would be up to 100 miles away. People who don't own cars cannot get there.

If you have 10 different people with doctors'

JEN KATES: That is a good question. Ron?

RONALD JOHNSON: Ronald Johnson from AIDS United. I appreciate all the panelists, but I want to focus in on Tim Westmoreland's comment about the synergy between Medicaid and the Ryan White Program, entitlement reform has always been in the air. It appears probably in the next few weeks we might see another proposal around block granting Medicaid.

I was wondering if you could comment on what projected impact a block grant approach to Medicaid might have on coverage, particularly given the differences between Medicaid expansion states and non-expansion states, and how block granting Medicaid might play out in that scenario.

JEN KATES: One question primarily for Laura was about what can Ryan White do in Georgia for situations like Shandora to maintain her Ryan White access, but also provide a fuller complement, what are the possibilities? Second, was this issue of not only linking providers and attorneys, but why is it easier to get antiretroviral treatment in rural Botswana than in rural Mississippi? I do not know if anyone here has the answer, but that is a good question.

Last I think a really important issue is the block granting of Medicaid comes up and again and again, what would

LAURA CHEEVER: I'll start then, so I guess starting with Carl. Certainly, we have provided a tremendous amount of technical assistance to ADAP in particular, but also Part A and B grantees to look at buying insurance. They by statute in terms of ADAP it's got to be cost effective to buy insurance, but we definitely have encouraged states to do that.

There are a lot of politics around different states and capacity, but I do think that all states are really looking at that very closely and moving towards doing that. In that, we have been very clear that Ryan White funds can be used to pay co-pays and deductibles.

On the AIDS Drug Assistance side, so on the ADAP side it's relatively easier, because they're often dealing with pharmacy benefits managers and that sort of thing.

On the like, how do we pay a co-pay or deductible to a specific clinician's office is much more technically complicated. Jurisdictions are working on that, and moving in that direction, but it is a jurisdiction by jurisdiction issue.

CARL SCHMIDT: Do you think they can?

LAURA CHEEVER: They can, yes, yes, we have a policy clarification notice we put out two years ago, that outlines all of that, that's something that we would encourage them to do if

we have information flowing in both directions in terms of what we can learn from places like Botswana, where or Uganda or other places that have done it very well, in terms of what we do here so that's something we're working on.

The US has an incredibly complicated healthcare system, I mean I don't even call it a system healthcare environment. That is really though because a lot of times a lot of case managers do is they try to help clients negotiate or navigate, how to get through that. We do have lessons learned, and there are a lot of, I think best practices when you look at rural community about telemedicine, about the ECHO project out of New Mexico, other things.

There are some really great things that have been done can be done to reach people. Frankly, the issues of stigma in the US, it's not a generalized epidemic, you know—in Africa where there is still stigma. The stigma here is a tremendous problem.

In a lot of rural areas, on Indian reservations, in certain communities, people do want to be here in their community. They would rather go to a different community and get care than get care in their community where they're going to see their aunty at the blood draw station and they're going to

there that significantly impacts our ability for people to access care.

JEN KATES: Thanks, to Carl's question, really quickly, we did a study looking at that very issue, what are states, localities doing around helping to purchase insurance and found a tremendous variety of responses and a lot of confusion.

Just as Laura said the politics were a big barrier, where some of the local Ryan White grantees were very much willing to do this, and were not allowed to do it.

Others, just not understanding the policy or the permission really to do it, so there was a lot of confusion. It's definitely an area where there could be more clarification but it's community by community. Yes, John?

JOHN CARLO: One of the concerns I have on that, we don't want the insurance process to create more barriers for patients living with HIV. While we all get the vision that having full coverage is a better option, I worry sometimes because insurance literacy is so challenging, it's such a complicated system, that it may not be the right choice for everybody.

Particularly, if you're having to come in with a program that subsidizes their retaining coverage, while it can

out of care. I think the political points that we've just been talking about, in Texas, absolutely, nobody wants to go online and say, hey I'm supporting Obamacare by paying state funds into keeping their coverage. We're not quite there.

TIM WESTMORELAND: First, medical legal partnerships, I have to say, I do teach at a law school, medical legal partnerships are very interesting and innovative things, both of law students and med-students, for lawyers and doctors working together. Georgetown is now working on one for oral health in the district, for medical legal partnerships.

One of my former students is now working on one about lead poisoning and medical legal partnerships. Those of you who don't know them investigate law schools and medical schools working together to try to solve systemic problems for health and public health, they're really great programs.

They're just—I mean it's been around for a while but they're just beginning to blossom. As far as the question of Mississippi, and Botswana and a little bit in response to your comments earlier about Texas, I mean I think these are evidence of the ongoing struggles within the federal government in large but in Medicaid particularly about what is federalism?

None of the problems that you've described is a federal

stopping reimbursement levels. It would stall—I mean obviously expansion and non-expansion structure of the networks, Medicaid allows for a successful solution for all of those things with full federal participation.

It's the problem with federalism here, and you know, we tried at one point in the ACA to expand Medicaid in a federal basis and the Supreme Court stopped us in that instance. There are just some political and legal limits to how far the federal government and Medicaid can go under the traditional—under the current structure of federalism.

In response to your question about grant block granting, see above, all those problems about federalism, and also that they just get worse. It just exacerbates here. I would point out, the block grant discussion has been around for very long time. As you said, it is important for states to recognize that the only way that the federal government gets savings in the budget, which is why people say—in Washington say they want to block grant is if the states don't get as much money as they would have gotten under a traditional Medicaid program.

If they're left holding the bag, they can have fuller control over the program, which I think only drives into the

I did take some comfort in the fact that during the last round of the 50 or so ACA repeals that the Congress has done, that there were Republican senators who said that they had to be sure that the repeal vote did not include repealing Medicaid, because their homes states had expanded Medicaid and it was working, and that their state could not have the rug pulled out from under them.

I do take comfort that there are some Republican senators who have recognized at least at the beginning, that Medicaid has some benefit even in red states.

Finally, you asked me to prognosticate, Mrs. Clinton has a very strong record during the Clinton administration of opposing Medicaid block grants. She was a very strong opponent during her husband's administration.

Mr. Trump has been less clear, about his stances on Medicaid, but I have to add that New York values would say support the ongoing structure of Medicaid, and see how much federal money you can get out of it. I'm hoping that his New York values prevail in that instance.

JEN KATES: Thank you, next round of questions. Over here, back there and then over here.

ELAYNE HEISLER: Hi, I’m Elayne Heisler from the

perhaps avoiding care because they're worried about expense and the explanation of benefits being sent to their parents?

JEN KATES: Thank you.

BERNARD AZUBUIKE: My name is Bernard from the House of Hope Medical Clinic. My question goes to Mr. John, you said you're a great supporter of ACA. I'm also a supporter of ACA and one of the objectives of the ACA is to try to close the gap between the insured and uninsured. The ACA are adopting different strategies to try to close the gap. Currently from the current data, just like the one we just saw from Ryan White, the gap between the insured and uninsured, it's a little on the high side. My question is, do you predict the future of 0-percent uninsured population in America?

JEN KATES: We'll come to you in the next round. We'll take one more question this round after Andrea.

ANDREA WEDDLE: Hi, Andrea Weddle with the HIV Medicine Association. Dr. Carlo, thank you for your comments, they were sobering but really reinforce the work that some of us are doing to try to make the ACA work better. My organization represents HIV providers, so particularly discouraged to hear your—the news about the networks in Texas.

I'm wondering, at the federal level or national level,

insure that Ryan White providers are included in the exchange networks?

JEN KATES: Thank you, and our last question for this round?

MALE SPEAKER: Yes, and good morning and thank you for this presentation from Kaiser. I always look forward to your leadership in this area, it's really great to have you around. Anyway, my question came from Laura. She mentions that people that seem to have access to both Ryan White and Medicaid seem to be doing better. I wonder why that's true because the reason I worry about that is because we have many jurisdictions that have expanded beyond the federal requirements, so we're moving more people from Ryan White into Medicaid. That would imply that if we're doing that there might be an issue of a quality of care?

JEN KATES: Thank you, we have a question about young people and the explanation of benefits going to their parents or guardians, if they're still on their health plans. The second is a prediction, will there ever be 0-percent uninsured in the United States? Lastly—I'm missing my older network provider issue, and then lastly, this question; is there a risk there if clients are really moving primarily to Medicaid or—and I think it get back to some of the things we were talking about that

JOHN CARLO: We have seen that and I don't have any data specifically on that, but it particularly came up around PrEP, we've had young adults come in seeking PrEP but don't want that information on what would be received, so we've seen it anecdotally but I don't have any data on it.

LAURA CHEEVER: The thing that I would add is that I think where you can—the people that are further ahead than we working on HIV are the STD people, people that treat STDs I think have done a lot of work and thought in that area, and I would turn to them to see what kind of data there are.

JEN KATES: Other question about, will we ever get to 0-percent uninsured in the United States. Anybody?

JOHN CARLO: I will say this before, I think we've seen some movement and some improvement even in the non-Medicaid expansion states such as Texas. We've actually noticed our number of insured patients and clients has increased by about 10-percent over the last three years.

It's actually not because of exchange plans, so we have very few clients on exchange plans. What I think's happening is because the economy is improving in Dallas, people are healthier, people are working, there's more employee based coverage, so that there is more affordable options out there for

I don't necessarily look into the future and say that we would achieve 0-percent but I'd certainly like to get less than the 39-percent that we're currently faced in Dallas, Texas.

TIM WESTMORELAND: I would say, I doubt that we'll ever get technically to zero. First of all, and most obviously, because the federal and state systems both treat immigrants very badly and as long as we have a substantial immigrant population, both legal immigrants during their five-year ban, and undocumented people who will always be treated badly by the statute under as they exist, we're going to have a substantial uninsured problem.

Secondly having said that, I don't think it's bad to aspire to that. For that, I would point you towards our coverage for children. We have made remarkable progress in reaching almost zero uninsured children for eligibility.

It's always a problem between Medicaid and CHIP and private health insurance, almost all children in America, except the immigrants should have some access to insurance.

It's a problem to get everybody who is eligible enrolled, but we've made remarkable progress when we put our mind to it and gotten our country together around health care for children. I think we can aspire to it for everyone.

JOHN CARLO: Yes, I've got two, I'm glad you asked that. The first one, one of the things we noticed and I think it's a gap, is during the open enrollment period, the health plans were very in transition in terms of what their provider networks are going to be. If you're a consumer, and you're going on the network exchange and you're looking for whether or not your doctor is in the plan, they're saying, well we're not—we don't have all that up.

There's a gap there in terms of health plans having accurate provider directories during the time of open enrollment. I mean that just makes sense, right?

The consumer needs to have the accurate information. The second thing is, the reason we have not been able to get into the networks, and what they are telling us, the little sort of dirty little secret is this; they only want to work with primary care providers that are affiliated with the hospitals that in their network.

They're not telling us this when we're calling, but when we finally get to the bottom of the health plans they're saying, because you're only privileged to this hospital we don't want to work with you because we don't want you to refer to an out of network hospital, right? Which makes sense.

we can encourage our hospital systems, which most of them are nonprofit, to taking exchange plans and not dragging their feet on getting into these networks.

JEN KATES: I don't know Laura, if you want to add anything about Ryan White's role, but a lot of what we're hearing is not a Ryan White problem, it's much bigger than that. Anything on the essential community providers that the federal government can remind…—

LAURA CHEEVER: I think we can continue to try to improve, even making sure that everyone that's in the Ryan White program is listed in that essential community provider list and making sure that list is up to date and accurate, as different insurers are coming to look at that list and who's on that list. That's something that we've done a lot of work with in the last couple of years.

JEN KATES: I think here's one last question about this issue of states going beyond and having very high levels of eligibility for Medicaid, will that implicate quality?

LAURA CHEEVER: I think the important issue there really gets back to one of the studies that was published last year, with the Medical Monitoring Project data, is that if a clinic is receiving Ryan White funds, they have lots of other services

Medicaid is paying for their doctor and the medications and their labs, Ryan White is doing a lot of other things during that patient visit and for that patient.

On the other hand, if someone's in a particular part of Medicaid managed care where they have to go to a certain provider that is not really affiliated with Ryan White, doesn't know how to make those referrals and connections in the community then, I do think that they're not going to have those benefits that they currently get by going to a provider that takes both Medicaid and has both Ryan White funds and services available. So I think that's the key, is really as individuals are getting different types of insurance, I think you brought this up too, that they need to be cognizant in a way that they're not right now, about what are the services that are going to be available at that particular site that could help support me beyond just getting a prescription from a clinician which is like the bottom rung of access to care.

JEN KATES: Shandora, this is what you were saying you were concerned about if you do—are able to secure coverage, wanting to make sure that Ryan White is still in place.

I think we have time for maybe two other questions, one here and one here. We'll do three because we neglected that

ask is this; is there no way the federal government or the state government can get the price of AIDS or HIV related medication so low that it could still be on Ryan White and still be able to afford the other medications?

STEPHANIE SLOWLY: Good morning, I'm Stephanie Slowly, I work with Maryland State ADAP. My question is, where is the intersection in terms of care? When you have someone enrolling into an ACA, it kind of piggybacks on this question where you have a client who is wanting to get case management or now has to go on to their health plan, and what they consider to be case management is not Ryan White case management.

That's just one example and how that really can be a barrier in itself, so we're advocating and telling clients to get into this ACA program than the services, kind of speaking to what you were saying is not fulfilling all of their needs, and then that becoming a deterrent.

Do we foresee or the panelists foresee a way that we can have the insurances adopt more of the Ryan White model, not exactly the same but more of a Ryan White model to meet this comprehensive needs of the client?

JEN KATES: Good question.

ANIL PANDYA: I'm Anil Pandya from the Health Council of

As the longevity increases with—and the viral suppression has been increased, it seems like the chronic conditions are certainly one of the primary concerns. I know the Ryan White Care Act allows for the provision of medical services for HIV related conditions, I would just like to hear your, basically your take on the interpretation of that term, while being a proponent of a more broad interpretation in the spirit of whole health as the epidemic has sort of evolved over the years?

JEN KATES: One last question, but then we're going to have quick answers.

STACEY FALARDEAU: I'm Stacey from the Cystic Fibrosis Foundation and we're interested in hearing what you have to say today because there's a lot of intersection, we have high Medicaid population. About half of our patients are served by Medicaid or public programs and we have some really expensive drugs. In my previous life, I was at a national plan so I know that HIV drugs are increasingly being reclassified as specialty therapies. I was just wondering if this is impacting patient's coverage decisions? And also, what strategies are being considered to deal with this?

JEN KATES: Wow, these are big questions. We'll do

wants to start with drug pricing or tiering? I'm looking at Tim.

TIM WESTMORELAND: I can't answer it quickly. I mean it's a problem not just for people with HIV but for people in all kinds of diagnosis with the advent of new treatments, as you suggest, it's a problem with a lot of other situations as well. It's a problem not just for the Ryan White Program or the Medicaid program, it's a problem for Medicare and private insurers. We should have another discussion on the topic.

JEN KATES: In short, there's no standard pricing across even government programs and driving them lower is very hard, yes. On the tiering, anybody want to take that?

JOHN CARLO: We see this, it is a challenge. I think we've recognized it, we'd need another panel discussion to even go into all of that. The problems I see is how fluid it is, how much it changes even in your plan here, it's just—it's a disservice to the consumer.

JEN KATES: Really quickly, and Carl from The AIDS Institute, who is here, and Lindsey on my team did some work on this as well. This has been an issue that's been brought to the attention of the federal government and states. On a state level, there's been progress in saying that that practice is

but it is an ongoing issue. It would have direct implication for the population you're talking about for sure. Case management? I think the question was around getting different—getting less than Ryan White case management?

LAURA CHEEVER: I don't have an answer to the question of how do we get insurers to move to that, because that is something that's definitively not been covered by insurance. I think as we look for value-based financing, in that you need to look at good outcomes, then that I think will put insurers away because case management is critically important to very vulnerable populations.

Once again, we talked about payer of last resort, but if a patient enters a Medicaid managed care program, where they have what they call case management, which is one case management for 5000 clients, that is not the same as what we talked about in Ryan White in terms of intensive case management.

Certainly someone could be receiving case management as a covered service under Medicaid and still be getting case management through Ryan White because those are two very different and distinct services. As long as that can be well articulated, I don’t think you have a payer of last resort

getting a different type of case management, really a completely different type of service through their insurance.

JEN KATES: Do you want to answer me on that?

JOHN CARLO: You know, and this is something where I actually do see an opportunity because we are familiar with case management and how effective it can be. We sat down with the health plan, presented them this exact concept that, you know, the whole health concept, the medical home concept, they actually did their homework so they knew exactly how much we cost, compared the private practice offices and they were very, very happy to talk to us. We're at lot less in terms of what our costs are. I think that there is some opportunities that are right here. We just have to think about the strategy, about how we effectively implement and really sell what we offer to the health plans.

JEN KATES: I think this relates to question over here around how broadly Ryan White can be interpreted to support whole health. I think you already kind of touched on it, can pay for co-pays and premiums for health insurance, that would obviously provide a broader set of services.

LAURA CHEEVER: When we look at some HIV related services, given that HIV causes inflammation, which causes

sort of happens at a state and local level, depending on resources available, and what they think they can cover. As a systemic disease, it can be quite broad.

JEN KATES: Clearly we could have a few other panels on some of these issues, maybe we will. I'm going to actually ask Shandora to maybe say one last thing, which is—because someone had said, wow, I wish we could get you on the Hill, to talk about what you would say about Ryan White and after today, and thinking, what would you say if we say right now we're going to do it. No, we're not going to take you, just what would be the message you would want to bring about your experience?

SHANDORA LANE: My experience? I want to understand the question right.

JEN KATES: The importance of Ryan White in your life?

SHANDORA LANE: I've done said it, I love Ryan White. You can put my face on a billboard with Ryan White, and the benefits that it has given me, we talked about the safety net, I am so safe with Ryan White. Ryan White covers all of my HIV related issues. From my wonderful relationship with my doctor, also talk about the copay, I have to go have mammograms that I just present a Ryan White letter and the copay is taken care of.

My case management, you know it's covered through Ryan

As far as what I can do within my schedule, with my doctor's appointment, copays, case management, all of that, Ryan White fulfills. That's what you know—to be all honest, I don't push myself like I need to afford the marketplace, because Ryan White got me covered with those needs, you know?

Just venturing with the marketplace, which I'm going to process and I'm going to pursue more diligently, but it's just that fear in the back of my neck that I just don't want to lose Ryan White, this is my comfort zone. It has taken care of Shandora for 26 years almost. Outside of the little time with Medicaid, on and off with Ryan White for the last seven years, fully dependent and reliant on Ryan White.

Yes, I am eternally grateful to have Ryan White dealing with—and it has given me the opportunity to be up here, because never once without the Ryan White care would I be able to speak to anyone. Because I am one of those that I don't want to go to—didn't want to go to certain pharmacies, I would go 30 miles away to get my medication at one time because of the stigma. Because of working with Ryan White and case management it has given me an opportunity to speak out, to be more boastful about what's going on with Shandora, yes, I am HIV positive.

HIV is part of my life, so to deal with me, you're

know, the educational part and that comes through Ryan White. Yes, I do thank you.

JEN KATES: Thank you. I actually can't think of something better to end on, so please, once again, just thank our panelists and you for being here.

[END RECORDING]