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# The ACA and People with HIV: An Update

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## Summary

The Affordable Care Act (ACA) provides new health insurance coverage opportunities and extends non-discrimination protections to millions of individuals, including people with HIV. Greater access to insurance coverage has the potential to improve continuous access to care and treatment for people with HIV which can positively impact individual health outcomes and reduced the risk of HIV transmission.<sup>1,2</sup> Therefore, as the major coverage reforms under the ACA are implemented, it is important to monitor how people with HIV are impacted. To provide greater insight into what the ACA has meant for this population, focus groups were conducted with HIV positive individuals in five states – California, Florida, Georgia, New York, and Texas – in the Summer and Fall of 2014. These groups provided an early look at how people with HIV were experiencing care under the ACA. As a follow-up, this report provides a second look at how the ACA is impacting people with HIV two years into these new coverage opportunities, based on focus groups conducted with HIV positive individuals from the same states in early 2016, after the third round of open enrollment. Groups were conducted with HIV positive individuals who gained insurance coverage – through either the Marketplaces or Medicaid expansion- in California and New York and with those who remained uninsured, largely because they fell into the coverage gap, in Florida, Georgia, and Texas.

Key findings include:

- While in 2014, participants who gained insurance coverage were still in the early stages of figuring out how to use it, insured participants in this round of research reported using their coverage regularly to meet their HIV care and treatment needs. They reported that their health is easier to manage as a result of gaining coverage and appear better able to navigate using insurance than their 2014 counterparts. They have found relief and security in becoming covered.
- Still, despite some increased comfort with coverage, participants remain unsure of how to fully assess plan options and, as in 2014, put a lot of trust in case managers to help make enrollment decisions. They continue to lack some basic insurance literacy but unique to this round of research, many participants across the sites knew that access to health care varied across the country.
- Those with insurance recognized its benefits but some worry about being able to maintain coverage. Those with private insurance worry about costs and those with Medicaid find recertification stressful.
- Only a few participants have made changes to their plans since first enrolling. One individual switched to a different metal level plan by choice and was unexpectedly met with higher costs and two others were moved into new coverage automatically.

- As was found in the 2014 groups, those who live in non-Medicaid expansion states and remain uninsured, largely because they fall into the coverage gap, feel that they can meet their HIV care and treatment needs through the Ryan White Program, which they say is lifesaving, but have many other health problems that are going unaddressed. When they learn that their state chose not to expand Medicaid, they are dismayed but not surprised. Almost all say if their state later expanded the program they would enroll, especially those who have past experience with Medicaid coverage.
- More than gaining insurance, most report that their finances are the biggest stress in their lives; they struggle to make ends meet and many face substantial medical debt.
- Just as in 2014, many respondents report close relationships with their HIV providers. They say having a provider who is a specialist and who has a consistent role in their lives is important and in seeking out new coverage many prioritize being able to maintain these relationships. Choice in pharmacies was also important with respondents identifying a range of preferences regarding how they get their medications.
- The Ryan White Program continues to provide a crucial role in the lives of almost all the participants, especially the uninsured. Ryan White clients were enormously grateful for the program but like Medicaid enrollees, faced challenges around recertification time. Unlike in 2014, those who have gained coverage tend to be less aware they are still connected to the program despite reporting using support services like case management that are funded by Ryan White.

## Introduction and Background

The Affordable Care Act (ACA), signed into law in 2010, aims to expand access to affordable health insurance to millions of Americans, including those with HIV, providing new coverage options, non-discrimination protections, and eliminating other barriers to care. For people with HIV, these pathways to coverage and protections have particular importance given that many faced exclusions and other discriminatory hurdles in gaining individual health insurance in the pre-ACA era. Provisions with an especially significant impact include: the creation of health insurance Marketplaces in each state where individuals can purchase private insurance with subsidies available to those with low and moderate incomes; the ability for states to expand their Medicaid programs to cover individuals based on income alone<sup>3</sup>; and prohibitions on discriminatory market practices such as rate setting based on health status, preexisting condition exclusions, and use of annual and lifetime coverage limits. Improving access to and engagement with health care for those with HIV is important to both individual and public health because continuous access to quality HIV care and treatment improves the health and longevity of those who are infected and also reduces the risk of HIV transmission.<sup>4</sup> However, despite the potential offered by the ACA, some with HIV have remained uninsured, often because they are ineligible for coverage or available options are unaffordable. Additionally, some will have HIV care needs that go beyond what is provided through traditional insurance. For these individuals, the Ryan White HIV/AIDS Program, the nation's HIV care safety net, remains a critical resource.

In order to explore how those with HIV were impacted by initial coverage changes under the ACA, we conducted focus groups with HIV positive individuals after the close of the first open enrollment period in the Summer and Fall of 2014.<sup>5</sup> The groups were conducted in five states --California, Florida, Georgia, New York,

and Texas--which together represent half of all people estimated to be living with HIV in the United States and reflect different state level approaches to ACA implementation.<sup>6</sup> Two of the states – California and New York – expanded their Medicaid programs while the remaining three - Florida, Georgia, and Texas – did not. In addition, California and New York run their own health insurance Marketplaces while Florida, Georgia and Texas rely on the federally-facilitated Marketplace. Within these states, focus groups were conducted in the cities of Los Angeles, Miami, Atlanta, New York City, and Dallas.

The 2014 groups occurred at a time when coverage opportunities were new and enrollees, as well as those working within health care delivery, were only just becoming familiar with navigating the systems and doing so after Marketplaces initially struggled to operate as planned. The [resulting report](#) provided a first look at how people with HIV were accessing and using new insurance and at the experiences of those who remained uninsured. As a follow-up, in February 2016, after the third open enrollment period, we returned to the same sites to conduct a second round of focus groups to see whether and how experiences with coverage had changed since the early rollout. In three states (Florida, Georgia, and Texas), focus groups included those who remained uninsured, falling below 139% of the federal poverty level (FPL). Because these states have not expanded Medicaid, many of these focus group participants were caught in the “coverage gap,” that is they lived in states that did not expand Medicaid and had incomes below 100% of the poverty level, leaving them ineligible for Medicaid and Marketplace subsidies, with limited coverage options. In two states (California and New York), focus groups consisted of those who gained coverage through either the Marketplace or through their state’s Medicaid expansion. This report identifies key findings from the 2016 research and makes comparisons to the 2014 groups. It is organized around the main themes that emerged from the focus groups. (See Appendix for detailed Methodology).

**Table 1. Focus Group Site Details**

City	Date	Composition
Miami, FL	February 18, 2016	Uninsured, Under 139% FPL
New York City, NY	February 22, 2016	Marketplace and Medicaid Expansion Enrollees
Dallas, TX	February 24, 2016	Uninsured, Under 139% FPL
Los Angeles, CA	February 25, 2016	Marketplace and Medicaid Expansion Enrollees
Atlanta, GA	February 29, 2016	Uninsured, Under 139% FPL

## Findings

### KNOWLEDGE OF THE ACA AND INSURANCE COVERAGE

Understanding insurance coverage options and how to select an affordable plan that meets health care needs is essential to any enrollee but especially for those with HIV. For people with HIV finding a plan with benefits that promote engagement in care and treatment is a medical necessity. Yet, even two years into the ACA, as found in 2014, many still do not have basic insurance literacy that would help them identify coverage options best suited to support them. At the same time, focus group participants expressed an awareness of the variability in access to HIV care across the country, not expressed by those in 2014.

**While some participants seemed to have a better basic understanding of ACA coverage opportunities compared to the 2014 groups, most still lacked any detailed knowledge about**

**what it meant for them.** For instance, some of the uninsured knew that they would not be penalized for being without coverage and some had heard of states making different decisions around Medicaid expansion. Yet, many remained confused about their eligibility for ACA coverage and for pre-ACA Medicaid based on disability. Those exploring coverage were often overwhelmed about their options and lacked the insurance literacy to make well informed decisions. One Marketplace enrollee in New York remarked “I’m still not quite sure if I understand when they talk about out-of-pocket, what does that mean actually mean?” For some, this lack of knowledge about the law and coverage options created a significant barrier to gaining insurance. For one uninsured Georgia man, for example, it meant that he was paying higher out-of-pocket costs as a result of being uninsured than he would if he had purchased coverage. He is paying \$2,000-\$3,000 out-of-pocket each month for his non-HIV medications: blood thinners, thyroid pills and high blood pressure pills. In addition, he has bills from a recent hospitalization. Nobody had explained to him that it would be less expensive for him to purchase high quality Marketplace coverage despite not qualifying for a subsidy than to continue to pay cash prices for his medications. He says that he is “living month-to-month,” that he can only just afford what he is paying now, and that money is “very tight.” Others still said they know “nothing; zip” about the ACA saying “I have no clue” about the law.

**Despite the lack of knowledge about the ACA and its options, there was a fair amount of understanding that access to care for those with HIV varied across the country.** It was specifically noted by participants that those in New York and California have particular good access to care, including by those not from these states. California and New York participants were grateful for their access while those outside of these states pointed to the disparity, saying they knew HIV positive people in other locations received better access to care and coverage. In fact, one participant in the New York group had recently moved to the state from Georgia, specifically to gain access to better health coverage despite knowing nobody in New York. He believed that the AIDS Drug Assistance Program (ADAP), the component of the Ryan White Program that provides access to HIV treatment, in Georgia did not provide quality access and he lacked the ability to get coverage there. While he qualified for a tax credit, he said the premium in Georgia would have been unaffordable to him at \$208/month. In New York he was eligible for and enrolled in Medicaid and he is very grateful. He says “if you are HIV positive, New York is the state for you.”

*“When it comes to being HIV positive, I guess we live in a part of the country that [has] so many options available for people that have our condition, unlike other parts of the country...So now that I have Medi-Cal [California’s Medicaid Program] I feel grateful, I can choose whoever I want and there is no problem. [I’m not thinking] in the back of my mind, ‘oh I need to pay this...I need to pay this company.’ I’m not facing this burden.” – Los Angeles Medicaid Enrollee*

## ENROLLMENT & PLAN SELECTION

Focus group participants who gained Medicaid and Marketplace coverage under the ACA were asked to discuss their reasons for enrolling and their experiences doing so. Those who remained uninsured were asked if they had ever attempted to enroll in coverage. Conversations also focused on the reasons enrollees had for selecting the plans they did. After three open enrollment periods, confusion about enrollment remains, yet overall the process was smoother for most than for those in the 2014 groups.

**Respondents reported first enrolling in coverage at different times over the past few years.**

While some had gained coverage more recently, a few New York Medicaid enrollees had enrolled into New York's early expansion of the program in 2013 which was put in place prior to the ACA in an attempt to smooth the transition to coverage. As intended by the early expansion, these enrollees did not seem to notice a difference as they technically rolled over into the expansion population.

**Focus group participants who gained new coverage reported a variety of reasons for enrolling, often citing the coverage mandate and desire to avoid a penalty as key factors.** Compared to those in the first round of focus groups in 2014, more participants cited the coverage mandate or avoiding the penalty as reasons for enrolling. This may reflect the fact that in 2014, the penalty was waived for those that did not gain coverage but by 2016 the penalty had increased to \$695 or 2.5% of one's income, whichever is greater. Respondents also more commonly reported enrolling at the urging of family members, case managers or social workers, who sometimes explained the legal requirements around coverage and sometimes highlighted the health benefits. One marketplace enrollee from Los Angeles who initially said he enrolled to avoid paying the penalty, says he now feels grateful for his coverage, despite finding the enrollment process itself a little confusing.

*"Well my social worker told me that, you know it was mandatory and yeah, that's why I enrolled" – Atlanta uninsured participant who initially enrolled before learning he could not get assistance with premiums*

*"When I moved back to the city from college I didn't have insurance from college anymore and I wasn't making that much money so I needed to get insured just God forbid, something happens and since I wasn't making much money like my family was saying you should sign up for Medicaid." – New York City Medicaid Enrollee*  
*up and there were like three people helping me." – Los Angeles Marketplace Enrollee*

**Many of those who remain uninsured looked into getting care through avenues created by the ACA but were either told they did not qualify or felt it was too expensive.** Some went to Healthcare.gov on their own, but most had help from a social worker or their case manager. A few say they got to the point of seeing different plans and prices but felt none of the options were affordable. In some cases seemingly eligible respondents believed they were "denied" Marketplace coverage which means they were either given misinformation or misunderstood Marketplace eligibility. However, in most of these cases it would be true that they were ineligible for subsidies which could help them to afford coverage. One man in Miami reported he was (incorrectly) told by the Marketplace that he did not need to enroll because he had HIV and was already covered by Ryan White. Another man in Dallas says his doctor told him the ACA did not affect him, so he should not bother looking into it. One individual explored options, but did so too late, after the close of open enrollment. An Atlanta man had hoped he could get premium assistance through ADAP or through the county, a function Ryan White programs can provide beyond assisting with direct drug access, but was disappointed to learn he was ineligible because he did not meet a minimum income threshold so he did not enroll in coverage. One respondent said he asked a Marketplace representative what plan would be good for someone with HIV and was told the representative would get back to him but after never hearing back, he did not further pursue looking for coverage. Many of the situations described above depict an individual who made



the one effort to enroll or explore options but never did so again, suggesting there might be a very small window when consumers can be engaged in coverage, that the first point of contact with the system matters, and that those who remain uninsured may need a significant push to explore options a second time.

*“The first time I tried it and I did they denied me for Obamacare. I never tried again so...” – Miami uninsured*

In addition, a few participants were ineligible for coverage because they are recent or undocumented residents. A few say they felt looking into coverage was unnecessary while they have Ryan White. A couple of other respondents may have been eligible for Medicaid based on disability but they had either been denied coverage and had not explored that denial further or did not understand that they are potentially eligible and had yet to investigate the option.

**Most focus group participants received help enrolling in coverage.** Participants sought out assistance from counselors within their clinics, assistants outside of their clinics, brokers, and through the 1-800 numbers for the Marketplaces. Similar to the participants in the 2014 groups, many respondents reported putting a lot of trust in case managers during the enrollment process. As discussed below, case managers played an important role in demystifying the enrollment process for those who were. While participants were grateful when they had assistance from a case manager, some reported that they were not personally very involved with the selection of coverage, saying that plans were essentially selected for them

*“I got a [booklet of plan options in the mail] and I was like I don’t know what the hell this is all about. [So my case manager said], ‘Let me figure out what’s best for you,’ [So] he looked at my medical history and stuff and said, ‘This one’s probably the best for you.’” – Los Angeles Medicaid Enrollee*

**Even after three open enrollment periods, confusion continues.** Several respondents with both Medicaid and Marketplace coverage said that enrollment paperwork was confusing, overwhelming, and burdensome. Problems seemed to be especially apparent for California Medicaid enrollees. One California Medicaid enrollee first went to the state office to enroll but described the scene as worse than the DMV; for recertification he now works with a case manager. He also says he submitted the full packet of paperwork to Medicaid, much of which he said was redundant, to be told later he was missing a page that he knew was turned in. Another California man took three appointments to sign-up for Medicaid but despite this, reported enrollment was not too difficult for him. A Medicaid enrollee in New York felt overwhelmed by the process so went through the basic enrollment steps but let Medicaid auto-enroll him in a plan which was he was okay with but he was frustrated that once assigned to a provider, he did not receive that providers address. Some who were confused by enrollment packets and other documents they received in the mail brought their packages into their clinics to get help sorting through the paperwork and enrolling.

*“But when they was talking about [enrolling in Medicaid] and you know you [are] picking insurance plan I was too busy doing other things. So as long as I had something, whatever it was they sent me, it didn’t matter to me. ...when they gave it to me they chose my doctor and it’s like everything that they chose for me you know you [they would] send me a doctor’s name with his phone number but ... no address...it was confusing.” – Los Angeles Marketplace Enrollee*

A further source of enrollment anxiety for some was not knowing how to report information accurately. One California Marketplace enrollee reported feeling anxious about how to report a fluctuating income. He said his tax return from last year reported his income as one amount but that it was not reflective of his current situation. Another issue that presented a challenge for one individual is that they learned they would not be able to select their own provider as a primary when enrolling and were instructed by their clinic to instead identify the clinical supervisor when they enrolled.

*“... And you know when people ask about financial information because I’ve gone through periods of making money and then making no money and being unemployed; and it’s hard to like communicate that because they look at a number. You know maybe it’s your last tax return and the reality of it is, is you’re sitting there with no income. So I had some anxiety about that and also choosing the right plans.” —Los Angeles Marketplace Enrollee*

**Other respondents however found enrolling in Marketplace coverage and Medicaid fairly straightforward.** These individuals were able to handle it on their own or said that using a case manager made things easy. Potentially contributing to this perspective, unlike in the 2014 focus groups, there were no reports about dysfunctional websites, problems with logging onto the marketplace itself, or lengthy waits to get through to Marketplaces assistance. One New York participant with Medicaid who handled enrollment himself said “I thought it was pretty okay. It seemed pretty simple to me.” A California man with Medicaid coverage said with the help of his clinic, enrolling “...was really easy once they had basically the concierge situation where they were giving people somebody to work with.”

**Enrollees also had different experiences with the length of time it took to enroll in coverage.** While some enrolled fairly quickly, it took others several months. At the extreme end, one individual in Los Angeles received contradictory information about his eligibility and it ultimately took him about six months to enroll in Medicaid coverage. At first he was worried about maintaining his HIV treatment and says he was “freaking out” but his case manager reassured him he could stay on ADAP until his coverage transition was complete.

**Participants had different reasons for selecting the plan they did.** An individual in New York reported selecting a Medicaid plan based on its rating on the state Marketplace which simplified an otherwise complicated decision. Some looked at costs but many felt that it was difficult to fully understand what out-of-pocket expenses might look like. One Los Angeles man said that co-insurance made understanding costs in actual dollar terms particularly confusing. When enrolled in a plan with premium assistance through ADAP a New York individual said that while he had no out-of-pocket expenses, he selected a plan based on cost-sharing in case later on ADAP was unable to help or he forgot to recertify and lost ADAP assistance. Many prioritized ensuring they could stay with their providers with whom they had developed long term relationships and trusted or wanted to be able to stay on their treatment regimens. Others selected a plan from an issuer that they had positive experiences with in the past and several followed case manager recommendations.

**Only a few participants reported changing their coverage over the course of the different open enrollment periods once they became insured.** One participant from Los Angeles initially chose a

platinum plan but felt like the premiums were too high so he switched to a gold plan. He has been disappointed to find that he has not found relief and as a result of new higher out-of-pocket costs, he has put off some follow-up care. Another participant recently found out he was no longer going to be able to stay on his Medicaid plan, presumably because the plan was pulling out of the market. He had just selected a new plan with the help of his clinic but had not yet started using it at the time of the group. He said this change was confusing to him and he was unsure of why he could not keep his previous coverage but just knew it was being terminated.

*“Now I'm with the Gold Plan, but it costs as much as the Platinum Plan. Instead of \$40 it's \$50 [to see a provider]. So...I'm reluctant to maybe...like the doctor says, “That's okay, everything looks good, why don't you see me in you know three months.” Sometimes I won't do that because I'm feeling fine and I don't want to pay the 50 bucks. So those...that seems kind of ironic that I'm paying as much as I'm paying on a monthly basis.” —Los Angeles Marketplace Enrollee*

One New York participant reported experiencing “churning” through various insurance programs. He has gone from being a Medicaid enrollee to being a Marketplace enrollee to now being enrolled in New York's Essential Plan, coverage offered in New York for those with low incomes but ineligible for Medicaid.<sup>7</sup> In addition, he has received ADAP assistance from the Ryan White Program to help with costs associated with coverage in both the Marketplace plan and now in the Essential Plan. With the exception of a one month lapse and a pharmacy change, he reports that the transitions between programs have been okay.

#### Stories from the Field

A 25 year old man from New York lost his college based insurance coverage after graduating and enrolled in Medicaid at his family's encouragement. He also personally thought it would be good have coverage in case something happened to him. He enrolled into a Medicaid plan through New York's early expansion of the program in 2013. In 2014 he found a job and reported this change to the Marketplace which he remembered he had been told to do. In doing this he learned that he was no longer eligible for Medicaid but qualified for a Marketplace plan with a subsidy. He navigated the transition on his own and says the process was simple – he filled out an enrollment form online and was able to compare different plans. He was able to find a silver level Marketplace plan by the same issuer as his previous Medicaid plan. He thought this was positive since he had been happy with the coverage and believed his doctor would accept the new plan as well. He then enrolled in ADAP insurance assistance to get help with premiums and out-of-pocket costs. The plan he selected was \$480 a month from which a \$250 monthly tax credited was deducted. ADAP covered the remainder of the premium and other out-of-pocket costs. In late 2015, he lost his job and he reported this to the Marketplace. After reporting this job loss, he was enrolled into the state's Essential Plan (again with same issuer) which is a New York state coverage option for individuals with low incomes that exceed the Medicaid eligibility limit. He says that while for the most part each of these transitions have been relatively easy to manage, the move to the Essential Plan caused a month lapse in coverage when his old plan had been cancelled but his new plan had not yet been activated. He had some anxiety that something like this might happen but was not overly concerned as he had his medication for the month and did not have any scheduled doctor's appointments but says “thank God... I didn't break a leg or



something.” He says he did get a cold that he had to treat himself when he did not have coverage. In addition, he had to change his pharmacy but he did not mind this adjustment since he now uses a national chain with many locations and the ability to get home delivery, which he prefers. While he says the \$20 monthly premium for the Essential Plan would be manageable for him, ADAP covers the cost. He says that he hopes to have a job soon, and in fact had an interview the day of the focus group, and knows that ADAP support for Marketplace coverage, which he anticipates rejoining, will be essential. “When I do get a new job, which hopefully is soon, I know they’re gonna change me to a different plan so I’ll have to choose like a silver or platinum...and I’m sure I’m not gonna be able to pay that premium and so ADAP will pay it, which is very helpful.”

Still, most participants indicated they remained enrolled in the same plan they had first selected. One possible reason few have changed coverage in the last few years is that comparing plans during a renewal period remained confusing. In addition, few reported seeing any significant changes to their plans, though one privately insured individual did say his premiums has been creeping up.

## EXPERIENCES GAINING COVERAGE (NEW YORK AND CALIFORNIA PARTICIPANTS)

Focus group participants in New York and California gained insurance as a result of the ACA. Some had enrolled in Medicaid through the expansion of the program and others enrolled in a plan in their state’s Marketplace. While there were some challenges, most participants reported positive experiences with new coverage noting they could meet both their HIV and non-HIV health needs. Compared to the participants in the 2014 groups, these individuals appeared to have become more comfortable navigating their coverage despite some continued insurance literacy gaps. Those who gained Medicaid coverage report general satisfaction but say that recertification is a particularly stressful time, something that 2014 participants had not yet experienced at the time of those groups.

**Most of those who gained coverage had been uninsured for several years.** Some said that they had insurance on and off before gaining ACA era coverage. A few Medicaid enrollees had not had insurance since they were children and some had been without coverage for well over a decade. One California participant who manages an art gallery points out that the type of work he does typically doesn’t offer coverage so was grateful to be able to get it under the ACA through the Marketplace.

**As with the 2014 groups, those who gained insurance coverage through Medicaid and the Marketplaces are generally very grateful and report feeling more secure.** However, because coverage was so new for participants in 2014 this feeling was more theoretical for those groups whereas now the feeling of security appeared based on actual experiences with insurance coverage. This coverage makes them feel more secure, less worried about bills, less stressed, and more independent. They worry less about what will happen to them in case of a serious accident and realize they can use emergency care with less concern about high bills and significant debt. Some participants report that if they were not insured they would be in worse health, including some who said they would likely be dead. Those with Medicaid in particular say they feel lucky. One woman now covered by the program spoke about using other people’s insurance cards to see a doctor in the past, an action that made her feel badly about herself. She is glad to have her own coverage and feels she can honorably access care. Others report feeling that they are treated more respectfully having

coverage and see coverage as opening up care opportunities. A California Medicaid enrollee had been uninsured and receiving health care from a community clinic through the Ryan White Program before enrolling. He thought the clinic was overcrowded and he felt as though he was treated like a number. After enrolling in a private plan, he changed doctors, describing the experience as “a Godsend.” His doctor is now closer to his home, and he feels she takes the time to get to know him as a person. He also had to switch pharmacies, which he saw as a positive change – his new pharmacy is close to home and open twenty-four hours a day. He says his health is easier to manage now that he has private coverage and he cannot imagine losing it.

*“It makes me feel like I'm safe if something's wrong with me or a pain come up somewhere I can go to the doctor. I don't have to worry about the bill.” – New York City Medicaid Enrollee*

*“Blessed. I feel blessed. You know because I can honestly say if I didn't have health insurance and I'm HIV positive, the meds would be like forget about it; going to the doctor, you can forget about it...” - New York City Medicaid Enrollee*

*“[With] private insurance, I felt I was treated differently. I didn't have to go to the emergency room and wait. I called my doctor and she said, ‘Meet me in the emergency room,’ and I showed up and she showed*

**Those in Marketplace plans with out-of-pocket costs report they are a challenge to afford. They prioritize having coverage at the expense of other things but wish these expenses were lower; they worry about maintaining coverage in the future.** Those with marketplace coverage in Los Angeles for example say having health insurance gives them a sense of relief and security, but they wish it were more affordable and they worry about cost increases in the future. Indicating that their health care costs represent a large part of their monthly budget – about twenty percent –they are putting off care like vision and dental and not taking vacations in order to cover these expenses. One individual receives a tax credit and pays over \$400 a month; another was told his income was too high to qualify for a subsidy and he pays over \$750 a month. Marketplace respondents in California were not accessing premium assistance from ADAP which could potentially have relived some of this stress. One marketplace enrollee would likely not have qualified for assistance in the past given his relatively high income but he has since lost his job. Another enrollee appeared as though he may have qualified for the program but reported only getting ADAP assistance with copayments, not the premiums. They say that the costs they face are bearable but worry about them increasing in the future. Despite the real challenges these costs presented, nobody reported enrolling in truly unaffordable coverage as was the case in 2014 when some participants enrolled in plans with extremely high deductibles. Their struggle facing these out-of-pocket costs contrasts with a New York participant who had premiums covered through ADAP when he had Marketplace coverage which he saw as essential to being able to stay insured. Similarly, these experiences contrast with Medicaid enrollees who face no or very nominal costs and report that coverage is affordable.

**Once enrolled, both those with Marketplace and Medicaid coverage report good access to HIV care and treatment, knowing that maintaining this level of care is essential for being healthy,**

**but express some anxiety about staying enrolled.** In 2014, many who had just gained coverage were not yet fully using their new insurance and were just transitioning off of Ryan White. By 2016, those enrolled in coverage were regularly using that insurance to meet HIV care and treatment needs. Despite this, some worry about maintaining coverage. For Marketplace enrollees this concern is largely centered on costs. Their biggest concerns are around losing their jobs or assistance through ADAP and suddenly being faced with unaffordable costs. Each say if they could not afford or get help paying for their Marketplace plans, they would look into Medicaid coverage. For those with Medicaid, staying on top of recertification creates some stress. One woman in New York had a recertification issue when mail stopped coming to her building for about a month due to the condition of the mailboxes. She missed her recertification notice and became quite panicked when she was told she no longer had coverage at a doctor's visit. While she says she was able to resolve this fairly easily, it caused some stress for her. Another man described a time when he got a Medicaid termination letter in the mail after submitting his paperwork. He says, laughing, that he knows they are backed-up and he ignored it. One individual worries that his clinic's lack of bandwidth may result in lapses in care and coverage if he is unable to work with a case manager to recertify in time. Some also express concerns about program sustainability given political rhetoric threatening the ACA.

*"I mean Democrats want to keep [the ACA]; the Republicans, they want to get rid of it. So it's just, I don't know how it's gonna end." – Los Angeles Medicaid Enrollee*

**Only a few have seen changes in their HIV care as a result of gaining coverage and these are minor. For some these changes have not been a problem.** One individual switched to a generic drug. A few individuals switched providers or pharmacies but reported seeing this as a positive change. One individual reported that their plan required them to get x-rays before an MRI they needed while in the past they would have been able to get an MRI right away with a referral but despite this minor frustration, she says that she has no complaints about her plan.

**Many who have gained coverage feel their health is easier to manage now.** During the 2014 groups many of those with new health coverage had only used their insurance to a limited extent, typically to access HIV drugs. In this round, most participants had been using their coverage for much longer and appeared to be relying on it to access HIV and other health care services regularly. One man says he feels more knowledgeable about his HIV status now that he has an established relationship with his doctor and health center. Another man says it is easier to manage his care now that he does not have to worry about unexpected bills or out-of-pocket costs. A California man explains that his care is more streamlined and that he likes being able to go online to access his health information and communicate with his clinic through the patient porthole. The man who moved from Georgia to New York to gain coverage says things have gotten much better for him since moving to a state where he could enroll in Medicaid. However, one man in Los Angeles says his health is more difficult to manage now than when he was uninsured – he feels the volume of patients and wait times at his clinic have drastically increased since California expanded its Medicaid program and the providers at his clinic are struggling to keep up. He says this increase in volume is having a negative impact on his health as he will avoid going to the doctor unless he is seriously ill.

*"I was not doing well [ when I was living in Georgia]. I wasn't doing well...it was bad. So I've been doing good since I've been up here [to New York]. I get all my medication. I've been doing a lot better." – New York City Medicaid Enrollee*

*"For me it's really been great because I can see all my results online and I order my medications...on the phone...it's very kind of easy and it's very comforting to know that you have access and you can get to your doctor fairly easily." – Los Angeles Medicaid Enrollee*

**A few have put off some health care, but do not see these needs as life threatening or particularly serious.** They are a relatively healthy group – most say their only health care needs are related to their HIV. Still, for the remaining health needs they have, some continue to put off care. One man in Los Angeles says he would like to see a therapist. He says it would be covered by Medicaid, but it takes so long to get an appointment he has not pursued it yet. Another man in Los Angeles with Medicaid has referrals to see a proctologist and a dermatologist but says it has been difficult to secure specialist care appointments. Several now insured participants discuss the continued barriers to dental care which is not always covered by insurance.

## **EXPERIENCES OF THE UNINSURED (FLORIDA, GEORGIA, AND TEXAS)**

Most of the uninsured participants in the focus groups fell into the coverage gap but at least two individuals appeared to be undocumented immigrants and thus unable to access Medicaid and Marketplace coverage for a secondary reason. Participants in these groups had similar stories to those we met in 2014 - they meet their HIV care and treatment needs through Ryan White, which they feel indebted to, but suffer from other health problems that are going unaddressed. They are dismayed by their state's decision not to expand Medicaid and say that if their state policy changed, they would enroll.

**Among the participants who remain uninsured most have had prior coverage experiences, but it was typically many years prior.** For those with past experiences, a few fell out of coverage with the loss of a job and could not afford COBRA. One man who lost his job, and with it his health insurance, says he could not afford COBRA and went about year without treatment once he lost his insurance. He says he went through a phase of depression as a result saying he had been diagnosed with HIV for eleven years at the time and had "always kept up on everything" in the past when he was covered. One person said they could just no longer afford to pay their premiums. Several of those who are now uninsured had prior experience with Medicaid despite living in non-expansion states. A few reported that they had Medicaid as children, while pregnant, as a parent when their children were young, or when they lived in another state. All who had previous experience with Medicaid have a positive view of the program and would be interested in reenrolling, if they were able. They were particularly upset to learn that they were unable to re-enroll because their state had not expanded the program. One man in Atlanta spoke of the downward spiral that occurred as his children became adults and he lost Medicaid eligibility. While most respondents say they have had an insurance source at some point in the past, a few say they have never had coverage, including one homeless man in Florida.

### Stories from the Field

A forty year old uninsured single father from Georgia had Medicaid coverage when his children were younger and lived at home. He is originally from Kentucky and trained as a Certified Technical Medical Assistant but is not working at the moment. He was comfortable with the care and treatment he received through Medicaid and felt able to meet all of his HIV care needs. During that time, he was not enrolled in Ryan White and had never heard of the program. He did not realize that he would lose Medicaid coverage when his children turned 18 and only found out he had been terminated from the program when he started receiving bills for his HIV care in the mail. He describes being cut-off from the program and losing HIV and mental health treatment and services as a traumatic experience. His health quickly declined and he describes a depression associated with this loss in services. He was without care for seven months and eventually stopped working because his health was so poor, saying his T cell count quickly plummeted without access to HIV treatment. Nobody at his clinic prepared him for this loss in coverage or eased a transition into the Ryan White Program. He received calls that he had missed appointments but nobody at his clinic tried to re-engage him in care. He found out about Ryan White on his own doing research online and went to a separate HIV service organization to get more information and to enroll. Once enrolled he was able to start receiving care again at his old clinic and get HIV medication through ADAP. In addition, his case manager recently found an assistance program to get him access medication for his depression which he has been off for a year. At the time of the focus group, he was planning to get his first dose the next day and was looking forward to his depression lifting. He says he is feeling a little better about things but he doesn't "know the security behind" Ryan White and that "kind of scares" him. He has a pending case with Medicaid trying to get coverage as a result of disability and says if he could get Medicaid again he would be relieved "because [with it] I was able to stay on top of my health. I didn't have to worry about different funding running out. I was able to work, go to school and me just being focused and everything was fine."

**Almost all uninsured participants say their finances are the biggest causes of stress in their lives.** Most are unemployed, struggling to make ends meet and just barely getting by month-to-month. Many have budgets where just meeting the bare necessities exceeds their incomes (see examples below). One individual is homeless and others are living with family. They worry about finding work, their finances, and are trying to establish greater independence. Some are struggling with trying to stay sober which can get in the way of these plans. Others struggle with transportation needs, food security, child support, and debt (including medical, bank and school loans). Some worry about not having credit. Several say if they had additional income they would purchase food and one woman says she has a place to live but does not have a bed. Some say they feel their health is made worse by their financial stress and that if they had the means, they would address their health issues. They feel their biggest barrier to overcome is their low income and relatedly their employment status. Despite this, participants report that getting HIV care and treatment through the Ryan White Program means that they are not as worried about meeting HIV health needs and that is a relief.



**Table 2. Budget for Uninsured HIV Positive Man Living in Miami, FL with a Two Person Household and an Income of \$750 per month.**

Expense	Amount Spent Per Month
Rent	\$750
Food	\$250
Car/Transportation	-
Utilities	\$120
Health Insurance	-
Other Medical	\$100
Child Care	-
Loans/Debt repayments	\$300
Total Monthly Expenses	\$1,520 (exceeds monthly income by \$770)
<i>Three things he identified that he would want or needs but currently cannot afford because of a limited budget are: Health insurance, gym membership, and English classes.</i>	

**Table 3. Budget for Uninsured HIV Positive Woman Living in Dallas, TX with a One Person Household and an Income of \$900 per month.**

Expense	Amount Spent Per Month
Rent	\$323
Food	\$200
Car/Transportation	\$125 (gas)
Utilities	\$100
Health Insurance	-
Other Medical	-
Child Care	-
Loans/Debt repayments	\$100
Phone Bill	\$125
Other Household	\$53
Total Monthly Expenses	\$1,026 (exceeds monthly income by \$126)
<i>Three things she identified that she would want or needs but currently cannot afford because of a limited budget are: Putting money into savings, a car, and shoes.</i>	

**Many have medical bills – some in the tens of thousands of dollars – from emergency room visits and hospital stays, and most are not able to make payments.** Their medical debt is not a priority for them when they are living paycheck-to-paycheck and struggling just to get by. Most are so in debt that these bills do not seem to make much of a difference in their lives – they say they just ignore the calls from collections and throw the bills in the trash. One man from Dallas says he cannot be expected to make payments when he has no income, so does not feel concerned about the debt. One man has \$87,000 in debt and says he is working with a lawyer trying to get that amount reduced but in meantime is not making any payments. Some talk about the experience of sitting in an emergency room knowing that they will not be able to afford the bills that are sure to follow. Only a few with hospital bills report being able to make small payments when checking out of the hospital and one man says he committed to paying \$50 per week to a bill that was tens of thousands of dollars.

*"If I don't have an income, what do they expect me to do? I can't do anything about [making payments]."* – Dallas uninsured

*"I ended up going to the ER ... I was sitting in the ER knowing that I'm not gonna be able to pay for this ER visit"* – Atlanta uninsured

**Many have non-HIV health care needs that are not being met.** Just like in the 2014 groups, while all get HIV care and treatment through Ryan White, several are dealing with other health problems such as addiction, depression, or other mental health issues that are not fully being addressed. While several report being able to access some mental health care, others do not know the mechanism to get into care or do not bother as they are not satisfied with the speed of access. Sometimes it can take months to get these services and they feel that when they are in acute need of mental health care they are not able to get it due to the wait. Two men in Dallas have chronic heart issues and want to see a cardiologist – one had a heart attack in December and ended up with over \$50,000 in hospital bills. The hospital gave him a referral for a cardiologist, but it would have cost him \$150 per visit without health insurance to see the provider so he never went. He is able to get the medication for his heart from his HIV doctor who found a funding source, but he is going without follow-up care. Others are putting off treatment for ulcer colitis, chronic staph infections, high blood pressure, foot problems, and painful varicose veins. Another man has gout but tries to control it himself with lifestyle adaptations. One man in Dallas says he recently learned that he has stage three liver disease. He says he did not find out until the disease was advanced because he was going without any preventive screenings. Now he is dealing with the stress and expense of treating advanced liver disease. One individual in Florida has been unable to get hepatitis care through Ryan White. A Florida woman pays \$40 a month for a non-HIV medication and says that it is a real struggle for her and that she often has to borrow the money. Many participants also lack adequate dental coverage. A few have received dental care through the Program and say that wait times are long and services are limited. Similar to those in these groups, uninsured participants in 2014 also reported that trying to meet their non-HIV needs was a struggle.

Those without serious comorbidities discussed the fear of getting sick in the future and being unable to afford care without coverage. A few say heart disease and cancer run in their families and feel that with health insurance they would be able to get the preventive care they need to avoid those issues and deal with them should they come to pass later on.

*"A lot of things run in my family...they all have heart problems, high blood pressure ...So I know at some point I have to be on the lookout for something. And the issue with ADAP and Ryan White [is] what if I want to see a specialist to follow-up with cancer; colon cancer or anything? I would have to do it out-of-pocket."* – Atlanta uninsured

*"Because you can go see somebody for the HIV but you don't have nobody to go see about your heart and that's the main thing. Because you so stressed out...you messing up your health...So I think yeah, we should have [access to Medicaid]."* –Dallas uninsured

**Most were unaware that their states did not expand Medicaid but when this was explained, they say they are not surprised.** They say they expect it from their states – many in Dallas felt it was “typical of Texas,” and a man in Atlanta says he is “not surprised that Georgia is behind.” They are frustrated by their state’s decision and feel disappointed to know they could have had coverage. Most say they would enroll if their state expanded the program and that it would be a “big load off for a lot of people.” Some say they could expect to lead a longer life with coverage. They say that Medicaid coverage would allow them to feel more “complete” and some would like to access care outside of HIV specific clinics and pharmacies saying that this would offer them greater privacy. Several say they would hope that having Medicaid coverage would mean faster access to mental health care. However, they do want assurances that their care would not be interrupted and that they could stay with their providers.

*“It’s a disappointment knowing that we could have more.” – Dallas uninsured*

*“I didn’t know [Georgia did not expand Medicaid], but it doesn’t surprise me that Georgia is behind.”  
– Atlanta uninsured*

**While all are grateful that Ryan White can help them meet care and treatment needs related to HIV, all say they wish they had coverage; living without insurance is scary and frustrating.** One man in Dallas says it feels “like you’re falling” without insurance – they feel they have to be much more careful in their everyday lives. An accident could mean thousands of dollars in hospital bills that they have no means to pay. All say they want the security and peace of mind that having health insurance would offer. One individual took an altruistic approach to the benefits of coverage, saying he would want to enroll in Medicaid to relieve some financial strain on the Ryan White Program.

*“Personally my concern with Ryan White is being that it provides so many services. I mean it’s a stressed fund. I would just enroll [in Medicaid] ...just to relieve that fund and provide services on a broader spectrum.” – Dallas uninsured*

*“It’s like night and day as far as having health insurance or just knowing that if something happens you don’t have to worry; you don’t have to get anxious or let your pride in because you know whatever hospital you go to, you have insurance; you’re covered. You’re gonna be taken care of. But now the reverse is [as an uninsured person] you can’t get sick; you cannot get...you cannot break a leg or anything like that because you got to wonder, how is this gonna be covered? How is it gonna affect HIV? You know?” –Dallas uninsured*

*“[Being uninsured] you know you’re very mindful ...I should not subject myself to get a cold, get a flu; you know do anything that compromises my current stability and health because how am I gonna pay for that?...It’s that mindset or that feeling you get when you know you have to go to the hospital and you don’t have the money. And so you have to deal with the emotions around I do not have the money to go to this hospital, but I have to go to the hospital. And so that’s where I’m at.” – Atlanta uninsured*

## THE ROLE OF THE RYAN WHITE PROGRAM

As found with the 2014 focus groups, the Ryan White Program has touched the lives of all the participants and for those who remain uninsured, the program serves as their lifeline. However, this time around, focus group participants with coverage were less likely to see how the program continues to impact them unless they receive copay or premium assistance, despite many seemingly continuing to use some of the Program's support services.

**Nearly all participants have relied on the Ryan White Program at some point in their lives and uninsured individuals feel their lives depend on it.** Again and again those without insurance said they would be dead without the program. They are very thankful for the program saying, Ryan White them a sense of relief and takes a "burden off" knowing that no matter what, at least their HIV needs will be taken care of. In addition, many receive case management, dental, and mental health care through the program.

*"[Without Ryan White] I would die a horrible death because I couldn't take my... medicine. I can't afford that stuff, that's a million [dollars]." – Miami uninsured*

*"[Not having Ryan White would mean] death obviously. I mean I'd be dead without the medicine that I need." –Dallas uninsured*

*"Like you know I'm just thankful that [I have] Ryan White...because I do have HIV you know but this no insurance thing has been you know since I was a kid..." –Dallas uninsured*

**Most who gained insurance coverage however, seemed unsure about the role Ryan White continues to play in their lives, unlike participants in the earlier focus groups.** Those who now have coverage relied on Ryan White in the past for all their HIV care needs at some point and while a few know they still have a connection to the program, most are unclear as to whether any services they receive are paid for by it. Participants did not seem to realize that case management or other support services they receive are likely still funded through Ryan White. While in 2014 those who gained coverage still identified Ryan White as an important source of their care, many of those participants had not yet fully started using their new insurance coverage so may have felt more strongly tethered to the Program. Similarly, some lack clarity as to whether Ryan White or their new insurance is covering care. One person who now had Medicaid was under the mistaken impression that Ryan White was paying for labs and provider visits while Medicaid covered prescriptions. Those who did understand that some of their care was Ryan White funded received premium or cost-sharing assistance through ADAP. One individual we spoke with received premium assistance through Ryan White and saw that as essential to being able to afford his care. Another California man was initially getting premium assistance but then his income went up. He recently has become unemployed so may be again eligible for help through Ryan White.

**Some who are uninsured worry about how buying health insurance or enrolling in Medicaid would affect their Ryan White coverage.** Their biggest concern is losing Ryan White and experiencing disruption in their care, so some would rather stay uninsured than take the risk. A few who do not have other serious health issues feel insurance is unnecessary as long as they have access to Ryan White but each of these individuals fell into the coverage gap so have limited insurance options in any case. One man in Atlanta says he

deliberately keeps his income low enough to qualify for Ryan White. He says he feels a tension between wanting to find gainful employment and wanting to retain eligibility for Ryan White services, a sentiment echoed by one other respondent in the same group. They are not confident that they could see the same providers if they became insured and this creates some hesitancy.

*"I'll stay with Ryan White because I mean, I know my physicians and I know my doctors very well and I have developed a relationship with them and that might change." –Miami uninsured*

**The main complaint participants had about receiving care under Ryan White was related to recertification which they described as burdensome.** As with Medicaid recertification, Ryan White clients also reported stress around biannual recertification. Many participants said they had missed recertification at some point or on multiple occasions. It seems that sometimes there are system problems with the paperwork but in other cases issues surface when clients do not turn in paperwork on time. Participants sometimes lost access to the program and had to reenroll but typically were able to maintain their HIV treatment during this period thanks to their clinics and case managers facilitating emergency drug access. One individual explained that getting his paperwork in on time is difficult because his clinic is only open during business hours and during that time he is at his job and is unable to get off work. A few participants from Texas describe frustration with the an ADAP requirement to give the state access to IRS/tax information. They say this has caused delayed renewals and a few have gone without medication as a result. In addition there was some discussion about poor communication between ADAP and pharmacies which made timely renewal of prescriptions a problem for Texas participants.

*"I didn't get my viral load ... results back, I got my blood work done and I was already running out of medication so what happened was my doctor went into the pharmacy...and was able to get me 20 pills. So I could continue on because yesterday was my last day for me to register myself again through the Ryan White, but...they cannot register you again until you give them the results of your viral load."- Dallas uninsured*

**Some who gained coverage, particularly Medicaid enrollees, seem to no longer think about the Ryan White Program being available to them if they lost their insurance.** Some say they would be dead or would be sick all the time, in and out of the emergency room if they lost their new insurance coverage. Others say it would be impossible for them to afford their HIV medications without insurance coverage and they would be forced to go without care. They all recognize the importance of keeping their coverage and plan to renew or recertify on time but do not seem to consider Ryan White as being able to help should they face gaps in coverage. This is in contrast to those we met in 2014 who were quick to say that they would go back to Ryan White if they encountered a problem with their coverage.

*"It'd be sad [not to have Medicaid]. I'd be sick all the time. I wouldn't be healthy right now...Things just cost so much, if you don't have insurance you're not going to pay it." – New York City Medicaid Enrollee*



*"If I didn't [have Medicaid] I'd be completely screwed. The HIV meds alone would cost me a fortune. I'm somewhat embarrassed to say I'm not paying a copay. I don't have any additional conditions or anything that I need to be treated for...So I feel really fortunate." – Los Angeles Medicaid Enrollee*

## ROLE OF PROVIDERS AND PHARMACIES

Just as in the 2014 groups, providers with HIV expertise play an important role in the lives of participants with many expressing that staying with their longtime HIV provider is a critical component in their coverage decisions. Case managers too played an important role helping to ease coverage transitions and retaining clients in coverage by assisting with recertification. Respondents also reported very individualized pharmacy preferences, pointing to different features that made access easier or harder depending on their situation.

**Most respondents have positive views of their providers, including both those with coverage and those who get their care only through Ryan White.** All say it is important and helpful that their doctors are HIV specialists and are up-to-date on changing science and the new medications coming to market. Many describe having personal relationships with their providers, saying that their doctors know everything about them. A Georgia man who had fallen-out of care for about a year credits his provider's persistence with signing him up with Ryan White and getting back into HIV care. Participants also discussed the importance of being able to stay with their provider when they gained new coverage saying that the consistency improved their lives.

*"It's very important, especially when you have HIV, you need to have someone that is actually involved because HIV, nowadays it's not the same HIV that it was ten years ago. There are so many medications now... I think that's wonderful; that's fantastic. And the fact that you know that this doctor is going to be on top of the updates in medicines, that's very important." –Los Angeles Medicaid Enrollee*

*"[My provider] called me and she kept calling me and kept calling me to make appointments. You know I let her know that I ... [lost my job and insurance coverage and] I just can't afford it. And then that's when she hooked me up with a social worker and then they put me on ADAP." - Atlanta uninsured*

*"Because I've had the consistency with my physician you know that's tended to spill over into other areas to make things a little bit easier and that why I'm kind of adamant about trying to keep that." –Los Angeles Marketplace Enrollee*

Those who reported less positive experiences with providers shopped around to find someone they are more comfortable with or plan to do so in the future. In addition to their primary and specialist care, some who have received dental care through Ryan White and say it was helpful that their dentists were knowledgeable about HIV but they wish the dental services were more expansive.

**Many had positive reviews of case managers, saying that they help with navigating health and social service resources tremendously.** Those who enrolled in coverage often relied on case managers to

help with plan selection and felt it was important that their case managers could help them pick a plan where they could remain in care at their HIV clinic. Those who are uninsured found case managers were helpful in dealing with Ryan White recertification paperwork. For many case managers were very helpful in navigating care and support services. In some instances case managers helped find funding sources for non-HIV drugs or helped with access to HIV treatment during a gap in coverage or Ryan White eligibility. A few however, did not have a positive view of their case management and felt as though case managers made things more complicated.

*“The reason why I like [my case manager] is because anytime, well when they open; whatever I need she gets. If I need a referral for this and that she gets it. If she can’t do it, she ain’t gone never say she can’t do it, she will tell you why.” -Miami uninsured*

**Choice in pharmacies was important to respondents.** Given the centrality of medications to their care, consistent access to HIV treatment is critical and participants expressed a wide variety of pharmacy preferences. A few preferred HIV specialty pharmacies which they say have more HIV drugs in stock. Others valued mainstream pharmacies for discretion and convenience. Others still say they did not care whether a pharmacy specialized in HIV or not but selected a particular location based on their efficiency or friendly personal service. Some respondents spoke about liking certain convenience features such as using a pharmacy that was open 24 hours a day. While some had a preference for mail-order pharmacy services others valued in-person access at brick and mortar stores. As with providers, some report changing pharmacies to find one that better met their needs. One individual said at first he thought he was going to be forced into using a mail-order pharmacy but after rereading the correspondence he received from the issuer realized he could opt-out. He was glad to discover the opt-out provision, but was confused initially thinking that he would be paying full price, if he didn’t go with the mail-order pharmacy.

## Conclusion

This study provided a second opportunity to look at how people with HIV are navigating the health insurance landscape in the ACA era. During the first visits to the field in 2014, participants who gained insurance coverage were still in the early stages of figuring out how to use it and thinking through what being insured meant to them. During the second round of focus groups that informs the content of this report, participants who had gained coverage appeared more comfortable navigating health insurance and felt they were benefiting from coverage. However, most still lacked basic insurance literacy and remained unsure of how to fully assess plan options. Like in 2014, many put a lot of trust in case managers to help make enrollment decisions. Those with private coverage and without additional assistance worried about costs, while the biggest concern for those with Medicaid was the stress around recertification. The Ryan White Program continues to provide a crucial role in the lives of almost all the participants, especially the uninsured, though those who have gained coverage tend to be less aware they are still connected to the program despite using support services like case management. For the uninsured, they say Ryan White is their lifeline though as with Medicaid enrollees, Ryan White clients also experience anxiety around the recertification process. Just as in 2014, those who live in non-expansion states and remain uninsured, largely because they fall into the coverage gap, feel that they can meet their HIV care and treatment needs through the Ryan White Program but have many other health problems going unaddressed. Taken together, these findings suggest that insurance coverage is becoming more of the “new normal” for those who are able to get coverage, though challenges remain in understanding how coverage

works and meeting all of their care needs. For those who remain uninsured, it is clear that Ryan White functions as their lifeline. Understanding how ongoing implementation of the ACA is impacting people with HIV helps to provide a policy and clinical roadmap for improving retention and engagement in care and treatment going forward, and for considering the future role of the Ryan White Program and its interaction with the ACA.

## Appendix

### METHODOLOGY

The Kaiser Family Foundation and PerryUndem Research/Communications conducted one focus group in each of five states – California, Florida, Georgia, New York, and Texas in February of 2016 just after the close of the third open enrollment period. Within these states, focus groups were conducted in the cities of Los Angeles, Miami, Atlanta, New York City, and Dallas. These sites were selected for geographic diversity, burden of the epidemic (these states alone account for about half of the nation's epidemic)<sup>8</sup>, and their different state approaches to health reform implementation, including Medicaid expansion decisions. Two of the states – California and New York – have moved ahead with Medicaid expansion while three – Florida, Georgia, and Texas – have not. Additionally, California and New York run their own Marketplaces while Florida, Georgia and Texas rely on the federally-facilitated Marketplace. Focus groups conducted in California and New York included participants who gained insurance through an ACA era coverage opportunity, via either the Marketplace or through Medicaid expansion. The groups conducted in Florida, Georgia and Texas included participants who remained uninsured, largely because they fell into the coverage gap, though two individuals who are undocumented also participated. The uninsured respondents all had incomes below 139% of the federal poverty level which means that had these states expanded Medicaid, and the respondent was otherwise eligible, they may have been able to find coverage. (See Table 1 in report.)

All focus group participants were older than age 18 and younger than 65. Groups were racially and ethnically diverse and represented a range of sexual orientations. The groups were predominantly male but female participants were also represented. Each focus group consisted of between 4-10 HIV positive individuals. Given the very narrow parameters for the focus groups, respondents were over recruited and individuals who did not appear to meet the eligibility criteria were excluded from participating. The narrow parameters prevented “full” recruitment at each focus group site with identifying Marketplace enrollees being especially challenging. This is a limitation to the research. Individuals gained coverage at different times over the past few years and thus had coverage experiences for varying amounts of time. All participants were recruited using professional focus group facilities and community based organizations (CBOs), and groups took place within both settings. Participants and CBOs were compensated for their participation.

It is important to note that focus groups are intended to help explore experiences and themes around a given subject, but do not offer definitive explanations or answers and are not necessarily representative of the entire population being studied.

This issue brief was prepared by Lindsey Dawson and Jennifer Kates of the Kaiser Family Foundation and Michael Perry and Kathleen Perry of PerryUndem Research and Communication.

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## Endnotes

<sup>1</sup> Heather Bradley, et al. Centers for Disease Control and Prevention. “Vital Signs: HIV Diagnosis, Care, and Treatment Among Persons Living with HIV — United States, 2011.” *Morbidity and Mortality Weekly Report*. 63(47);1113-1117. November 28, 2014

<sup>2</sup> Myron S. Cohen, et al. “Prevention of HIV-1 Infection with Early Antiretroviral Therapy.” *New England Journal of Medicine*. 365(2011):493-505.

<sup>3</sup> Prior to the ACA, Medicaid eligibility for low income childless adults was quite limited and under pre-ACA Medicaid eligibility rules, to qualify for the program, one had to meet financial eligibility criteria and belong to a group that is “categorically eligible” for Medicaid (such as children, parents with dependent children, pregnant women, and individuals with disabilities). Federal law categorically excluded non-disabled adults without dependent children, unless a state obtained a waiver or uses state-only dollars to cover them. These Medicaid eligibility rules presented a “catch-22” for many low-income people with HIV who could not qualify for Medicaid until they were already quite sick and disabled (usually having progressed to an AIDS diagnosis).

<sup>4</sup> Myron S. Cohen, et al. “Prevention of HIV-1 Infection with Early Antiretroviral Therapy.” *New England Journal of Medicine*. 365(2011):493-505.

<sup>5</sup> J. Kates, L. Dawson, T. Undem, and K. Perry. The Kaiser Family Foundation. Health Insurance Coverage for People with HIV Under the Affordable Care Act: Experiences in Five States. 2014. Available at: <http://kff.org/hivaids/issue-brief/health-insurance-coverage-for-people-with-hiv-under-the-affordable-care-act-experiences-in-five-states/view/footnotes/>

<sup>6</sup> Centers for Disease Control and Prevention. “Diagnoses of HIV Infection in the United States and Dependent Areas, 2012.” *HIV Surveillance Report*, 2012. vol. 24. November 2014.

<sup>7</sup> The Essential Plan is New York’s Basic Health Program (BHP). New York adopted the BHP option available under the ACA to provide coverage to those with incomes between 138-200% FPL that is more affordable than the coverage they would have otherwise purchased in the Marketplace.

<sup>8</sup> Centers for Disease Control and Prevention. “Diagnoses of HIV Infection in the United States and Dependent Areas, 2012.” *HIV Surveillance Report*, 2012. vol. 24. November 2014.