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Health Insurance Coverage for People with HIV Under the Affordable Care Act: Experiences in Five States

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Executive Summary

Assuring that people living with HIV have continuous access to high quality health care, particularly antiretroviral therapy (ART), is essential for addressing the ongoing HIV epidemic in the United States. Indeed, antiretroviral therapy is not only critical for the health and longevity of people with HIV, it has also been shown to significantly reduce the risk of HIV transmission.¹ However, the majority of people with HIV in the U.S. are not yet engaged in care and not on ART.² Improving access to health coverage is one key component to addressing this gap.

The Affordable Care Act (ACA) provides new health insurance coverage opportunities for millions of individuals, including people with HIV. To provide greater insight into what the ACA has meant for this population, this report examines the experiences of people with HIV based on focus groups conducted in five states – California, Florida, Georgia, New York, and Texas – between June and September of 2014. Participants were asked to discuss their enrollment and coverage experiences in either their state’s health care marketplace or an expanded Medicaid program. Those participants who did not gain new coverage, largely because they lived in a state that did not choose to expand Medicaid, discussed that experience. In addition, all participants were asked about the role of the Ryan White HIV/AIDS Program, the nation’s safety net for people with HIV who are uninsured or underinsured.

It is important to note that because these focus groups were conducted relatively soon after coverage began, they represent the early experiences of people with HIV in these states and may not fully capture their ongoing coverage and care experiences. Ultimately, understanding the experiences of people with HIV in accessing new coverage, including successes and challenges, has important implications for both individual health outcomes and the nation’s response to the HIV epidemic.

Key findings include:

- At the time of the focus groups, the ACA’s health insurance expansions, through health care marketplaces and Medicaid expansion, were already playing a role in the lives of many with HIV who reported gaining new coverage.
- Those enrolling in private coverage sold on the marketplaces found that they had access to more comprehensive health services. While in the past many received HIV related care and treatment through the

Ryan White Program, participants faced economic and health insecurity related to other, non-HIV, healthcare needs. Some participants found they were able to find much more affordable coverage through the marketplace compared to pre-ACA insurance costs. However, many faced barriers during enrollment and although most of these were surmountable, some became discouraged and did not enroll. A few participants enrolled in plans with very high deductibles and as a result were concerned that their out-of-pocket costs would be prohibitive. In addition, several enrolled in plans without fully understanding their coverage or knowing if their HIV doctor would be in their plan's network or whether their HIV medications would be covered. Where focus group participants had used their new coverage, it was mostly to access HIV drugs. A smaller share of participants used their coverage more broadly and while they reported staying in care, some had to change providers, pharmacies, and switching to different non-HIV drugs.

- Participants gaining new coverage through Medicaid expansion reported continuing to get their HIV care needs met, as they had in the past primarily through Ryan White, while also receiving care for other health problems that had previously gone untreated. These enrollees generally reported smoother coverage transitions compared to those in the marketplace. In addition, most had already used their coverage for accessing HIV care and treatment.
- Focus group participants living in states not expanding their Medicaid programs, but who would have otherwise been eligible, continued to receive their HIV care through Ryan White but worried about how to meet other health needs. They were frustrated by their state's decision not to expand and continued to be worried about health and economic insecurity that accompanied being uninsured.
- The Ryan White Program was cited as a key source of care, treatment, and support for many focus group participants, including those gaining new coverage, helping to ensure a smooth transition into new forms of health insurance, helping them to afford new coverage, and supplementing coverage with needed services where gaps remained. In addition, Ryan White continues to be the main source of HIV care for those who remained uninsured.

Introduction

Assuring that all people living with HIV have continuous access to high quality health care, particularly to antiretroviral therapy (ART), is essential for addressing the ongoing HIV epidemic in the U.S. Indeed, antiretroviral therapy is not only critical for the health and longevity of people with HIV, it has also been shown to significantly reduce the risk of HIV transmission.³ For these reasons, current federal HIV treatment guidelines recommend initiation of ART as soon as one is diagnosed, as well as regular care and monitoring.⁴ However, the majority of people with HIV in the U.S. are not yet engaged in care and not on ART.⁵ Improving access to health coverage is one key component to addressing this gap.

The Affordable Care Act (ACA), signed into law in 2010, aims to expand access to affordable health coverage for millions of Americans, including people with HIV. While several provisions of the ACA have implications for people with HIV, two are expected to have the most far reaching effects on coverage – the expansion of Medicaid, in states that choose to expand, and the creation of health insurance marketplaces in each state where individuals can purchase private coverage, along with subsidized coverage for those with low and moderate incomes. However, despite the ACA's reforms, not all people with HIV will gain new forms of insurance. In addition, even those who do may need further assistance in accessing and paying for health coverage and certain types of services that are important for HIV care, such as case management, may remain

unreimbursed in traditional systems of care. For these individuals, the Ryan White HIV/AIDS program, the nation’s safety net for people with HIV who are uninsured and underinsured, will continue to be critical.

To provide greater insight into what the ACA has meant for people with HIV, this report examines their early experiences based on ten focus groups conducted in five states – California, Florida, Georgia, New York, and Texas – between June and September of 2014 (see Methodology for more detail). Together, these states represent half of all people estimated to be living with HIV in the United States. Within these states, focus groups were conducted in the cities of Los Angeles, Miami, Atlanta, New York City, and Dallas. Participants were asked to discuss their enrollment and coverage experiences, as well as their experiences with maintaining ongoing HIV care, obtaining HIV medications, accessing experienced HIV providers, costs, and the role of the Ryan White HIV/AIDS program. The states were chosen for geographic diversity, burden of the epidemic, and varying 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 the remaining three - Florida, Georgia, and Texas - have not; in addition, California and New York have chosen to run their own health insurance marketplaces while Florida, Georgia and Texas have defaulted to the federally-facilitated marketplace (see Table 1). It is important to note that because these focus groups were conducted during 2014, they represent the early experiences of people with HIV in these states and may not fully capture their ongoing coverage and care experiences. In addition, the views of focus group participants are not necessarily reflective of all people with HIV in a particular state or nationally.

Table 1: Focus Group Details

| City, State | Date | Composition |
|-----------------|--------------------|--|
| Dallas, TX | June 25, 2014 | Marketplace Enrollees or Attempted Enrollees |
| | | Uninsured Under 139% FPL |
| Los Angeles, CA | June 26, 2014 | Medi-Cal (California’s Medicaid program) Enrollees |
| Long Beach, CA | June 26, 2014 | Marketplace Enrollees or Attempted Enrollees |
| Atlanta, GA | August 21, 2014 | Uninsured Under 139% FPL |
| | | Marketplace Enrollees or Attempted Enrollees |
| Miami, FL | September 4, 2014 | Uninsured Under 139% FPL |
| | | Marketplace Enrollees or Attempted Enrollees |
| New York, NY | September 9, 2014 | Medicaid Enrollees |
| | September 24, 2014 | Marketplace Enrollees or Attempted Enrollees |

Background

HIV remains a serious public health challenge in the United States (U.S.). More than a million people are living with HIV in the U.S. and approximately 50,000 become newly infected each year.⁶ Critical to addressing the HIV epidemic is getting those who test positive engaged in care, onto ART and, ultimately, virally suppressed.⁷ Early initiation of antiretroviral therapy not only significantly delays progression of HIV disease and reduces the occurrence of adverse health events and death, it has also been shown to significantly reduce the risk of HIV transmission.⁸ As a result, current treatment guidelines recommend initiation of ART immediately after HIV diagnosis.⁹ Guidelines also recommend that people with HIV be treated by experienced HIV providers,

have regular medical visits and laboratory monitoring, and maintain continuous access to HIV care without ART interruptions in order to achieve optimal health outcomes.¹⁰ However, it is estimated that 6 in 10 people with HIV in the U.S. are not engaged in ongoing HIV care, and therefore most are not on ART or virally suppressed – some are not yet diagnosed, but others are not yet linked to care or have fallen out of care, due to access barriers including the lack of adequate insurance coverage.¹¹ Health insurance coverage is one key factor in helping to improve health care access, and ultimately health outcomes, for people in the United States, including those with HIV.¹²

The ACA provides new health insurance coverage opportunities to millions of individuals, including thousands with HIV. As mentioned above, the ACA's Medicaid expansion and creation of health insurance marketplaces in all states, both of which went into effect in 2014, are expected to have the most far reaching effects on coverage for people with HIV, as follows.

Medicaid Expansion:

- One of the most important components of the ACA for people with HIV is the expansion of Medicaid eligibility. 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).

The ACA changed this by establishing a new minimum Medicaid income eligibility level of 138% of the federal poverty level (FPL) (about \$16,000 for an individual in 2014) for most citizens and legal residents and removed the categorical eligibility requirement. The law required all states to expand eligibility as of 2014. However, a Supreme Court ruling in June 2012, while upholding the ACA, effectively made Medicaid expansion a state option. As of December 1, 2014, 28 states have expanded their Medicaid programs and 23 states have indicated they will not expand or are in the process of deciding whether they will expand their Medicaid programs. (Approximately 40% of people with HIV live in these non-expansion states.¹³)

Health Insurance Marketplaces:

- The ACA requires most U.S. citizens and legal residents to have qualifying health insurance as of 2014. To help people access affordable coverage, the ACA created new health insurance marketplaces in every state. Marketplaces are intended to create a more competitive market for individuals and small businesses buying health insurance. They offer a choice of different qualified health plans (QHPs), certifying plans that participate and providing information to help consumers better understand their options by making it easier to compare benefits across plans. Importantly, the ACA provides financial assistance for people with low to moderate incomes to purchase insurance in the marketplace. These include tax credits to offset premium costs for those with incomes between 100% FPL and 400% FPL and subsidies to reduce cost-sharing

expenses for those with incomes between 100% and 250% FPL. Because the ACA also prohibits health plans from denying, rescinding, or charging higher amounts for coverage based on health status, and ends annual and lifetime caps on coverage, alongside the creation of the health insurance marketplaces, people with HIV now have greater access to the private insurance market than in the past.

Despite these reforms, access to health insurance alone does not equal access to continuous quality HIV care. While these coverage expansions will certainly mean that many individuals with HIV will have greater access to more affordable and more robust forms of health insurance, there will also be significant challenges as the law is implemented. In states that do not expand their Medicaid programs, many low-income HIV positive individuals will find themselves in “the coverage gap,” below 100% FPL and neither eligible for Medicaid or subsidized coverage purchased in the marketplace (which begins at 100% FPL). In addition, implementation will take time and individuals, especially those most vulnerable and unfamiliar with health insurance and systems, may not enroll in coverage overnight and may not be familiar with processes for accessing health systems. As people with HIV move into new forms of coverage under the ACA, understanding gaps, challenges, and successes surrounding those transitions will help to inform future enrollment periods and policy needs. It will be particularly important to assess and monitor the adequacy of provider networks, drug formularies, and the ability of people with HIV to maintain continuous coverage.

Also important will be assessing the role of the Ryan White HIV/AIDS Program (RWP), which operates as payer of last resort for people with HIV who have no or limited coverage. The RWP plays an integral role as a safety net provider of HIV care and treatment but is not comprehensive form of insurance. In addition, because Ryan White is a payer of last resort, there is an expectation that clients newly eligible for Medicaid or marketplace coverage under the ACA will make those transitions. For those who cannot gain new coverage under the ACA, the Ryan White Program will continue to be their main source of HIV care and treatment. For those who do gain new coverage, Ryan White will likely continue to play an important role for many by filling in gaps in benefit packages and assisting with the cost of insurance (prior to the ACA, most Ryan White clients had insurance and were relying on the program to help supplement and/or pay for their coverage¹⁴). In fact, the federal government has encouraged Ryan White grantees to help educate and enroll clients into new forms of coverage for which they are eligible and to provide financial support through premium assistance when possible.¹⁵

Findings

VIEWS ABOUT HIV CARE AND OTHER HEALTH CARE NEEDS

All focus group participants were asked to discuss their HIV and other care needs, including their views on health care providers and what barriers they may have experienced in accessing care. Assessing whether new health coverage can meet the unique health needs of people living with HIV will be important going forward. Engagement and retention in care and treatment is critical to good HIV related health outcomes so defining what aspects of care people with HIV value in particular and what previous barriers to care have existed will be important.

Almost all participants say receiving ongoing quality HIV care is vital to their health and life.

Participants in all groups stress the necessity of continuous HIV care, particularly the importance of avoiding

any disruptions in taking their HIV medications. Missing just a small number of doses of medication, they say, can affect their health as well as their resistance to medications. For these reasons, health care issues related to their HIV status take priority when choosing and transitioning to new health care coverage.

Participants want a health care provider who has HIV expertise and one with whom they can form a relationship. Participants say having a physician with HIV expertise is critical to receiving the best, most up-to-date HIV-related care. They also feel an established relationship with their doctor is important to build a level of trust. Many explained that it was important to them that providers knew about all aspects of their lives so that they could be treated comprehensively, including if they were struggling with addiction, explaining that it is more difficult to be open and honest with a new doctor when that trust is absent. Several have encountered physicians who were judgmental, and some participants say they have felt stigmatized as a result of being HIV positive in healthcare settings. These factors can make changing physicians or finding a new doctor challenging for people with HIV.

“...I would rather a doctor that knew my particular situation, that I have a rapport with that I feel comfortable discussing just all the things that I'm going through in terms of emotionally and physically and mentally with everything else. Juggling kids...having this illness and other things that I have going on in my life, I need a certain type of empathy...” –New York participant, QHP enrollee

Many have significant non-HIV related health needs including cancer, diabetes, mental health, and substance abuse issues. In addition to HIV, many participants also report having other health needs that warrant medical care and treatment. Several participants reported current or past experiences with various types of cancer. One participant had Crohn’s Disease, another suffered from migraines, and several others had nagging ailments from past injuries. A large share of participants spoke of current or former mental health and substance use problems. Some have put off care for these other health issues and report that this is a stressor in their lives. In many cases participants incurred medical debt as a result of seeking care while being uninsured and without other options are unable to do anything to address this debt. Some of the uninsured participants are facing serious illnesses without a way to receive care for non-HIV related medical issues. Many discussed being grateful for assistance the RWP provides but noted that they were left without resources to address these other non-HIV related health problems.

I've given...up [on the medical debt]. Sometimes, it depends on your stability; do you want to stress out about something you can't do anything about? And you get sick again and get some more bills?” – Atlanta participant, uninsured

There are many hurdles participants have to overcome to improve their health and access to care, including: mental health issues, addiction, transportation concerns, medical debt and unemployment. Mental health, addiction, and transportation issues represent major obstacles to coverage and care and studies indicate that the prevalence of mental illness and substance use, complex co-morbid conditions that often require more intensive and coordinated services, is much greater for those with HIV.^{16,17,18} Addressing these challenges, therefore, is fundamental to ensuring that people with HIV are able to obtain health coverage and to access and remain in HIV care and treatment. Many focus group participants reported that they were struggling day to day with untreated mental health issues. Several participants have received or need ongoing treatment for addiction issues. Participants in Texas and Florida, in particular, say lack of

transportation has impeded their ability to go to their doctor's appointments. Several in Florida recently lost their monthly bus pass after a round of budget cuts in the RWP, which caused stress about how they would get to their doctor appointments, a critical part of HIV care.

EXPERIENCES WITH PRIVATE COVERAGE IN THE HEALTH INSURANCE MARKETPLACE

Five groups were held with participants with HIV who attempted to enroll (successfully or unsuccessfully) in Qualified Health Plans (QHPs) through state and federal marketplaces, including one in each of the following cities: Dallas, Long Beach, Atlanta, Miami, and New York City.

People with HIV were motivated to enroll in QHPs for a variety of reasons. Several participants who are or were self-employed reported purchasing individual coverage in the past but at very high rates and were burdened by the costs. In recent years, some saw premiums become unaffordable and had to drop their coverage. Prior to the ACA, private insurance companies could charge higher rates based on health status, including HIV disease, and coverage, when it was available, was often not affordable. The ACA provided them, for the first time, with an opportunity to access affordable coverage. One participant in Los Angeles reported that prior to the ACA, his premium had increased to \$1,000 per month before he dropped his coverage and became uninsured. Others had been previously uninsured because coverage was not accessible or unaffordable to purchase in the first place. These participants were hopeful and excited by the ACA and were motivated to enroll by the promise of more affordable coverage. Other participants say the mandate and avoiding the penalty were the main reasons they decided to enroll. In addition to other reasons compelling individuals to seek out coverage, many were looking for greater protections offered by being insured or wanting to take care of health problems they had been ignoring. Some also say their case manager or a counselor at their health center encouraged them to enroll.

The most important factors in choosing a plan include the premium amount, whether their HIV medications would be covered, and whether their current HIV providers were in network. For most participants, the biggest decision factor in choosing a plan was the premium amount. They say they chose a plan based on trying to get the most covered for a price they could afford. Many participants were previously receiving their HIV treatment through Ryan White and in looking at other coverage options say their main question and concern in choosing a plan was whether their HIV medications would be covered. Some got answers to these questions through seeing a list of medications on a formulary, through case managers, or by calling the plans directly. Others made enrollment decisions based on which plans included their current HIV doctor in-network. Several called their current provider to ask whether he or she accepted a specific plan, and others looked on the insurance carrier's list of providers.

Still, many selected and enrolled in a plan without knowing whether their HIV medications, doctors, lab work, and other vital care would be covered. While some were able to get answers about whether their HIV medications would be covered, some individuals did not know how to ensure that pre-ACA standards of care were continued into new coverage. For instance, staying with a particular provider or making sure a particular drug was covered by a plan at the outset. Many simply assumed medications would be covered and that they would be able to stay with their providers and did not ask questions or did not know where to get answers. Many participants also say they did not know if lab work would be covered.

Participants reported learning about the ACA and open enrollment from a wide range of sources. Many say they heard about the ACA by seeing commercials on TV and through news sources, including CNN. One woman who enrolled in a QHP in New York City says she saw an ad when she was checking her email on Yahoo – she clicked on the link and it took her to the Marketplace website. Others saw friends post on Facebook about their experiences and decided to look into coverage themselves. Some say they heard from friends and family through word of mouth. Many also saw advertisements at their health clinics and doctors’ offices or heard about the ACA from their case managers. A few participants in residential living settings had a navigator visit their residence to educate them on the ACA and enrollment.

For many, case managers played an important role in accessing and navigating the health care system. Case management has been shown to be particularly important for HIV care, helping with linkage, retention, and adherence.¹⁹ Indeed, participants frequently cited their case manager, often a Ryan White case manager, as a source of information and help. Participants who felt choosing a plan was too overwhelming and that questions were difficult to get answered were relieved that their case manager could narrow choices and help them choose a plan. Several in California say their case managers assured them of the availability of additional financial assistance through Ryan White to help pay for QHP premiums. Knowing this seemed to take the pressure off of choosing “the right” plan while also weighing premium affordability. In some instances, case managers were central to participants successfully enrolling in a QHP or Medicaid. Some participants felt their case managers at HIV community based organizations had a better understating of what would be “good” plans for someone with HIV to select. In a few cases it seemed that case managers had such an intimate role in decision making that client’s wishes were dwarfed. For instance, one Los Angeles woman felt she was not in the best plan for her but had selected it based on her case manager’s recommendation. In other cases still, participants felt that case managers had very large case loads and that they had to “stay on them” to receive the assistance they needed, saying that the “squeaky wheel is gonna get the grease” when it comes to case management services. Despite the role case managers played for many, other participants reported that they navigated the enrollment process, including starting an application and choosing a plan, without help or outside resources. Still others stuck some kind of a balance seeking some assistance from case managers and doing other parts of enrollment on their own.

“...well the person who was in charge...he helped me kind of, well he didn’t help me pick, but he gave me information as to what plan would be in-network for [my clinic] because that was important to me, to stay with my doctor.”- Dallas, participant QHP enrollee.

Most faced technical problems with marketplace websites and felt frustrated during the process and these issues are the main reason a few did not enroll. Almost all participants who tried to enroll in a QHP faced some type of technical problem, including those attempting to enroll in the federal marketplace (healthcare.gov) as well as, though to a lesser extent, those attempting to enroll in the state exchanges in both California and New York. These included frozen screens, getting kicked out of the website, having to restart their applications, and very long wait times and uninformed representatives when calling for help. For some individuals, these negative experiences were cited as the reason for not enrolling. One man living with HIV in Atlanta tried to enroll in the fall of 2013, but got frustrated by the glitches and gave up. In December, he had open heart surgery followed by two heart attacks in April. Care for these issues resulted in more than \$300,000 in medical bills for which he is now in debt. A man in Dallas, who, in addition to being

HIV positive is diabetic, also had problems with the website and was unable to enroll. He is looking forward to attempting to enroll during the second open-enrollment period but as a stop-gap measure is getting HIV care and treatment through the Ryan White Program and insulin from a friend, which he sees as his only way to access this medication. A New York woman also experienced website issues so called the state 800-number where she was helped after a twenty-minute wait but she was ultimately able to enroll. Several California participants spoke of waiting on the phone for hours at a time.

“[The website] said ‘please wait, please wait, please wait’ when everybody was first trying to get [on.] Then I tried for a couple of weeks, different times of the day, middle of the night, early in the morning, and I still was never able to get through. And then I started having health problems and I just kind of forgot about it.” - Atlanta participant, uninsured

Participants were confused about basic insurance terms and were unsure of cost-sharing obligations. Participants’ comfort level with insurance terminology and how to use private insurance varied. While some had previous experience and were fairly insurance savvy, many others had low levels of insurance literacy. Insurance terms such as deductible, premium, and copayment were often used interchangeably. Most participants said they did not have a good sense of what out-of-pocket costs would be for different types of care. This was particularly the case since many enrollees had not yet used their coverage at the time of the focus groups.

Another barrier to QHP enrollment was a lack of understanding of the health needs of people with HIV. In some instances the main barrier was that enrollment workers were unfamiliar with the needs of someone with HIV. A man in Miami says that he gave up after multiple website attempts and after speaking to a navigator who was not knowledgeable about HIV and could not answer his questions. A participant from Texas explained that while he thought those that helped him in the enrollment process were knowledgeable about his HIV related care needs, he was not so sure that they were as knowledgeable about whether the plan could meet those needs. He said, that they were “knowledgeable about the care” he would need, but how that aligned with plan benefits “still kind of like remain[s] to be seen because it was so new.” Another Texas participant was frustrated that marketplace call center operators could only give basic information about plan benefit designs and could not help him make a decision about how different plans might meet his HIV needs.

Participants also reported facing high deductibles and unexpected costs. A few participants say they feel disappointed that they finally have insurance only to have a very high deductible they do not think they can afford. One participant in Texas was very upset when he found out after enrolling that his plan had a \$6,000 deductible. He, like other participants, did not understand the concept when he purchased his plan. As a result, he feels like care is unaffordable. At the time of the group he was receiving help with his medication from his community based organization (CBO) but he knew that was a temporary fix and was not sure how he would get his treatment in the longer term. A participant in Miami enrolled in a QHP with a monthly premium of \$1.85 after his subsidy; even though he knew the plan came with a \$6,000 deductible, he was hoping to avoid using his coverage at all. In addition to HIV, he suffers from chronic migraines and would like to receive care, but says he will manage untreated because he cannot afford the costs. Some participants in this situation were hoping to continue receiving treatment through Ryan White.

“I’ve never had insurance besides the job...and we didn’t have a deductible. I have the \$6,350, \$6,000 amount for a deductible. And I didn’t know how it worked...Talking to family is how I ended up figuring out: if you get a high deductible, you got to pay that before you’re able to go in and get it for free.” – Dallas participant, QHP enrollee

Aside from deductibles, some faced unexpected costs. One participant had pneumonia which required an ambulance to take him to a hospital that was not in-network, resulting in a bill that he did not anticipate and could not afford. Some faced issues when trying to use their new insurance at the pharmacy before coverage had been activated. One participant in Miami paid his premium but only learned his coverage had not been activated when he was told by his pharmacy that his prescription would cost \$1,600, presumably the cost to someone without coverage. He was able to get the issue resolved, although the situation caused him stress and frustration. A New York participant had a similar experience. He says he skipped his HIV medication for a day after his pharmacy told him it would cost almost \$2,000. Others still saw some increased prescription costs with their new coverage. A few participants in New York said their co-pays went up with their new coverage and some were able to secure lower cost prescriptions by going to different pharmacies. Some individuals were fearful of prescription costs under their new plans so were putting off using them for pharmaceutical coverage. Other participants discussed receiving help through pharmaceutical company patient assistance programs.

At the time of the focus groups, many QHP enrollees had not yet fully used their coverage and those who had did so mostly for accessing their HIV medications. Still, enrollees felt better protected by being insured. At the time of the focus groups, many participants, particularly those enrolled in QHPs, had not yet had the opportunity to use their coverage for all of their needed care. Most QHP enrollees who had used their coverage say it was primarily for their HIV medication. Participants in the last round of focus groups conducted in New York in September, those who been covered for the longest period of time, had used their coverage most broadly. Many were relying on back supplies for prescriptions and some were still using the Ryan White Program while making the transition to new coverage. Despite having used their coverage to a limited extent and having faced other barriers, participants who enrolled in QHPs say they feel “relief” as a result of having coverage. Some say they have peace of mind for the first time in years both in terms of protecting themselves in case of emergency but also in terms of being able to access more affordable coverage. For instance, a Los Angeles participant explained that in the past he had paid \$10,000 per year for coverage on an annual income of only \$24,000. He described the fact that the ACA passed as “kind of a dream.” He continued, prior to the ACA “...insurance has been killing me for 15 years...I've spent half of my savings from my career that was supposed to be for my retirement on health insurance.” Those that had used their coverage more extensively explained that they had been able to stay retained in care but some experienced changes related to their providers, pharmacies, and drugs.

After enrolling in new coverage, several participants reported more limited networks, and having to switch doctors, and some also switched to generic versions of drugs. Some enrolled in their insurance plans not knowing whether or not their doctor would be covered. As a result, a few found out they had to change to a new physician. In New York, one man was grateful to keep his HIV specialist but was upset by having to change his primary care provider and was unhappy with his new physician. Some say they felt stressed having to establish a relationship with their new doctor and rebuild trust. In California, several participants had issues making sure their HIV provider was able to remain their primary care provider and was

not designated a specialist which could make visits more expensive or require a referral. In some cases this required some back and forth with their health center and their new insurer or finding a new primary care provider that could refer cases back to their previous provider. A Texas man found that under his new plan, his provider was designation as a specialist and copays went up for him. He explained that the cost difference has an impact on him but that he is willing to pay the difference as he only sees the doctor every three months. He had not realized this cost difference at the outset and was not sure if it would have been a deciding factor in choosing a new plan if he had known about it when enrolling. In addition to changing providers, a few participants reported switching to the generic form of drugs for non-HIV related conditions.

“...my co-pay for my doctor’s visits changed because my HIV doctor change[d] ...to a specialist doctor instead of just a regular doctor...it went up to office visits from being under the new plan, instead of \$10, it’s \$60 for each doctor visit.” –Dallas participant, QHP enrollee

“I had more choices of doctors [in the past]. Now it’s like it’s, I’d say it’s cut in half. Like it’s, I don’t have that many options. And all of the doctors too that I used to use, like regular doctors, my GYN, doctors I used to use in the past, I tried looking for them and none of them are in [my new plan].” – New York City participant, QHP enrollee

Not all of those in the focus groups were able to successfully enroll in QHPs, largely because they lived in a non-expansion state and fell into the “coverage gap.” A few got as far as seeing the price of plans (without a subsidy since they were below 100% FPL) and say they quit the process because the premium amount was far outside their budget. Before learning she was in the “coverage gap” and exempt from the tax penalty, one woman in Georgia, a non-expansion state, decided she would rather pay a fine and not enroll in coverage after seeing that her premium would be \$180 a month. One participant planned to enroll in marketplace coverage but when he saw unaffordable premiums, changed his mind. Later he noticed an advertisement in the community that conveyed very affordable coverage, not knowing he was seeing higher premiums because he was ineligible for subsidies, he thought he might have done something wrong so tried again but saw the same unaffordable price. In another instance, a man in Texas, also a state not expanding its Medicaid program, signed up for coverage but realized he could not afford his medication when he went to the pharmacy. When he told the CBO he uses about the situation, he was informed that he should never have signed up, as he did not qualify for a subsidy. Others reported not even trying to enroll because they were told they would not qualify for affordable coverage. These individuals plan on continuing to rely on the Ryan White Program for their HIV care and treatment. Some enrollees weighed the cost of premiums against other household expenses and decided they were not able to prioritize the expense.

“[A navigator or assister] said I fell below the level that they were looking for, I think like, it was like \$11,500. My gross income was like \$10,800, so there was no sense in me trying to apply for it. So after she said [that], I just left it alone.” – Atlanta participant, uninsured

“I could not afford a \$200 [premium] and then afford to send [my kids] to school, make sure [there is] food put on the table, lights paid. They’ll turn the power off, if you don’t pay the bill, so I got to pay them.” – Atlanta participant, uninsured

EXPERIENCES WITH MEDICAID

Two groups were held with people with HIV who enrolled in new Medicaid coverage in the two states expanding that program, California and New York. In addition, the views of people with HIV in the three states not expanding Medicaid were also captured.

In California, most participants with HIV had been enrolled in the Low Income Health Program (LIHP), a precursor to Medicaid expansion run by participating counties. For these enrollees, case managers helped with seamless transitions to Medi-Cal (California’s Medicaid program).

Despite some of the widely publicized problems Californian’s have faced with Medicaid enrollment, including the substantial backlogs, none-of the participants in the Medicaid group in this state shared those experiences. This may have been in part because LIHP transitions were supposed to happen automatically bypassing parts of the enrollment process. All participants worked with a case manager to transition to Medi-Cal from their previous programs, including the RWP and Healthy Way LA (the Los Angeles LHIP program). Most participants were in Healthy Way LA prior to Medi-Cal coverage and transitioned fairly easily. Some described transitioning without having to do anything at all while others talked about having to do paperwork with case managers. One individual described being enrolled into Health Way LA in November 2013 as a way to ensure that they transitioned to Medi-Cal coverage in 2014. A few enrolled directly into Medi-Cal. No participants reported any significant problems with the enrollment process, though those transitioning from Healthy Way LA to Medi-Cal were sometimes confused about the transition taking place. Several described receiving plan pamphlets and booklets in the mail but not knowing if they needed to do anything with them. Some said that they were overwhelmed at first, but their case managers were able to walk them through the process. While New York also had an early Medicaid expansion ahead of the program under the ACA, no participants reported being a part of that cohort.

Similar to those who enrolled in QHPs, most who enrolled in Medi-Cal / Medicaid assumed their HIV-specific care needs would be covered. Participants are very grateful to have had support from case managers and relied heavily on them to navigate enrollment and get their questions answered. In Los Angeles, much of participants’ knowledge came from their caseworkers, including whether or not their medications would be covered. One participant went so far as to refer to case managers as also being “benefits counselors.”

“In addition to being the case manager, they’re really benefits counselors. So if I have a question about whatever and I don’t even understand it, I know that I can defer to them.... I’m really grateful that we have case managers here.” – Los Angeles participant, Medi-Cal enrollee

“It would be a nightmare [if my case manager did not help me enroll in Medi-Cal]... The volume of paperwork, the bureaucracy, fear about my medical care... and continuity of care.” – Los Angeles participant, Medi-Cal enrollee

Most participants in New York also had some form of help enrolling in Medicaid, which contributed to a fairly easy enrollment process but fewer reported that support coming from a case manager. In New York, several enrolled through clinics and CBOs, some with LGBT and HIV expertise, which gave them assurance that all of their HIV care would be considered in making enrollment decisions,

including the HIV/AIDS Services Administration (HASA). One participant signed up over the phone, and another participant received a package in the mail and submitted a paper application. Several New York participants reported checking with providers about their networks and selecting a plan recommended to them. In the case of one New York man, a parole officer helped him with enrollment. None reported being in one of New York's pre-ACA Medicaid programs for non-disabled adults prior to enrolling in a Medicaid expansion plan.

Participants who had enrolled in the Medicaid expansion had used their coverage more broadly than those enrolled in QHPs. Participants discussed having used Medicaid coverage to access both HIV and non-HIV medications and none reported having to switch regimens. When asked if he had used his coverage for HIV medications yet, one New York participant responded that yes, “that’s especially what they’re for.” Barriers that surfaced for participants were relatively minor and most acknowledge they were easily surmountable. One participant discussed having to switch from a combination drug for a dermatological problem to two separate drugs but he was grateful that his pharmacist was able to find a way to fill the prescription so it was covered. Participants also were able to use their Medicaid coverage to see their same doctors, though one participant reported having to switch back to his regular provider after an auto-assignment placed him with someone new. He said that it was an easy change and that it probably would not have happened if he had been more proactive during enrollment. One individual reported now having to get labs drawn at an offsite laboratory rather than at his clinic which was frustrating for him at first. Overall though, the process of using coverage for Medicaid enrollees was a fairly smooth one.

Those who newly enrolled in Medicaid, but had only had Ryan White for care in the past, felt reassured by having new coverage. While many felt they could rely on the Ryan White program to help address their HIV care needs, other health problems sometimes went untreated. Enrollees reported feeling secure knowing that they would be able to receive non-HIV care if they faced an unexpected accident or illness. Some say they have more opportunities to receive care and can now be more proactive about their health. Several have chronic health issues and some talked about now being able to care for those needs. One participant who lost his job and private health insurance qualified for Medi-Cal under the expansion. As a result, he is able to get physical therapy and pain medications to care for injuries from an accident he had two years ago and is now considering returning to work.

“I’ve had sciatica for the last seven years...then I was hit by a car two years ago and my back’s been in a lot of pain ever since. I’m just now getting physical therapy and pain management because of Medi-Cal. And the doctor was able to make referrals and I was able to get connected to great services and it’s just been wonderful.” – Los Angeles participant, Medi-Cal enrollee

On the other hand, focus group participants who lived in non-expansion states say they feel scared and lack security as a result of being uninsured. While they say the RWP program is vital for accessing HIV-related care, participants worry about accidents or an unexpected illness unrelated to their HIV status. Several are managing other serious conditions that they lack any form of coverage for including cancer and diabetes, to name a few. They worry about the impact of needing care, without coverage, on their lives and their families. Some say they feel as though they are treated as “second-class” without insurance and believe

they receive lower quality care when they try to seek it. Several say being uninsured aggravates their anxiety because they do not know where they would go if something went wrong.

Nearly all uninsured participants in non-Medicaid expansion states, who would otherwise have been eligible, express anger with their state’s decision not to accept funds to expand Medicaid and say they would enroll if their state later chose to expand the program. Many are aware of their state rejecting funds to expand Medicaid and they direct their frustration specifically toward their governor. Participants feel angry and frustrated that people who are most in need do not have options. Many described feeling as though they had been left out or “written off.” They also are upset that people like them in other states receive coverage, while their state rejects available funds. Right now, uninsured participants feel limited in where they can go for services and many say they currently receive substandard care. They say Medicaid coverage would enable them to take a more active role in addressing their health problems by seeing more diverse physicians and receiving the types of care they are not currently able to. Participants say Medicaid would provide a security blanket and could help reduce the stress in their lives.

“[Medicaid would give] an opportunity to see diverse physicians. It takes a lot of stress off of you, being able to [get care] if needed.” – Atlanta participant, uninsured

THE ROLE OF THE RYAN WHITE PROGRAM

Participants in all groups discussed the Ryan White Program and in most instances reported a strong connection to the program. The extent to which individuals relied on Ryan White for their care needs varied and was directly related to whether they had access to other forms of coverage or were transitioning to new coverage.

The Ryan White HIV/AIDS Program has played a major role for participants in accessing HIV care in both Medicaid expansion and non-expansion states. Most participants in the focus groups have relied on the RWP for HIV care at some point. A smaller share of participants did not report a connection to the program. Many participants who enrolled in new coverage due to the ACA were receiving care through the RWP before and during the enrollment process. Most participants who remain uninsured still rely on the RWP for primary care and treatment. Without the RWP, these participants say they would be unable to manage their disease and get their essential HIV medications. Participants, but especially those in non-expansion states, place enormous value on the Ryan White Program. They explained that getting care through the RWP provides them with a sense of security that, at the very least, their HIV care needs will be met. However, those who did not enroll in new coverage are cognizant that Ryan White does not meet all their care needs and worry about how they will address non-HIV health problems. For example, one participant in Florida has mental health issues for which she is going untreated, coupled with just finding out she has a recurrence of cancer. She says “all I need is therapy and cancer care,” yet does not know how to get either without health care coverage. Another Florida participant had to stop seeing his psychiatrist because he lost his coverage.

“I had cervical cancer and by me not having insurance, I can't go take care of myself. I just found out two weeks ago... that it's back....But by me not having Medicaid ...I can't even go see about myself...I mean Ryan White takes care of my medication, but ...I can't take care of myself...So I just have to sit there, in pain, I'm

hurting, I can't do anything...I don't have no insurance. I can't see [the doctors] and honest to God, I need my therapy and I need to go see the oncologist.”-Miami participant, uninsured

Most did not face any disruption in HIV-related care during the enrollment process, in part because the RWP acted as a safety net during this time. As they transitioned to coverage, many people continued to rely on the RWP to avoid interruptions in their care, particularly around medications. Participants who experienced confusion, delays in premium assistance (discussed below), or other enrollment hurdles continued to receive care and medications via the RWP until they knew they were fully covered. In some cases this meant providing care after enrolling in new coverage but before it was activated or before the participant had learned to use it. In other cases this meant filling in when an individual enrolled in a plan without knowing that out-of-pocket costs would be unaffordable. For instance, one participant who enrolled in plan without knowing he had a \$6,000 deductible learned his two HIV medications would \$2,000 per month when he went to the pharmacy to pick them up. He couldn't afford this so turned to the AIDS Drug Assistance Program (ADAP), the component of the Ryan White Program that assists clients with accessing treatment and costs related to insurance coverage, to ensure he could continue getting the medication he needed.

Ryan White provides a sense of security that some participants do not feel with their new plans and some are confused about RWP's role now that they have coverage. The RWP has given many participants a sense of security that, no matter what happens, they will always be able to get the HIV care they need. Many place tremendous value on the program with one Atlanta woman stating “without Ryan White I couldn't afford the drugs that keep me alive.” With new coverage, however, several are confused about the role of the RWP. Some want to continue receiving care through the RWP. Several worry that their coverage will not be adequate or affordable. One participant in Atlanta had just received news from her pharmacy that ADAP would no longer cover her medications since she had a QHP. She is alarmed because she had assumed ADAP would continue covering her medications. With the news, she is worried about what her out-of-pocket costs will be under her new plan and whether she can afford them.

A key role played by Ryan White for some participants was the provision of premium support to help with the cost of new coverage. Providing premium assistance through Ryan White, an authorized use of Ryan White funds and one encouraged by the Department of Health and Human Services in the context of the ACA, helps HIV positive individuals with low to moderate incomes obtain affordable health insurance. Such assistance is often needed even for those who also receive subsidies in the health care marketplace. Several focus group participants with HIV in California reported that they were able to get help paying their premiums through the state run ADAP, a component of the Ryan White Program. Some clients vocalized that without the state's Ryan White program stepping in to assist with the cost of HIV prescriptions and premiums, they would not be able to afford coverage. One California participant receiving premium assistance said that without the additional help, coverage “would be way too expensive for me to, I wouldn't be able, not even close to affording it.”

New York participants were largely unaware of the Ryan White premium assistance even though it appeared that some might be eligible. No participants in the New York QHP group were receiving premium support but when the issue was discussed in the group, several expressed interest in the program, saying it would bring needed relief. While smaller or pilot programs were operating in Georgia and Florida at the time of the focus

groups, no participants in those groups were receiving premium assistance through ADAP in those states and Texas' ADAP program does not support QHP coverage. Some participants did however report receiving premium assistance from alternative sources such as local community based organizations (CBOs) and county offices. In one instance in Dallas, an individual decided to stop receiving premium support from his CBO because he felt he could manage costs on his own with subsidized coverage under the ACA.

"[Having access to premium assistance] would mean relief. It would make me feel less stressful. Um, I feel like I'm proactive with my health in terms of taking my medications and things like that, but I don't feel like I'm as proactive in terms of actually going to the doctor regularly and checking my counts and my levels and I don't think I'm as good at going to the doctor as I could be. But I feel like it's a lot of it is because every time I go to the doctor I feel like I get hit with a bill..." New York City participant, QHP enrollee

Despite the importance of premium support, many faced significant challenges in negotiating this process in the early months. While Ryan White premium assistance may have helped make insurance more affordable, enrolling in that support was in many cases very challenging. In California, several participants who enrolled in a QHP with premium assistance through the RWP had help from case managers or in-person assisters who connected them with the assistance. For some the process of getting premiums paid was problematic. Several participants received initial premium bills from their new QHP and were confused about whether they should pay or ignore the bills. They could not get clear answers from any source, including case managers. Some participants tried to resolve the issue by navigating communications with the marketplace, their new insurer, and ADAP on their own. One participant said that while ADAP paid their premiums six months in advance their issuer continued to send monthly bills to their residence and when they questioned their issuer, they were told to ignore the bill.

Other participants discussed having to front premiums for several months while ADAP premium support was processed. For one participant, the delay and confusion had severe consequences. After she enrolled in her plan in early 2014, she spent hours in communications with her insurer, RWP's ADAP office, and the marketplace trying to resolve premium payment issues. On several occasions, her insurer had no record of her at all, while the marketplace assured her that she was enrolled. On one call to her issuer she learned that her enrollment had never been processed at all because her premium payment from ADAP had not been received. During these first few months, when she was waiting on her enrollment to be processed and her first premium paid by ADAP, she was admitted to the emergency room for an asthma attack (care for which she was putting off while uninsured). Her emergency room expenses that totaled \$5,000 and were her responsibility as her insurance had not yet been processed when she fell ill. She says the entire experience has been incredibly stressful and time consuming.

"I don't know what really happened. ADAP was supposed to pay for the premiums. That check was never received, I guess. The problem is that when you call, you don't get any information from [the issuer]. You call ADAP and they tell you, 'oh, we paid that already.' So that went on for several months, like three months." - Los Angeles participant, QHP enrollee

Conclusion

The HIV positive participants in this study demonstrated that the ACA's health insurance expansions are already playing a role in the lives of many; even those who remained uninsured know about the law and new coverage opportunities. The themes that rise out of these focus groups show that implementation will take time. Some participants have already navigated care transitions with relative ease and have found comfort in new coverage but many HIV positive participants are still figuring out how new coverage opportunities might meet their HIV care and treatment needs; others still have not yet enrolled. For many participants, the Ryan White HIV/AIDS Program continues to play an important role under the ACA, including helping in their transition to new coverage, helping them to afford new coverage through premium support, and serving as the safety net for those who remain uninsured. Taken together, the experiences of focus group participants help to shed light on how people with HIV are navigating a new health care environment, including how new coverage may be affecting their HIV care and treatment. Understanding these challenges and successes is important for assessing the implications of the ACA for a particularly vulnerable group of individuals who have often faced barriers to accessing care in the past and for informing policymakers, providers, and client advocates seeking to help people with HIV gain new coverage and achieve optimal health outcomes.

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

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Appendix– Methodology

The Kaiser Family Foundation and PerryUndem conducted ten focus groups in five states – California, Florida, Georgia, New York, and Texas. Within these states, focus groups were conducted in the cities of Los Angeles, Miami, Atlanta, New York City, and Dallas. The states were chosen for geographic diversity, burden of the epidemic, and varying 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 the remaining three - Florida, Georgia, and Texas - have not; in addition, California and New York have chosen to run their own marketplaces while Florida, Georgia and Texas have defaulted to the federally-facilitated marketplace. Five of the focus groups were conducted among participants who (successfully or unsuccessfully) attempted to enroll in a Qualified Health Plan (QHP) through the ACA. Two groups were conducted among participants newly enrolled in Medicaid coverage through the ACA. Three were conducted among uninsured participants in non-expansion states (See Table 1).

All focus group participants were age 18 and older. A total of ninety individuals participated in the focus groups, which were racially and ethnically diverse and represented a range of sexual orientations and gender identities. The groups were predominantly male but female participants were also represented. All groups took place between June and September of 2014 after the close of the first open enrollment period (which was intended to end on March 31, 2014 but was extended to mid-April in most marketplaces). As such, they represent the experiences of participants during that period only. Given that the groups were conducted fairly early into participants experience with coverage, some had not fully used their new insurance and the findings presented here are limited to that extent. 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 while focus groups are helpful for exploring experiences and themes around a given subject and enhancing our understanding of a particular phenomenon, they are not intended to offer definitive explanations or answers and are not necessarily representative of the entire population being studied.

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