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The ACA and People with HIV: Profiles from the Field

Lindsey Dawson, Jennifer Kates, Tresa Udem, and Kathleen Perry

Introduction

The Affordable Care Act (ACA), signed into law in 2010, has provided millions of individuals with new health insurance coverage, including thousands of people with HIV. To explore what new ACA era coverage opportunities have meant for this population, we [examined](#) the coverage and enrollment experiences of people with HIV, by conducting focus groups with HIV positive individuals in five states (California, Florida, Georgia, New York, and Texas).¹ These focus groups were conducted after the end of the first open enrollment period and consisted of participants who enrolled in or attempted to enroll in private coverage through the marketplaces, those who enrolled in Medicaid as part of the expansion population, and those who remained uninsured, largely because they lived in a state that elected not to expand its Medicaid program.

In this brief, we report on findings from follow-up, one-on-one interviews conducted with a subset of twelve individuals from the focus groups to provide an in-depth look at how the ACA has affected them. The interviews that inform these profiles took place after the second round of open-enrollment, which ended in February 2015, to see how participants were faring with respect to their health and insurance coverage after two enrollment periods. Participants came from both states expanding their Medicaid programs and from states that have elected not to expand. Similarly, participants were from states relying on the federally facilitated marketplace as well as those running their own marketplaces. During the interviews, which lasted about one hour each, participants were asked to discuss their enrollment and coverage experiences, including whether they got new coverage, and how their HIV care was affected. Participants were also asked to describe the role that the Ryan White HIV/AIDS Program, the nation's safety net for people with HIV who are uninsured and underinsured, played in their care.

Key Findings

While the experiences of each of the twelve individuals profiled in this report are unique, several key themes related to their health care and coverage in the ACA era emerge:

- First, the Ryan White HIV/AIDS Program is a linchpin in their lives, without which many feel their HIV care would be compromised. Most of those profiled had been uninsured for years before the ACA and were only able to get their HIV care through Ryan White, including accessing medications through its AIDS Drug Assistance Program. Today, for those in states that have not expanded Medicaid, Ryan White remains their primary vehicle for accessing HIV care and treatment. Ryan White also continues to support many who gained new coverage under the ACA, including by providing premium support to make insurance more affordable for those in private marketplace plans, through the provision of wrap-around services such as case

management, and by offering assistance during gaps in coverage. Almost all talked about the critical role Ryan White plays in their HIV care.

- Second, among those who were able to get new coverage, either through Medicaid or in the marketplace, most said they were satisfied with their insurance but many faced enrollment or reenrollment/recertification challenges and delays. In some cases, these challenges caused individuals to fall temporarily out of care. In addition, some individuals had trouble selecting a plan that met their needs and chose coverage without fully understanding benefit designs- for instance not knowing whether a provider was in network. One individual chose a bronze plan because of the low premium but knew that he would not be able to use it unless he had an emergency because of the very high deductible.
- Third, knowledge of ACA coverage increased over time and systems got better. Several of those profiled reported improved experiences in the second open enrollment period compared with the first. A few individuals changed plans, finding new coverage that would work better for them and a couple of those profiled gained Ryan White premium support that they had not had in the past, making coverage more affordable.
- Finally, those with new coverage reported a tremendous sense of relief and feeling much more secure. In particular, some of the people profiled have complex and serious, non-HIV health complications and were able to meet these needs with either Medicaid or private coverage under the ACA, including getting physical therapy and pain management for a back injury and receiving mental health and substance use services. Conversely, those profiled who did not gain coverage, largely because they lived in non-expansion states and fell into the coverage gap, were left without coverage options under the ACA. While they were still able to meet their HIV care needs through the Ryan White Program, they were unable to address other health problems, which in some cases were very significant, including cancer and heart disease, issues that could potentially impact their HIV disease.

The below table details the state and insurance coverage status (marketplace enrollee, Medicaid expansion enrollee, or uninsured) of the twelve individuals profiled in this report.

Respondent	State	Coverage Status
Valentine	NY	Marketplace Enrollee
Jorge	FL	Marketplace Enrollee
Eric	CA	Marketplace Enrollee
Maria	GA	Marketplace Enrollee
Al	TX	Marketplace Enrollee
John	TX	Marketplace Enrollee
Patrick (CA)	CA	Medicaid Expansion Enrollee
Patrick (NY)	NY	Medicaid Expansion Enrollee
Nick	NY	Medicaid Expansion Enrollee
Zena	FL	Uninsured
Shandora	GA	Uninsured
Darin	TX	Uninsured

Background

When taken regularly, antiretroviral therapy not only improves the health and longevity of people with HIV, it has also been shown to significantly reduce the risk of HIV transmission.² For these reasons, current federal HIV treatment guidelines recommend initiation of ART as soon as one is diagnosed alongside regular care and monitoring.³ However, less than one third of people with HIV in the U.S. have an undetectable viral load and many more are not yet engaged or retained in care and treatment.⁴ Therefore, improving access to insurance coverage under the ACA could play an important role in bringing more HIV positive individuals into care and treatment and is one key component to further addressing the domestic epidemic.

While many 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, subsidized for those with low and moderate incomes. In addition, key insurance reforms in the private market, including the prohibition on rate setting tied to health status, elimination of preexisting condition exclusions, and end to life time and annual caps means that those with HIV and other chronic conditions have more equitable access to coverage.

While these reforms could have a profound impact on those who enroll in new coverage opportunities, not all people with HIV will gain insurance. Many with HIV live on both limited incomes and in states that have not elected to expand their Medicaid programs. Individuals in non-expansion states below the threshold to gain subsidies on the exchanges (100% of the federal poverty level) will find themselves in the coverage gap- ineligible for Medicaid as well as subsidies to help to purchase coverage in the marketplace. There are many other reasons why individuals may not have engaged with new coverage opportunities as well. For one, having public or private coverage may be new to some and enrollment and ability to navigate insurance may take time. Others, such as undocumented immigrants, are not eligible for coverage at all. In addition, even those who gain new coverage may still face barriers to paying for that coverage or may find that some HIV-related services they need are not covered.

It is for these reasons that the Ryan White HIV/AIDS Program has played and will continue to play a critical role in the lives of many with HIV. In addition to providing HIV care and treatment to those ineligible or unenrolled in coverage, including those in the coverage gap, the Ryan White Program, along with other- often industry lead- programs, is helping some clients with affordability by assisting with the cost of health insurance premiums and other out-of-pocket costs.⁵ In addition, the Ryan White Program may support those who have gained insurance access with certain types of services that are important for HIV care but remain unreimbursed under traditional coverage (e.g. Medicaid or private insurance), such as transportation and case management. The program can also provide consistency for those experiencing gaps in coverage and will continue to be the primary payer of care and treatment for those who have been left out of new coverage opportunities.

HIV Profiles: Valentine

NEW YORK, NY: MARKETPLACE ENROLLEE

Valentine is a 34 year old African American woman living with her female partner. She works as an administrative assistant and is the mother to three children. She is living with HIV, the Epstein Barr Virus, rheumatoid arthritis, anemia and has battled cancer twice. In addition, her eldest son needs treatment for chronic asthma. Before the ACA, Valentine had coverage through an employer but lost that coverage and was uninsured for 8 months before finding out about new coverage available to her in the New York state marketplace. She learned about marketplace coverage after seeing a click advertisement in her e-mail during the first open enrollment period. However, she had a difficult time with the enrollment process which took her several months because her social security number was showing up as belonging to someone else and she felt the representatives at the call center were not helpful. Eventually, she worked through these challenges and qualified for a subsidy. She pays \$672 a month for herself and her three children which she says is “doable” but challenging.

“I was saying that with the Obamacare I originally thought it was going to be something where it was going to be affordable, like for what I made, I was going to be able to afford it...like it wasn't going to disrupt my life so to speak... And that wasn't the case...At the end of the month, I literally probably have like \$75 or \$100 to get by with three kids until the next paycheck. So it's hard. But what can you do?”

Valentine has been able to get her HIV treatment, which is in generic form, through her plan without a problem. She says that she knew her HIV drugs would be covered but not what the cost to her would be and she only learned her doctor was out-of-network when she called to make an appointment after enrolling and so had to change providers unexpectedly. She has faced the greatest difficulty meeting non-HIV care needs in the plan. Since enrolling she has faced several issues with her coverage and with unforeseen out-of-pocket costs, including being unable to fill two non-HIV prescriptions and overall, says she is not happy with her health insurance. She says her plan seemed like a good choice for her family and for her situation, but once she started to use her insurance for more than just basic check-ups, she encountered problems. She says her medical issues are “more than just a common cold” and feels her plan does not adequately cover her family’s health care needs and that her out-of-pocket expenses are more than they should be. She is currently dealing with medical debt, including bills for an EKG, medication, and blood work. In order to cope with these expenses, she talks about cutting back on things for herself so she can pay her bills and so her children do not go without.

“Certain things can be just patched up with \$60, \$70 you get medication and you're good. But then when you have to have like chemotherapy or radiation where it's thousands and thousands of dollars...And you're fighting to live, but in order to fight to live, you also have to be able to afford to live. It sucks.”

Valentine says making her health a priority is important because her children depend on her and she knows she is living with a health condition that could kill her if she does not take care of herself. She feels like her life and her health depend on her keeping her insurance and says she would probably die without it. When she first heard about the Affordable Care Act, Valentine says she was excited, but now she feels let down – she thought health insurance was going to be more affordable and she now still feels coverage is lacking. She had not spoken to anyone about the possibility of receiving assistance from Ryan White to help with premiums and only learned of this possibility during the focus groups but plans to look into this program.

HIV Profiles: Jorge

MIAMI, FL: MARKETPLACE ENROLLEE

Jorge is a nearly 50 year old Latino man who has been HIV positive since 2001. He lives with his husband in Miami. He is currently doing cleaning work; while he has a license to work security, he has been unable to find work in that field. Prior to the ACA, he received his HIV care through the Ryan White Program. In January 2014, Jorge enrolled in a marketplace plan through HealthCare.gov. He did this on his own which he says was a “difficult and traumatic experience” because of problems getting through the enrollment process and repeatedly having to provide additional verification documents. As a native Spanish speaker, he found it helpful to be able to seek assistance from the marketplace call center in that language. He selected a bronze level plan⁶ based on its low premium, \$1.85 per month, knowing it had a \$6,000 deductible. He knew that he would not be able to afford the full cost of routine HIV drug and medical care that would be required under the plan before hitting that deductible and viewed the policy as more of a safety net in case he had a real emergency. He hoped he would not have to use it and planned to continue getting his HIV care and treatment through Ryan White where he was comfortable. He also said that he enrolled in this plan to avoid paying the fine.

“I talked to my case manager and he recommend me to change to [a new plan] because it was better for me and my doctors take that insurance. It was a little difficult to do the changes, but I’m now enrolled and I saw my doctor last week without a problem.”

Because Jorge could not afford to use his plan, he received his HIV medications through the Ryan White AIDS Drug Assistance Program (ADAP) throughout 2014. In January 2015, Jorge’s case manager, who he has seen for the past six years at a local AIDS Service Organization, suggested he switch to a different health plan with a more affordable benefit design. Jorge says the process of switching plans was difficult – he had to cancel appointments with his doctor twice and called the new issuer several times before his new plan became active. Under his new plan his \$600 a month premium is cut in half through subsidies and Jorge’s case manager helped him enroll in premium assistance through the state Ryan White Program which covers the remaining \$300. He says enrolling in premium support was a little slow and required that he bring paperwork to his case manager who sent it on to another location in Miami. However, that seems to be sorted out and he has since seen his doctor of seven years, who was also in-network in his new plan, without a problem. He is now paying nothing out of pocket toward his monthly premium and pays \$10 to see his primary care physician and \$35 to see a specialist. He feels these costs are affordable and knew what they would be when he enrolled.

“I feel good with this [plan]. I think it’s a very good thing; Ryan White can help people with HIV like me. Because medication is very expensive. That premium is very expensive.”

Jorge has not yet used his new plan to fill a prescription because he is taking the medication he had previously received through ADAP. He says he has a few months left of medicine and has been told Ryan

White will cover any out-of-pocket costs associated with his HIV medicine in the future. He hopes this will be a smooth process as he will begin accessing his medication through his new plan in the near future. Under his new plan he is excited to be switching from a three pill regimen to a once daily singlet-tablet-regimen. He will have to change pharmacies and use a mail-order service but he is pleased with this change and thinks it will work well for him.

For the most part, Jorge says he is in good health and generally able to get the care that he needs. However, he is currently putting off treatment for chronic migraines because in the past he could not afford the care. He says now that he has a plan with more manageable costs, he will look into finding a neurologist. He says having coverage makes him feel good and that the assistance he receives through Ryan White to cover his premiums is essential.

HIV Profiles: Eric

LOS ANGELES, CA: MARKETPLACE ENROLLEE

Eric is a gay Latino man living in Long Beach. He is in his late 20s working in the art and design industry and has been receiving HIV care at the same clinic for two years now. His preference is to see the nurse practitioner rather than the physician as he has a better relationship with her and feels as though “she really cares.” Prior to enrolling in ACA era coverage Eric relied on the Ryan White Program and ADAP for his HIV care and treatment but knew he would be out-of-pocket if he were to have an unforeseen emergency and end up in the hospital. In December 2013, he enrolled in a plan with platinum level coverage through Covered California (California’s health insurance marketplace) with the help of his case manager and was able to stay with his same clinic. He tried to educate himself on his coverage options under the law in advance and purposefully waited until the end of the open-enrollment hoping that any system bugs would be worked out when he enrolled.

“Getting my monthly premium paid by OA-HIPP is absolutely integral to my life at this point. My premium is over 300 dollars and without their help my finances would be dramatically affected in a negative way. What OA-HIPP is doing in their help is amazing.”

His case manager helped him enroll in premium assistance through the state ADAP program’s Office of AIDS-Health Insurance Purchasing Program (OA-HIPP) which covers the cost of his insurance premiums in the marketplace. At first he had issues with payment delays and as a result his plan was not activated until March, three months after he first enrolled. During this time he was dis-enrolled and he had to re-enroll with OA-HIPP eventually overnighting payment after he received a warning from his plan in the mail. He describes the OA-HIPP premium payment process as frustrating and like “walking in the dark and really not knowing.” However, once his premium payments were sorted out, he says the rest of the year went smoothly.

During the second open enrollment period, Eric changed to a new plan because he was unhappy with his original coverage compared to insurance he had experience with in the past. During this second enrollment process he faced issues relating to payments again. He discovered that OA-HIPP had pre-paid his plan from the first enrollment period through the first three months of 2015 and could not send payments to his new plan until they were reimbursed the balance. He was told the fastest way to handle this would be to get reimbursed directly from the old plan and pay the new plan’s premiums himself with the rebate and that OA-HIPP premium payments would start when those funds were used up. He did this but Eric went without insurance for about a month during the transition to the new plan. Eric says going without insurance when he was between plans was not disruptive to his health because he

“I’m thinking about changing pharmacies, but I’ll be quite honest, there is such a fear in me ...I’m afraid that something could go wrong and just how I was stuck in the middle between two insurances, I could be stuck in the middle of two pharmacies where neither one is providing medications.”

did not need to go to his doctor during that time and ADAP covered his medications. This was a relief as he says his greatest fear is not having his medications paid for and describes ADAP as the “backbone” of his care. At the time of the interview, Eric was on his last month of insurance paid for with the rebate and was in the process of confirming whether OA-HIPP would be ready to pick up the premium bill going forward. Despite the hurdles he faced managing his premium payments, Eric says receiving assistance through OA-HIPP is essential to his life and his health and he is very grateful for it.

While Eric wishes that his cost-sharing for provider visits was lower, he says it is a relief to know that if he were to get sick or injured, he would be covered. He would also like to change pharmacies but is worried, based on his experience of trying to change health plans, that something in the process might go wrong and he would not be able to stay on treatment during the transition.

HIV Profiles: Maria

ATLANTA, GA: MARKETPLACE ENROLLEE

Maria is a 36 year old African American woman who has been HIV positive for nearly 20 years. She has been uninsured and receiving care from a county health department clinic, since moving to Atlanta in 2004. She left work in social services last year to pursue an internship as a pre-requisite before beginning graduate school this fall.

Maria enrolled in a silver level plan at the end of the first open enrollment period in April 2014. While Maria knew she would need to find a new doctor that accepted private insurance, she was surprised to learn that ADAP would no longer cover the cost of her medications. Soon after

enrolling, Maria made an appointment with a new provider but found that the \$60 office visit copay was too high. She had not thoroughly looked at the costs associated with accessing services when she selected the plan. As a result, she was hesitant to use her new coverage and put off going to the doctor. She also struggled to get her medications after she lost ADAP eligibility. While she had some medication to hold her over for a bit, she went without HIV medications for almost two months – she would have gone longer but was able to get two additional months’ worth of medication from her old doctor at the county clinic. Going without medication for that period had an immediate impact on her health – she went from having an undetectable viral load to having a significant amount of virus in her body and her T cell count fell by more than one third.

“When I signed up the first time I didn’t really ask the questions that I needed to ask. Like is my doctor going to be in network and all that because my doctor wasn’t in network. And then when I did try to change doctors the copay was so high that I couldn’t go see the doctor.”

During the second enrollment period, Maria called the Marketplace to switch to a plan that was more affordable for her. She says she felt more informed her second time enrolling and knew what questions she should be asking, which allowed her to choose a plan that better suited her needs. She says, “I knew that I needed to be able to go to the doctor, I needed to pay the copay, I know I need my medications.” Under her new plan, Maria’s copay to see her doctor is \$5 and her monthly premium is \$52 with a subsidy. Since enrolling in this plan, Maria has started seeing a new HIV doctor at general care practice with an infectious disease sub-specialty and says she has established a strong relationship with both her

“It didn’t really feel good to not be able to go to the doctor when I needed to or not be able to get my medication...I can only imagine if I would have [gone] without meds for any longer what would have been the outcome. So you know it’s just a good feeling to be able to take care of myself.”

doctor and the practice. She says that she knew the plan she selected had a narrow network but that she was okay with that so long as she could get the care that she needed. In addition, Maria’s case manager connected her with the Patient Access Network (PAN) Foundation, through which she receives financial assistance to cover the out-of-pocket costs associated with her HIV treatment. She says the second enrollment period and new plan has been a “much better experience.”

This summer Maria is moving to Tennessee to pursue her Master’s in Social Work. She says she plans to commute the couple of hours to see her current doctor until she enrolls in coverage in Tennessee. Staying insured is very important to Maria – she says that the Ryan White Program was wonderful for her when she was uninsured, but she feels better knowing that she can now also take care of non-HIV related health care needs.

HIV Profiles: Al

DALLAS, TX: MARKETPLACE ENROLLEE

Al is a gay African American man and a recent college graduate in his late 20s. He learned he was HIV positive in April 2014 – one month after he first enrolled in new coverage in the marketplace. When Al first enrolled he chose a plan with a high deductible because he was unemployed at the time and thought it would best fit his budget. He says that the plan he chose did not meet the needs of someone with HIV given the very high deductible but he selected it because the premium seemed manageable. After learning his HIV status, Al worked with the county health services to sign up for a county based insurance assistance program that leverages Ryan White funds to help him with the costs associated with his HIV care. Al received \$750 a month, which he put towards his monthly premiums and copays for doctor’s visits. He was also enrolled with a manufacturer’s copay assistance program that provided \$5,000 a year to help with HIV medication costs. Al says the process of signing up for financial assistance took several months during which time he went without HIV medication. He also believes it was a slow process because he was the first client health services had helped with premium assistance. However, he was grateful to have the support and help navigating different assistance programs and once everything was in place, Al had no out of pocket expenses towards his health care.

“...I was in a horrible plan too. My deductible was like \$6,600 to meet. And so I had to have like so many promotional discounts before I was able to get my first pill. So I literally sat in the pharmacy office for my first 30 day prescription for almost four hours just to get the 30 day pill selected just for HIV alone, for them to cover that because my deductible was so high.”

Then, in July 2014, Al got a job as an accountant and had the option of either getting health insurance through his employer or selecting a Marketplace plan for which his employer would cover a certain amount of the costs. Al did not want his employer to know his HIV status and was more comfortable with marketplace coverage. He had to wait until the end of the year to enroll but in the interim, he was able to remain covered with premium assistance through the county. In selecting a new plan, he wanted coverage that would best meet his HIV needs and after consulting with

“...I chose like five plans ...and then I went to Health Care Services and asked them if there’s a preference on insurance that a lot of other HIV clients have...and they helped me narrow down...And so every company that I chose that had a book that told how much the medicine was going to be every month... So, that was very helpful.”

different enrollment workers selected a new plan in January 2015. His monthly premium is \$153, but with his employer's assistance, Al is responsible for just \$1.50 a month. While his employer covers most of his monthly premium, health services continues to assist with office visit co-pays, which Al says would be manageable at \$30, if he did not have the help. Under his new plan, Al's HIV medication costs \$2,000 a month which must be paid in full until he reaches his \$3,400 deductible, but with help from the copay assistance program he does not have to pay anything out of pocket.

Tax time was a bit confusing for Al. He completed his taxes, including information about his coverage, and received notice that he was owed a refund related to his insurance but he was not sure what it meant or what he had to do. Al has tried to be in communication with the IRS without luck and is waiting on further follow-up.

Speaking broadly about insurance literacy, Al worries that young people graduate from college without knowing how to navigate the insurance world and wishes there was more education around this issue for them. As a recent grad himself, he notes that without the assistance from the county he would not have known how to get his own health care needs met.

HIV Profiles: John

DALLAS, TX: MARKETPLACE ENROLLEE

John is a gay man who has been living with HIV since 2004. He is self-employed and had private insurance for several years prior to enrolling in a health plan through the marketplace. Before marketplace coverage became available, he received help paying his monthly premiums from a community based organization (CBO) using Ryan White funding for this purpose. He signed-up for a plan in the marketplace in February of 2014 through the same issuer with which he had previous coverage, leaving his off marketplace plan behind.⁷ Once gaining marketplace coverage, however, he lost Ryan White premium assistance because he signed up for a gold metal level plan with the aim of enrolling in more robust coverage. He was told that in order to continue receiving premium assistance, he had to change to a silver level plan but elected not to go through the "long fiasco" of having to reapply. In addition, he wanted to retain what he believed was more comprehensive coverage. For the first year he forwent premium assistance but paying the \$400 a month premium out-of-pocket was sometimes a struggle for him.

"[The non-profit where I get some assistance] told me, oh well if you want to keep the program where you're reimbursed or Ryan White pays your insurance, you have to go back and change your coverage because you're on the gold level and Ryan White will only cover individuals on a silver level...for the first year I elected no, I'll pay my own insurance."

When the time came for him to renew his plan during the second open enrollment period, John stuck with the gold level plan because he liked having a lower deductible and more comprehensive coverage. The CBO, however, had changed their policy and John was able to get premium assistance once again. Now, John is paying a total of about \$65 out of pocket each month for his doctor's visits and non-HIV medication copays and does not pay monthly premiums. John gets his HIV medication without having to pay anything out-of-pocket because his pharmacist helped him enroll in a copay assistance program with the drug maker. He paid his first month's premium himself which he says helps ensure that the third party payments (from the CBO) get to the plan on time, and says that even if they are late, he is effectively paid a month in advance. This is important to him as he found getting his premium paid on time a challenge when he was receiving pre-ACA era premium assistance. John says access to premium assistance is very "significant" and allows him to use the money he saves to help pay down his debt.

"[It's] worthwhile to have private insurance. Just because you feel like a normal [person], you get normal medical care where you walk in, you have a doctor's appointment, you see your doctor, you're doing what you're supposed to do and then you leave."

Without premium assistance John believes his coinsurance would be over \$300 a month. He also was able to get his non-HIV prescription at a discounted rate negotiated through a website which he also learned about at his pharmacy, rather than directly through his plan. John goes to his psychiatrist twice a year to renew his non-HIV prescription and pays a \$10 copay for each visit. He says he will probably look at different plans during the next open enrollment period, but that he is comfortable with his current plan and does not plan on switching.

When John filed his taxes this year he gave his accountant a 1095-A form detailing his policy and subsidy information that he received in the mail. He learned that because his income had gone up a few thousand dollars from what he had projected, he owed some money back to the IRS related to his subsidy which was a bit surprising to him but says dealing with the tax issues around marketplace coverage was not a problem.

HIV Profiles: Patrick (CA)

LOS ANGELES, CA: MEDICAID ENROLLEE

Patrick is a white man in his late 40s and has been living with HIV for over a decade. He was able to enroll in Medi-Cal (California's Medicaid program) because the state expanded Medicaid eligibility as part of the ACA. Prior to enrolling in Medi-Cal, he had been enrolled in Healthy Way LA, Los Angeles' pre-cursor to the Medicaid expansion. As the program intended, he explained that this allowed him to easily transition into Medi-Cal in December 2013 (for 2014 coverage) with the help of his case manager.

He has faced some technical issues with the Medi-Cal program around renewals and has been dropped out of coverage twice since enrolling. On the first occasion, Patrick

was briefly dropped from Medi-Cal in May 2014 because he did not know he had to renew on his birthday, but he was able to quickly reenroll after talking to someone at his clinic. After that, he did not experience interruptions in care until January 2015, when he was dropped from coverage a second time because he again failed to renew his plan. He says that he, along with many others at his clinic, were not aware they had to renew

"I was expected to renew in January because that's when my year had ended, but not at the center where I had [initially enrolled in Medi-Cal], but at the Department of Social Services. I had no idea, I mean, why would I think that? And they didn't really get proactive about communicating that and boom, people were dropping left and right from Medi-Cal."

through the Department of Social Services. Many assumed renewals would be handled by the clinic where they receive care and case management and where they had initially enrolled in Medi-Cal. Patrick feels there was a lack of communication about renewals from both Medi-Cal and the clinic.

Patrick also missed the re-enrollment deadline to continue with case management in early 2015 and he was kicked out of the clinic's case management program. He was very frustrated and felt neglected by his case manager, especially because he felt these services would have been particularly helpful during the period when he lost coverage.

Patrick spent all of January without coverage, causing him to go without his HIV medications and without doctor's visits. He found it worrying that the clinic did not seem to be able to help with his medications while he was uninsured. Without case management services he decided to re-enroll on his own. He explains that it took a lot of effort to navigate the system but ultimately he was able to make an online appointment and go in person where he was re-enrolled with his plan after a 20-day activation period. He describes the month as "exhausting" and "overwhelming" and says he spent much of February recovering after getting sick and going almost a month without care.

"I can go [into the doctor's office] and tell them that I have a problem and they'll get me a referral and I have to follow-through on it, but it's all pretty amazing. Because it wasn't always that way, the pain was pretty much there for a long time and, you know, I was lucky to get [Medi-Cal]."

Despite the issues he has faced around renewing and lapse in coverage, Patrick says having Medi-Cal has changed his life. He has been able to seek care for health issues that he had been putting off for years, including physical therapy and pain management for a back injury from being hit by a car two years ago. Patrick also receives mental health care through Medi-Cal from a nonprofit organization focused on the mental health and wellness of people living with HIV and AIDS. Additionally, he has been able to see an eye doctor and a dentist who specifically works with people with HIV. He says his future looks good and his experience having coverage through Medi-Cal has been "amazing" overall, despite the administrative challenges.

HIV Profiles: Nick

NEW YORK, NY: MEDICAID ENROLLEE

Nick is an African American gay man in his mid-20s working as an actor and earning a limited income. He was first diagnosed with HIV in February of 2013. When first diagnosed he had insurance through his mother which he lost that summer upon turning 26. Nick first engaged in HIV care and started treatment 6 months after his diagnosis when he had become uninsured and had to rely on ADAP and Ryan White more generally. After urging from a social worker at his clinic, Nick signed up for a Medicaid managed care plan in March of 2014, which she helped him to select, pointing out that he could stay with them in-network, if he chose to. He signed up online at the LGBT Center with a counselor who was knowledgeable about his HIV status, which he says was helpful. The whole process only took him 15 minutes, and he faced no difficulties enrolling. His priority when choosing a plan was to be able to stay with his Ryan White funded clinic. Since gaining Medicaid coverage, Nick has been able to continue to receive care from his

"[Having Medicaid] feels good because I know that if I needed to do something or if there was an emergency that I have a plan that can cover it."

same provider and has been able to continue with his HIV medication at no cost. In addition, Nick receives substance use harm reduction services and attends support groups through a community-based organization that provides assistance for LGBT youth, services which are new to him since gaining coverage through Medicaid.

Nick says he has not had to pay anything out of pocket for care, including check-ups, dental visits, and HIV medication co-pays (he previously had a \$3 copay but that has now been waived). The only issue he has faced since gaining coverage was a short delay in getting his medication when he switched to a mail order pharmacy service, which he opted to do for the convenience. At first the pharmacy was unable to fill his prescription because their system listed his Medicaid plan as inactive but he was able to rectify the situation over the course of two days with the help of his case manager and only went one day without his HIV medication. When this occurred his case manager reassured him that if there was going to be any significant gap, ADAP could step in to assist to ensure he was able to stay on treatment.

“Well my social worker explained to me that ADAP is basically like a Band-Aid. It doesn’t really cover all of the things but with Medicaid I’m able to cover support groups and other things like that that I couldn’t get [before].”

He says having Medicaid makes him feel more secure knowing that he has coverage in case something happens to him. He feels Medicaid offers him access to more comprehensive health care and he is more aware of the health care services that are available to him. He also says he is more mindful of his health needs now that he knows those services are available to him, if needed.

HIV Profiles: Patrick (NY)

NEW YORK, NY: MEDICAID ENROLLEE

Patrick is a gay 32 year old African American man living with his partner and working in criminal justice social services. He has been living with HIV for several years. In June of 2014, Patrick enrolled in New York state’s Medicaid expansion program, with the assistance of an enrollment specialist at New York City Human Resources Administration/ Department of Social Services who helped him select a Medicaid Managed Care plan. Prior to enrolling in Medicaid, Patrick was not regularly seeking out care and treatment; though when he did seek out HIV care, he received it from a community health center that specialized in providing care to New York’s LGBT population. With Medicaid, his main priority in selecting a plan was to ensure he had options for and flexibility in where he could go to receive care. He also wanted to ensure he could stay with his doctor at the community health center. Patrick says the clinic has a philosophy of the doctor staying with a patient and describes his doctor as the best thing in his life.

“Well now, I’m able to get my meds I’m able to see the doctor and it makes you feel good about yourself now. It makes you feel like you’re doing self-care and you’re taking care of yourself.”

Overall, Patrick has had a positive experience with the care he receives under Medicaid, but he faced challenges with enrollment. He wishes that the process for enrolling were simpler and more straightforward; he also found plan selection complicated. He says it took him forty-five days to get coverage, during which time he went without his HIV medication and doctor’s visits. Patrick says he is very happy with his Medicaid plan and the care and treatment he receives related to his HIV needs, particularly not having to pay out-of-pocket for

care. He says he is able to make doctor's appointments when he needs them. Patrick had been paying a copayment for his HIV medication at the pharmacy at his clinic, but he recently switched to another mainstream pharmacy, which is closer to home, and where his copay is waived. Additionally, the new pharmacy has a pharmacist with whom Patrick has developed a good relationship and who he describes as a counselor, explaining he can go to him with general questions about health and nutrition. He says the pharmacy makes "life easier for you" and appreciates that they will call to remind him when his medication is running low and will get refills approved on his behalf. Patrick has also been able to take care of non-HIV care needs through Medicaid and recently went to the podiatrist – he needs foot surgery and was pleased when his plan approved it right away.

"... I went to the case manager and I'm not gonna sit here and lie to you; that's complicated when you have to go through a book and have to look at different health insurances and different you know and it's like okay; wait, wait, wait, wait, wait I just need health insurance."

Despite his overall satisfaction, Patrick faced an issue recertifying for Medicaid coverage. In October, when he went to an appointment at his clinic, the billing department told him that his card was showing he was no longer enrolled in Medicaid when it was scanned. They followed-up for him and learned that he had been terminated as he had not recertified. In order to resolve this he had to go through a fair hearing process, waiting until December for a hearing date. At the hearing he learned that he had been marked as homeless when he first enrolled in Medicaid (despite the fact that he was not and as a result he never received a recertification letter). He was able to demonstrate that he had resided in the same place for the past three years and that the error must have occurred at the agency end. After explaining his situation at the hearing, he was quickly reinstated but leading up to that time, he went without care.

HIV Profiles: Zena

MIAMI, FL: UNINSURED

Zena is a 47 year old African American woman, a mother and a grandmother. She has been uninsured for most of her life. While her HIV disease is well managed due to care she receives through the Ryan White program, she currently is not working due to her many non-HIV health problems and stress level. During the first open-enrollment period case managers encouraged Zena to enroll in marketplace coverage. She was frustrated by the process and ultimately did not enroll because she found it confusing and knew she would not be able to afford coverage. Nobody explained to her that she fell into the coverage gap because she lived in a non-expansion state.

"[Being uninsured] is very stressful because you know when it comes down to going to the doctor or trying to get medication, that's a really hard thing to do because if you don't have insurance you can't get medicine, and that's driving me crazy because it's stuff that I need and I sit and I cry because I can't get it."

Zena receives her HIV health care through Ryan White, including her medications and visits to an HIV specialist. She says without Ryan White she would not be able to afford her \$800 a month medication and says that "It would go bad, it would really go bad.

I probably would be so sick I'd die, just honestly I would die because if you don't have your medication, your T cells, your viral loads, everything drops and if you get sick, you're in the hospital with pneumonia or whatever else and you die." Despite this, when it comes time to recertifying her Ryan White eligibility, she sometimes struggles to wade through the "red tape" and recertify on-time and keep up with her medication consistently.

She says that sometimes there is a delay and she ends up stretching out dosing while she waits for her new prescription; she worries about the impact that this could have on her viral load and her health. Still, while meeting her other healthcare needs presents very real challenges, Zena says that it is a relief to know that at the very least she will have her HIV needs met.

Zena says she is unable to take care of her non-HIV health care needs and is living in pain. She has been trying to manage her worsening health without insurance, which she says has adversely affected her health and by extension her ability to find work. She says being uninsured is very stressful and that she is often sick with her various health issues, sometimes ending up in the ER where care and treatment is short-lived.

“I’m back and forth in the emergency room, you know ... they’ll give you a little medicine and you take that, and then you come back home and you still sick, you know not leaving the house, not getting out of my bed, just sick. I mean it wasn’t nothing I could do about it because I don’t have any insurance, I don’t have money, so I just do without.”

She is putting off surgery on her knee, treatment for chronic back pain, getting a machine to assist with her breathing difficulties, as well as regular blood pressure treatment, and dental and vision care because of the costs involved. In addition, she is a breast cancer survivor and in February, Zena had a surgery for cervical cancer, and is now receiving bills she cannot pay, adding to her existing medical debt of over \$10,000. She has been putting off follow-up care, including radiation and chemotherapy, and gets an over the counter treatment rather than the costly prescription drug she is prescribed. She is only sometimes able to get her medications filled for pain management and blood pressure because she hates to ask her children for help and finds it difficult to pay on her own.

Zena filed a disability application over a year ago but is told only that it is in process when she follows-up and her case manager tells her she must continue to wait. She is hopeful that once approved, she will be able to gain public insurance. She says getting insurance would “mean the world to her.” Zena wants to have control over which doctor she goes to and be seen by the doctor right away, rather than sitting for hours in the waiting room as she does now. She wants to get the care and treatment she needs. She feels the ACA was first conceived for people like her, but now feels left out and forgotten.

HIV Profiles: Shandora

ATLANTA, GA: UNINSURED

Shandora is a 50 year old African American woman who has been diagnosed with HIV more than 25 years ago, in 1989. She has been uninsured for thirty years. She explains that, in part, she has been uninsured due to a battle with drug and alcohol addiction that made seeking coverage in the past impossible. She started receiving HIV treatment in 1996 but was in and out of care as she battled substance use. Today, she has been in recovery for more than seven years and for the last six has been in HIV care consistently since moving to Atlanta. She says she is in “an extremely good place” right now. Still, she has been unable to get coverage, primarily because she earns only a limited income as a server in a restaurant and she can’t afford it.

“Certain areas of my health I’m neglecting because I’m not insured... I may need a knee replacement, and financially I don’t have the ends to do that right now, because I’m not insured, Ryan White does not cover orthopedic care.”

To obtain her HIV care, Shandora has been using a city university hospital’s Infectious Disease Program supported by Ryan White and gets her HIV medication at no cost through ADAP. The Ryan White Program covers the cost of her healthcare costs related to HIV, including visits with her primary doctor – who is an HIV specialist. She says she has a good relationship with her doctor, which is important to her because her doctor can make personalized recommendations for her. She now takes just two pills a day – her HIV medication and a water pill for high blood pressure – which is down from more than twenty pills she was previously taking daily.

In addition, for the past eighteen months, Shandora has been in a residential living program that provides housing to HIV positive low-income people who are at risk of becoming homeless. She describes this program as “the best thing that could ever happen to [her].”

Shandora tried to get coverage through the Marketplace last spring, with the help of a case manager at her residential program but later, at her clinic, learned her income was too low to receive assistance—she fell into the coverage gap, so she did not apply for coverage. She was relieved to learn that she would not have to pay the penalty, but wants the security that having insurance would offer. However, she also admits that she is afraid of what getting coverage would mean for the assistance she receives through Ryan White which she has come to rely on and she says that it is keeping her alive.

“[Getting insurance] would give me a sense of relief because I wouldn’t be hesitant about going to the doctor if there’s anything that I need to have checked out, because I know I’m covered. And now, just with Ryan White I feel limited because I can’t afford just to go to a doctor when I feel like something is going wrong, other than dealing with my HIV.”

While she is managing without insurance, Shandora says being uninsured makes her feel limited and afraid – there is care that she needs but is not seeking because of costs, including dental and vision care, which are important for helping to manage HIV disease. She also needs orthopedic surgery. She has also been putting off a knee replacement for over a year, describing the pain as “unbearable” and tells of several falls at work when her knee has given out, yet she is not pursuing treatment because she is without insurance coverage and fears large medical bills. She has an outstanding bill of a few hundred dollars from a sonogram that she is unable to pay and worries about the impact on her credit, which she is trying to restore.

HIV Profiles: Darin

DALLAS, TX: UNINSURED

Darin, who is 50 years old, has been mostly uninsured since 2009 when he relocated to Texas from another state and lost employer coverage, an experience which he describes as stressful. He briefly signed up for a health plan through HealthCare.gov in March 2014 before learning that he fell into the coverage gap and that, as a result, he would not be able to receive subsidized premiums through the marketplace or help paying his premiums from an AIDS Service Organization (ASO). Darin could not afford his premiums without assistance so let his plan lapse after just two months. He described the enrollment process and loss of coverage as frustrating and confusing and he remains unsure as to why he does not qualify for assistance, because the eligibility requirements were not explained to him. He says he feels like he has limited options to access health care without insurance. He feels aggravated since he will sometimes be denied care at county hospitals because

his income is too high but makes too little to qualify for subsidies in the marketplace. He says, “one place is telling me I don’t make enough and another is saying I make too much.”

In the meantime, Darin is receiving assistance for his HIV needs through the Ryan White Program at an ASO, including medications, lab work, and doctors’ visits. He describes his physical health, including being HIV positive, as “very strong” and says the providers he sees are extremely knowledgeable about HIV. He says without Ryan White “my health would definitely diminish because that would cut off my medications and if I can’t get my medications then my systems, the HIV would take over because I need those medications to keep my system up.” With the assistance he receives, he says he never misses taking his HIV medicine.

“They told me I had to make a certain amount and that I didn’t qualify because of the amount that I was making. So it was a little confusing because I really didn’t understand what the whole health care plan was...I thought it was supposed to be for lower income, but it wasn’t ...because they said I didn’t make enough.”

While his HIV care needs are met through Ryan White, Darin says he is putting off a visit to the cardiologist for his heart condition which is a problem because he recently ran out of medication and cannot get a new prescription without seeing this provider. He says the heart medication itself is affordable, at just \$20 a month, but is inaccessible because he cannot afford the \$200 office fee to see his cardiologist to get a prescription refill. He says he is trying to manage without his heart medicine by eating right, exercising, and taking fish oil and aspirin, but is afraid of what might happen if he goes too long without it. Darin had a heart attack in 2013 and now has \$15,000 in medical bills that he has no way of paying. Aside from his physical health, he says his mental health has been a “little rocky” but he is able to get mental health services and medications through a publically funded program providing these services to low-income Texans.

In November 2014 Darin enrolled in Supplemental Security Income (SSI) benefits but, at the time of this interview, had not heard from his case manager about how this might impact his eligibility for public insurance. He had thought, based on hearsay, that he may have a two year waiting period.⁸ He plans to follow-up on his eligibility.

“[Being insured] would take away a lot of stress because I do stress over it and I worry about if I get sick what’s gonna happen. And so it would have a sense of relief for me where I didn’t have to worry about if I get sick or if something came up that...or, if heaven forbid, I had another heart attack or something. So it would be a major relief. Because if I get sick, I can just go in and give them my insurance card and be done with it.”

Having insurance would give Darin a sense of relief and take away a lot of the stress in his life. He says he feels uneasy being uninsured because of the uncertainty of what might happen to him if he gets sick. He says he would be “ecstatic” if Texas expanded its Medicaid program and he was able to get coverage. He wants to be able to take better care of himself and get the care that he needs.

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

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ENDNOTES

¹ Kates, J, Dawson, L., Udem, T., and Perry, K. Kaiser Family Foundation. Under the Affordable Care Act: Experiences in Five States. 2014. Available at: <http://kff.org/hiv/aids/issue-brief/health-insurance-coverage-for-people-with-hiv-under-the-affordable-care-act-experiences-in-five-states/>

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

³ Department of Health and Human Services, Panel on Antiretroviral Guidelines for Adults and Adolescents. *Guidelines for the Use of Antiretroviral Agents in HIV-1-infected Adults and Adolescents*. April 8, 2015;. Accessed 5/4/15. at: <http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/o>.

⁴ 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.

⁵ For a discussion of the role The Ryan White Program plays in insurance purchasing see: *Cite insurance purchasing brief*

⁶ Marketplace plans are grouped into different metal levels- platinum, gold, silver and bronze- each is associated with an actuarial value (a percentage representing the share of costs a plan would cover for a typical enrollee). Typically platinum offer the most generous coverage and bronze the least, with gold and silver plans falling in between.

⁷ Marketplace plans are those health plans sold on the health insurance marketplaces set up by the federal government and some states. Most individual non-marketplace plans now have the same protections as marketplace plans but only those plans selected through the marketplaces afford access to the health insurance subsidies available to those 100-400% of the federal poverty level.

⁸ There is no waiting period for enrolling in Medicaid through an SSI pathway but there is two year waiting period for those enrolling in Medicare based on SSDI eligibility. This information was provided to the respondent after the interview.