Introduction

In July 2015, the federal government released the updated National HIV/AIDS Strategy, which provides a roadmap toward preventing Human Immunodeficiency Virus (HIV) transmission, engaging and treating those living with the illness, reducing health disparities, and better coordinating the national effort to combat HIV. The strategy identifies both the Affordable Care Act (ACA) and the federal Ryan White HIV/AIDS Program (RW) as key elements in helping people living with HIV (PLWH) obtain health insurance coverage and remain in medical and wrap-around care. For PLWH and their providers, coordinating between these two programs can present both opportunities and barriers to improving patient care. In particular, it can be challenging to navigate the various regulations and eligibility requirements to select affordable and accessible medical coverage(s) and services.

This document will provide brief overviews of the current state of HIV in the US and the interaction between the ACA and RW programs, as well as case examples that highlight important considerations for providers and PLWH.

Brief Overview of HIV in the US

In the US, an estimated 1.2 million people are living with HIV. In the early 1980s, when HIV/AIDS was initially identified, the illness was considered to be almost universally fatal, but much has changed over the years. Indeed, since 1996, there has been a substantial improvement in the number and types of medications available to treat HIV, and it is now known that a combination of medications can reduce viral levels, decrease symptoms and opportunistic infections, and extend life expectancy. In fact, if a PLWH is diagnosed soon after infection, placed on medications, and adherent to the daily treatment regimen; s/he can expect to live an almost average lifespan. However, it is estimated that less than 20% of PLWH in the US are in care, taking medications, and virally suppressed. The ability to engage and remain in care and consistently take medication is negatively impacted by a number of psychosocial factors. PLWH have a significantly higher incidence of living in poverty, engaging in substance use (active or historical), mental health challenges, and histories of trauma and/or interpersonal violence. In addition, stigma toward HIV and discrimination negatively impact daily life, interpersonal relationships, and overall wellness. Each of these factors creates barriers for PLWH to enter and remain in care, which place them at risk of worsening HIV, opportunistic infections, and, ultimately, early death.

Furthermore, increasing evidence demonstrates that remaining engaged in care and adherent to medications suppresses HIV and is, consequently, an important tool for preventing new infections. Several recent studies have shown that when undetectable viral levels are attained HIV transmission is reduced drastically. In contrast, over 90% of the approximately 45,000 new HIV infections in the US in 2009 could be traced to people who either had undiagnosed HIV (30.2%) or were not engaged in medical care (61.3%).

Brief Overview of the Ryan White Program

The Ryan White Comprehensive AIDS Resources Emergency Act (RW), first passed in 1990, was established to better ensure access to and utilization of HIV care. The program allocates funds to provide medical and psychosocial services to low-income PLWH. Over the years, RW has expanded to include a wide range of funding to provide services to PLWH. For example, RW Part A provides funding to large metropolitan areas with the highest incidence of HIV. RW Part B provides grant support to states with the goal of improving local HIV care and services. Part B includes the AIDS Drug Assistance Program (ADAP), which provides medication access to the uninsured and underinsured. Some
of the services provided under the RW program include: outpatient medical care, oral health, nutrition services, hospice, mental health care, substance use treatment, home health care, and medical case management. The program serves over 500,000 clients each year and targets PLWH with the fewest resources.9

On the provider side, utilization of RW funds requires serving clients regardless of their ability to pay, while still ensuring that all other funding options have been exhausted. This means that providers must make every effort to bill for services and find alternate means of support for client care.9 HRSA, the federal agency that administers the RW program, issued a policy clarification after the implementation of the ACA outlining the requirements of RW providers: “Grantees and their contractors are expected to vigorously pursue enrollment into health care coverage for which their clients may be eligible (e.g., Medicaid, CHIP, Medicare, state-funded HIV/AIDS programs, employer sponsored health insurance coverage, and/or other private health insurance) to extend finite RWHAP grant resources to new clients and/or needed services. Grantees and subgrantees must assure that individual clients are enrolled in health care coverage whenever possible or applicable, and are informed about the consequences for not enrolling.” However, this clarification notes that RW will “continue to be the payer of last resort and will continue to provide those RWHAP services not covered, or partially covered, by public or private health insurance plans.”10

Affordable Care Act

The Affordable Care Act (ACA) was signed into law in 2010 with a goal of expanding access to health insurance throughout the US. Since ACA’s insurance exchange marketplace enrollment opened in October of 2013, the National Health Interview Survey found that “among adults aged 18–64, the percentage who were uninsured at the time of interview decreased from 20.4% (39.6 million) in 2013 to 13.0% (25.5 million) in the first 3 months of 2015.”11

Initially, the expansion of access to insurance was two-part, based on: 1) the ability to purchase private insurance for people earning over 100% of the Federal Poverty Line (FPL) and 2) the expansion of Medicaid. As it relates to the first part, changes have been established, either at the state or federal level, to create a marketplace for those who do not have access to insurance through other means. Additionally, a financial support system was formed in order to subsidize insurance plan costs, based on income.12 Moreover, in order to ensure accountability, a tax penalty exists for uninsured individuals who are deemed able to afford purchasing a health plan through an exchange.13,14

In relation to Medicaid, the ACA offers substantial additional funding to states in order to offset costs of the expansion. Prior to the ACA, Medicaid largely served children, pregnant women, and people with disabilities. In general, non-disabled low-income adults were ineligible.15 The ACA proposed to make Medicaid available to anyone, regardless of health status, whose income was below 138% of the FPL with the condition that, if a state did not expand Medicaid access and accept the new funding and requirements, they would lose all Medicaid funding.16 However, the US Supreme Court, in National Federation of Independent Business v. Sebelius (2012), ruled that the requirement to accept all or no Medicaid federal funding was coercive and, therefore, not allowed. This ruling made it possible for states to decline the Medicaid expansion under the ACA, while maintaining their existing programs.16 Under this voluntary arrangement, 28 states have moved forward to expand Medicaid as of May 2015.17,18

Since the ACA anticipated national Medicaid expansion, people whose income is equal to or below 100% of the FPL are not eligible to receive financial support for the purchase of private insurance through exchange marketplaces.13,14 In states where Medicaid was not expanded, pre-existing programs remain in place. As was the case prior to the passage of the ACA, low-income adults living in these states are still largely ineligible for Medicaid coverage unless they have a disability, thus leaving them with little or no opportunity to obtain insurance and health care.

ACA and Ryan White Funding

Coordination between the ACA and RW has become an important challenge for both PLWH and HIV service providers. In particular, expanded Medicaid based solely on income enables low-income PLWH to access insurance coverage for medical care and medications, which had previously been covered, almost exclusively, by RW.19 Despite Medicaid expansion, it is likely that some PLWH will still not be able to
access public or private insurance coverage for a variety of reasons: homelessness, mental health issues, and other psychosocial challenges can become barriers to navigating these complex systems.

Although expanded private and public insurance coverage is an important step forward for PLWH, there is much more to HIV care than being engaged in medical care. It has long been recognized that effective HIV care includes services to help address emotional, social, and economic issues, along with medical treatment.20 However, many of these important, holistic wrap-around services are not covered by insurance. A white paper listed the services provided through RW in Ohio that received limited or no reimbursement from public or private insurances, including: outreach, transportation, language access services, respite care for caregivers, referrals for health care and other support services, food bank/home delivered meals, psychosocial support, case management, child care services, emergency financial assistance, health education/risk reduction, legal services, and treatment adherence counseling.21 This report specifically highlighted case management as a non-reimbursable service that is fundamental to helping PLWH navigate complex medical systems, obtain resources for housing, food, counseling and other support services, as well as receive psychosocial and emotional support. Although access to HIV medical treatment was significantly augmented by the ACA, “the Ryan White HIV/AIDS Program will still be needed to provide comprehensive, quality HIV care and to help engage and retain HIV-infected patients in that care.”19

**Case Example**

Peter, age 5, was diagnosed with HIV after an extended hospitalization in Philadelphia. Peter's diagnosis led to his mother (Sherry), father (Jacob), and two siblings being tested for HIV as well. His mother was found to have HIV, but the rest of the family was negative. Sherry, who moved to the US from Ghana when Peter was 2 years old, is a legal permanent resident under a visa provided to spouses of citizens. Jacob drives a cab, and does not receive employer-sponsored medical insurance, and Sherry is a homemaker. The family’s income is erratic, but often at or below the Federal Poverty Line. Due to the family's income, the children are enrolled in Medicaid and receive regular medical care. Peter will continue to receive Medicaid, which will cover his HIV specialty care and the antiretroviral medications he has been prescribed.

On the other hand, his parents’ access to health insurance and medical care is more complicated. Jacob was not eligible for Medicaid or the insurance exchange in 2013 prior to Pennsylvania’s Medicaid expansion. He may have become eligible for Medicaid under the 2014 interim plan, and is now clearly eligible under the full expansion in 2015. However, Sherry faces additional barriers; as a new legal resident of the US, she must wait five years before becoming eligible for Medicaid. Nevertheless, Sherry does have some options for receiving HIV medical care and medications. She could enroll in a RW funded program that would see her without regard to her ability to pay and in ADAP to receive medications. These are likely the best initial steps to engage Sherry in care and treatment right away. However, the RW program must certify both her eligibility for services and their efforts to help Sherry obtain other means of financial support for HIV care. In Sherry’s case, the ACA provides an avenue to purchase insurance through an exchange marketplace. Although, typically, people with income at or below the FPL are not eligible for financial subsidies through the exchange, legal residents within the waiting period prior to receiving Medicaid are offered an exception to this rule. Sherry may, finally, be able to purchase insurance via the exchange and receive a subsidy to make this option affordable.

Given the complexity of navigating RW and the ACA, having access to knowledgeable staff allowed Sherry to secure premium subsidies under the exception for legal permanent residents not yet eligible for Medicaid. Without this knowledge, Sherry would not have been able to afford the medical care she needs.

**Organizational Example**

A child and family HIV clinic receives grant funding under RW to provide a number of services, including medical care and medical case management. A condition of this funding is that the clinic must provide quarterly reports on uninsured clients, documenting each patient's eligibility for Medicaid or the insurance exchange marketplace, and noting what efforts have been made to assist them in obtaining insurance.

The clinic develops a system to review insurance coverage during weekly planning meetings for clients scheduled for the following week. For those without active insurance, the team assesses what type(s) of insurance the patient may be eligible for and any previous efforts made to help the patient. Then, a plan of action is agreed upon.

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Typically, it is agreed that the patient needs to be seen for medical reasons and will access services at no cost for that visit under RW. Moreover, the medical case manager will meet with the client to discuss the importance of obtaining insurance and explain the necessary next steps to achieve this goal. The clinic sees a very high volume of patients living in poverty and Medicaid is often the best option for them. The case manager will help the client complete the online application for Medicaid or the exchange and submit the required accompanying paperwork. If the patient needs medications that day, an application for ADAP will be completed, and a request for RW emergency support for HIV treatment will be faxed to the participating pharmacy. These applications will provide the patient with HIV care sooner than Medicaid would, thus immediately providing HIV care to uninsured patients.

Various obstacles have arisen in ensuring follow-through with the initial plan of action drafted for each uninsured client, in particular with those who face multiple challenges like housing instability, poverty, substance use, and mental health issues, since they already experience barriers to meeting their daily basic needs. In addition, Medicaid patients are required to recertify their eligibility every six months, which often leads to patients losing coverage and needing to re-apply. A key priority for the clinic has been to ensure that their clients remain in care and obtain the treatment and medications they need to remain healthy. The RW support enables the clinic to continue to work with clients, especially those who have the least resources, to get the medical and psychosocial services they need.

Case Example
Juan gets confidential HIV testing with his new boyfriend and is shocked to learn that he is positive. He does not know what to do, since he doesn’t have health insurance and has not seen a doctor in several years. He is at a loss for how he will pay for medical care and cope with his new diagnosis. The agency that provided the free HIV testing refers Juan to a comprehensive HIV service provider. The medical provider is able to see Juan for an intake appointment without payment thanks to RW funding, and Juan is also referred internally to case management for help in obtaining insurance. The case manager begins with an assessment of Juan’s background, current living situation, income, and residency/citizenship status in order to explore possible avenues for insurance coverage. Juan works 25 hours/week at a retail store and shares an apartment with friends. Juan’s job does not offer insurance to staff who work less than 30 hours/week. He has heard about buying insurance on the federal exchange, but doesn’t know much about it and feels unable to afford the extra expense. Juan earns about $13,000/year, which places him slightly above the FPL.

Juan lives in a state that has not expanded Medicaid access. Since he does not have a disability, he would not typically be eligible for Medicaid coverage. However, Juan was kicked out of his parents’ home at age 15 when he told them he was gay. He was then placed into a group home through child welfare until being discharged to independent living when he turned 18. While in foster care, Juan did have Medicaid. The ACA mandates that all states must continue to provide Medicaid coverage for youth who were enrolled at the time they aged out of foster care until age 26, regardless of income.

If Juan had not been in foster care, he may have been able to purchase insurance through the federal exchange and receive financial support through the ACA. Unfortunately, under the ACA, a new medical diagnosis does not necessarily qualify for special enrollment. Thus, Juan would likely have to wait until the open enrollment period in November to apply for insurance, and the coverage would become effective January 1 of the next year. In the meantime, Juan would need to utilize RW medical care and ADAP to support his HIV care expenses.

New Opportunities
Due to the ACA, RW programs will likely need to adapt their service delivery and business practices. For example, if visits with medical providers are largely covered by insurance, programs will have to demonstrate that any utilized RW funds are for non-medical services. In tandem with changes created by the ACA, opportunities are arising for the development of new resources and partnerships that will help achieve sustainability and maintain and/or expand the care provided to PLWH.

Patient Centered Medical Homes
Patient Center Medical Homes (PCMH) describes the concept of providing comprehensive and wrap-around care for patients. As outlined by the federal Agency for Healthcare Research and Quality, “The primary care medical home is accountable for meeting the large majority of each patient’s physical and mental health care needs,
including prevention and wellness, acute care, and chronic care. Providing comprehensive care requires a team of care providers. This team might include physicians, advanced practice nurses, physician assistants, nurses, pharmacists, nutritionists, social workers, educators, and care coordinators. This type of care is designed to be comprehensive, patient-centered, accessible, and coordinated. In addition, medical homes utilize electronic medical records, as well as quality and safety metrics, to ensure a high-level of patient care.

Although many organizations have begun to shift toward this model, a significant challenge is the lack of insurance reimbursement for many of the services provided, making long-term sustainability problematic. A review of a five state PCMH initiative concluded: “Operating as a medical home requires increased non-reimbursed activity and care management (e.g., care team meetings, patient self-management education, care coordination, data analysis, communication with other clinicians). In order for patient-centered medical home practice transformations to be sustainable, there must be payment reform to incentivize high-value, first-contact primary care and support medical home costs that are traditionally not reimbursed (e.g., non-face-to-face encounters).”

The PCMH model has been used in HIV care since the beginning of the epidemic and is strongly supported by the RW program. The ACA has created an opportunity for HIV care providers to begin obtaining insurance reimbursement for many of the provided services that were previously not billable. States that choose to expand Medicaid are encouraged, through enhanced reimbursement, to create PCMHs to provide wrap-around care to people living with chronic illnesses. The ACA provided additional funding for FQHCs by establishing the Community Health Center Fund, allocating $11 billion over a 5-year period for the operation, expansion, and construction of health centers throughout the Nation.

Although it is a very small percentage of the overall population served by FQHCs, about 10% of PLWH in the US received care at an FQHC in 2014. FQHCs are identified in the National HIV/AIDS strategy as a key component of providing accessible and comprehensive HIV care.

There is some clear overlap in the missions of the FQHCs and RW supported programs, and the possibility of collaboration exists. Both programs target low-income patients and provide care at low or no cost to those who cannot afford it, but with the proviso that efforts are made to help patients who qualify for appropriate medical coverage.

There are a number of challenges for RW HIV providers in partnering with or becoming FQHCs. Inter-agency partnerships can require a great deal of effort to establish and maintain. Similarly, mission expansion can create growth and sustainability, but requires a willingness to move beyond a traditional target population.

### Federally Qualified Health Centers

Federally Qualified Health Centers (FQHCs) have been funded through federal grants for almost 50 years. There are currently over 1,300 FQHCs, representing 9,000 service delivery locations. FQHCs are located in all 50 states and provide care to almost 23 million patients annually. The centers provide care regardless of a patient’s ability to pay and offer affordable health care to patients who may otherwise be unable to receive care. While FQHCs largely provide primary and preventive medical services, they are expected to coordinate with specialty care, as needed. The ACA provided additional funding for FQHCs by establishing the Community Health Center Fund, allocating $11 billion over a 5-year period for the operation, expansion, and construction of health centers throughout the Nation.

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As part of this effort, training and technical assistance is being provided to the FQHCs interested in developing or expanding their expertise in HIV care.

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### Purchase Insurance Plan via ADAP

As noted above, the AIDS Drug Assistance Program (ADAP), established under RW Part B, provided grants to states to improve access to prescription medications for uninsured and underinsured low-income PLWH. Since its inception, ADAP has served as both the primary purchaser of medications and a secondary insurance to cover out-of-
pocket expenses, such as private insurance deductibles and co-pays, in order to reduce barriers to securing medications. ADAP can also be utilized to directly support the purchase of insurance coverage, either paying the full cost or as premium support, if the cost of this support is less than the cost of directly paying for the medications themselves.

With the increased access to private insurance through the ACA, ADAP has begun to shift toward helping PLWH purchase insurance plans, rather than simply covering the cost of medications. The National Alliance of State & Territorial AIDS Directors reports that: “As of March 31, 2015, ADAPs have supported 47,697 ADAP clients with enrollment in Qualified Health Plans (QHPs) through the first two open enrollment periods of the ACA. Of the 50 ADAPs reporting, 44 ADAPs support clients to meet QHP premiums and prescription drug copayment and coinsurance obligations.”

As an example, as of January 2015, Alabama uses ADAP funds to purchase limited insurance coverage for PLWH. These insurance plans cover medications and outpatient care. These expenditures total, on average, half of what Alabama was previously paying for medications alone. This shift has improved patient care, is more cost-effective, and allows limited resources to be stretched to cover more PLWH.

Conclusion

HIV remains a critical public health concern in the US. Although HIV treatments have improved significantly, engaging and retaining PLWH in medical care continues to be a substantial challenge. Too few PLWH are actually receiving medical care, are prescribed and adherent to antiretroviral medication, and have controlled viral loads. These PLWH continue to be at risk for worsening health, opportunistic infections, and early death. The fact that a large proportion of annual HIV transmissions can be attributed to those who do not know their HIV status and/or who are not engaged in care amplifies the need to have a system that provides open and accessible care that meets the needs of PLWH. The updated National HIV/AIDS Strategy describes the current national efforts to continue to build such a system of care. On a client level, the RW program and the ACA provide a foundation to make HIV care affordable by increasing access to insurance coverage. Providers and PLWH can work together to determine how affordable HIV care can be accessed, whether through Medicaid, private insurance, RW, or a combination of programs.

For HIV providers, since fewer RW dollars may be needed to pay for medical visits, more of those funds can be directed toward the crucial wrap-around care that addresses the emotional and psychosocial challenges faced by PLWH. Enhanced reimbursement through the PCMH model, partnering with the FQHC network, and using ADAP to directly purchase or assist with insurance coverage are examples of avenues towards this goal. By understanding the ACA and how it interacts with the RW program, HIV care providers can improve the system of care and better engage and retain PLWH in care.

References


