

# Ryan White and the Affordable Care Act

## ADVOCATING FOR PUBLIC HEALTHCARE FOR WOMEN LIVING WITH HIV

March 2015

### Executive Summary

In 1990, the Ryan White Comprehensive AIDS Resources Emergency Act was enacted in the wake of the avoidable and early death of Ryan White, a young person diagnosed with AIDS at age 13. His death, resulting from a lack of effective treatment and care, helped to heighten public awareness about the urgent healthcare realities of people living with HIV, and emboldened public officials to pass what is now the largest federal program solely dedicated to HIV programming in the United States. The law was last reauthorized in 2009 and was renamed the Ryan White HIV/AIDS Treatment Extension Act (also known as the Ryan White Program or RWP).

Twenty years after the enactment of Ryan White in 2010, President Obama signed the Patient Protection and Affordable Care Act (ACA) into law, effectively increasing access to healthcare coverage for millions of people in the United States. The ACA represents a momentous shift in the U.S. healthcare system as a whole—marking a reform of a magnitude not seen since the passage of Medicare and Medicaid legislation in 1965. Four years since its enactment, the ACA is making headway in addressing health disparities that impact low-income communities and communities of color that disproportionately lack health insurance. However, significant gaps in access to full spectrum healthcare persist, which critically impact the 1.2 million people living with HIV (PLHIV) in this country, and the quarter-million among them who are women living with HIV (WLHIV). This is especially true for PLHIV in the 15 states that have explicitly declined to expand Medicaid under the ACA, as well as for PLHIV in the seven that continue to debate Medicaid expansion.<sup>1</sup>

In this significantly unsettled post-ACA environment, thousands of low-income and otherwise marginalized PLHIV still lack sufficient health coverage to meet all of their physical and mental health needs, including HIV-related healthcare and life-saving medications. As a result, many PLHIV rely on critical gap-filling funds administered through the RWP, for HIV care, medication, and support services.

The current political challenges to Medicaid expansion in many states, as well as the limits of the affordability provisions for private health insurance coverage through federal and state health insurance Marketplace exchanges, make Ryan White's functions indispensable for low-income PLHIV without adequate health coverage. HIV advocates

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This brief will discuss the unique needs of WLHIV, illuminate key opportunities as well as gaps in the ACA that affect WLHIV, and highlight the important role that the RWP serves in the current arrangement of public healthcare for PLHIV. Additionally, this brief sets forth recommendations that advocates can use and adapt in efforts to further align the ACA implementation with the needs of WLHIV.



SisterLove, Inc.



## Introduction

In the context of HIV, optimal healthcare and quality of life is achieved through accessible, consistent, and affordable coverage that facilitates the earliest possible detection of the virus, as well access to biomedical prevention options such as Pre-Exposure Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP). For individuals who have been diagnosed with HIV, comprehensive healthcare must meet physical, emotional, and mental health needs of the client. Care systems must ensure effective linkage, engagement, and retention in care, consistent access to affordable antiretroviral treatment, and the mental health and social support services necessary for clients to adhere to treatment regimens and achieve viral suppression. Successful treatment along this continuum of care can help WLHIV to achieve optimal physical and mental health outcomes that are necessary for WLHIV to exercise self-determination over their lives and their health.

Members of marginalized communities are disproportionately impacted by HIV and face discrimination in healthcare settings. These communities include low-income women of color, LGBTQ people of color, and youth of color, who are either living with or at high-risk of contracting HIV. For members of these communities, access to healthcare is stymied by the lack of affordable insurance options, in addition to other social determinants of health correlated with health disparities among these groups.

It is important to note that lack of access to health insurance coexists with other social determinants of health that simultaneously frustrate prevention efforts and also disempower PLHIV and people at high risk of acquisition. Structural barriers to access include lack of financial or geographic access to transportation, lack of employment providing livable wages, lack of income supports, and lack of education—including comprehensive sexual and reproductive health education. Sociopolitical issues that have been correlated with increased HIV incidence include sexual violence, intimate partner violence, post-traumatic stress syndrome, racism, as well as stigma and lack of candor regarding sexuality and sexual health in households and educational or cultural spaces. Ryan White attempts to address these social determinants of health by allocating funding for key needs, including transportation to medical appointments, case management for assistance meeting basic survival needs, psychosocial and peer-based support, and community outreach and prevention.

Ryan White is the largest federal funding source for HIV core medical and support services for low-income PLHIV. While ACA implementation has improved accessibility to health insurance to some extent, significant hurdles still remain in providing consistent and affordable coverage that relevantly addresses the complex set of health needs of PLHIV. As a payer of last resort, Ryan White provides critical gap-filling resources to clinics, training institutions, health departments, and healthcare providers across the country, in order to meet the needs of clients lacking alternative coverage sources for necessary care, prescription medications, and support services.<sup>2</sup> Ryan White serves over 500,000 PLHIV in the United States, providing coverage for people who either have no insurance coverage or inadequate coverage. Ryan White is designed to assist PLHIV at every stage of the continuum of care—from diagnosis, to linkage in care, engagement and retention in treatment, prescription of antiretroviral therapy, and viral suppression.<sup>3</sup>

The Ryan White Program is remarkably successful and serves those who most need care. For example, 70% of Ryan White clients have achieved viral suppression, compared to a viral suppression rate of 25% for all PLHIV nationwide.<sup>4</sup>

While women in the United States constitute approximately one-quarter of estimated HIV diagnoses, women account for 29.1% of all Ryan White clients nationwide.<sup>5</sup> Among WLHIV enrolled in Ryan White-funded programs, 80% are either Black or Latina.<sup>6</sup> In 2012, Ryan White also served 5,027 PLHIV who identified as transgender.<sup>7</sup> New HIV diagnoses are concentrated among women of color and transgender people.<sup>8</sup> Ryan White opens access to healthcare services for these high-need populations.

Ryan White is of particular importance for individuals in the Deep South, which leads the nation in HIV/AIDS prevalence and diagnosis, and has among the highest number of uninsured people in the nation. Notably, none of the states in the Deep South have elected to expand their Medicaid programs, leaving millions uninsured. Despite the fact that only 37% of the total U.S. population resides in the South, 49% of all new HIV diagnoses occurred in this region in 2010.<sup>9</sup> Nine southern states shoulder a disproportionate burden of the HIV epidemic: Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, and Texas. These states in the Deep South also have disproportionately high HIV prevalence and mortality rates.<sup>10</sup> Of all individuals diagnosed with HIV in the Deep South in 2011, 57% were Black. The percentage of HIV diagnoses that occurred among women, Black individuals, and people between the ages of 13 and 24 were higher in these 9 states than any

other areas in the United States. Additionally, Black people had the lowest survival rate of all races in the region, and survival rates among Black individuals have been shown to decrease with age.<sup>11</sup>

The most impacted jurisdictions within these states share common characteristics in social determinants impacting sexual health and HIV outcomes: lack of health insurance, high poverty rates, marked income inequality, poor overall health, higher levels of sexually transmitted infections, negative health outcomes for PLHIV, and heightened levels of stigma and structural racial inequity. To date, none of the most impacted southern states have expanded their Medicaid programs, and the resulting lack of a healthcare safety net for millions of individuals in this region is chief among the social determinants of health worsening HIV outcomes. The absence of a reliable health coverage safety net in the South underscores the need for a continued commitment to Ryan White funding.

### **The Affordable Care Act and Women Living with HIV: Significant Advances**

Several overarching policies in the ACA can increase healthcare access for WLHIV and potentially reduce some degree of reliance on Ryan White. Those who work for most large employers can no longer be denied private health insurance or charged higher rates because of a pre-existing HIV diagnosis; most plans can no longer limit the amount spent on an individual's medical care per year or impose lifetime caps; and some WLHIV may qualify for Medicaid if they live in a state that has expanded its Medicaid program, without having to demonstrate a disability.

Under the ACA, many WLHIV will have access to plans that cover some women's preventive services without cost, provide nondiscrimination protections, and coverage for 10 essential health benefits (EHBs). Some of the expanded benefits most salient to WLHIV or women at high risk of HIV acquisition, include screening for HIV, screening for intimate partner violence, prescription drug coverage, doctor visits, hospital care, pregnancy and maternity care, pap smears, among others.

### **Special Preventive Services for WLHIV**

The ACA requires all health insurance plans to cover specific preventive services for women without cost sharing. The Health Resources and Services Administration (HRSA)

outlined the specific services that would be covered for women in the Women's Preventive Services Guidelines.<sup>12</sup> Plans are required to provide free access to well-woman visits, HIV screening and counseling, and must also provide free screening and counseling for interpersonal and intimate partner violence.<sup>13</sup>

Including screening and counseling for interpersonal violence within preventive health services is an especially important advancement for WLHIV, who face sexual and intimate partner violence and trauma at an exponentially higher rate than the general population of women in the United States. More than 50% of women living with HIV have experienced intimate partner violence, compared to only 36% of women who face intimate partner violence nationally.<sup>14</sup> Thus, addressing the lifetime effects of trauma and violence is necessary to improve health outcomes for WLHIV. By implementing intimate partner violence screening as a component of comprehensive preventive services, the ACA has taken a much-needed step to promoting the health and wellbeing of women. But screening is just an initial step. In order to eliminate gender-related health disparities, ending violence and incorporating services that address past and current trauma (i.e., trauma-informed care) is crucial comprehensive care.

*Ryan White services. Ryan White Part D provides funding for culturally relevant family-centered services that specifically help women, children and youth living with HIV maintain continuous care. Services include:*

- 1) Case management**
- 2) Peer support**
- 3) Comprehensive reproductive health**
- 4) Mental health**
- 5) Health education**
- 6) Transportation to and from medical appointments.**

## The Affordable Care Act and Women Living with HIV: Who Is Left Behind

### Cost Sharing

The ACA mandates that preventive services be provided without cost sharing, but treatment for diagnosed conditions can be very expensive. For example, a woman with health insurance coverage can be screened for HIV for free, but there is not much support to assist with the cost of her care after receiving an HIV-positive diagnosis. The high costs of post-diagnosis treatment and care has negative consequences for PLHIV: a recent study showed that the majority of PLHIV are *not* receiving antiretroviral therapy (ART).<sup>15</sup> This finding is alarming, considering that the medical community recommends ART immediately after a patient is diagnosed with HIV.<sup>16</sup> The study suggests that theoretical "access" to health insurance does not often translate to continuous, quality HIV care for PLHIV.<sup>17</sup> Women, especially women of color, will bear the brunt of heightened cost sharing for ART and other recommended treatment for HIV. On average in 2013, women made only 78% of what their male counterparts made.<sup>18</sup> That pay gap is even worse for women of color: Black women, who are represented in over half of new HIV diagnoses, earned only 64% of what white men made, and Latina women earned about half as much as white men in the same year.<sup>19</sup>

### Discriminatory Benefit Design

Medication access and adherence is necessary for successful management of HIV. HIV medications must be taken daily and failure to do so can result in development of drug resistance and treatment regimen failure. However, several issues have been identified in the way certain insurance plans cover prescription drugs. While issuers have technically been including prescription drugs in their coverage, as they are required to do as an EHB, some plans have been unlawfully discriminating against people living with HIV by charging them more for their prescription drugs.<sup>20</sup> Section 1557 of the ACA prohibits discrimination in healthcare activities and health insurance marketplaces on the basis of race, color, national origin, sex, age, or disability. The provision prohibits health plans from discriminating against individuals based on disability and from discouraging enrollment by people with significant healthcare needs.

Notwithstanding section 1557, some insurance companies have been placing all HIV medications, including generics, in the highest cost-sharing tier of the plan. A recent study

estimated that a person living with HIV could pay more than \$3,000 for treatment out-of-pocket every year based on discrimination in HIV medication pricing.<sup>21</sup> Such a practice will discourage or preclude PLHIV from enrolling into such plans, and place discriminatory cost sharing barriers on enrollees who need to access these medications. High out-of-pocket drug costs directly counter the celebrated benefits of the ACA, the end of discriminatory coverage for people with chronic health conditions, and hinders access to healthcare coverage for PLHIV.

AIDS Drug Assistance Programs (ADAP), a medication assistance program administered through Ryan White, ensures that the medication needs of PLHIV are met when insurance programs are inadequate. Emerging research demonstrates that instances of high out-of-pocket drug pricing are occurring despite purported best intentions of increased access under the ACA. Ryan White has the capacity to meet the medication coverage needs of PLHIV who would otherwise fall through the cracks under the current tier arrangements and high out-of-pocket drug costs. Ryan White advocates who understand these impacts on PLHIV can help to guide advocacy in addressing medication pricing discrimination.

### Non Expansion of Medicaid and the Supreme Court

Probably the most impactful benefit of the ACA is the expansion of Medicaid eligibility to millions of previously uninsured individuals. Single, childless, low-income adults who live under 138% of the federal poverty level (FPL) (approximately \$32,913 a year for a family of four in 2014) should be able to access Medicaid in every state. Increased access to Medicaid for the aforementioned underserved populations would have a beneficial effect for PLHIV. Because HIV disproportionately affects people of color, especially women of color, and low-income individuals, new eligibility for Medicaid under the ACA would bring access to life-saving care for a large portion of PLHIV in the United States.

This pillar of ACA expansion was thwarted, however, in 2012 when the Supreme Court decided *National Federation of Independent Business v. Sebelius*.<sup>22</sup> The Supreme Court ruled that states were permitted to opt out of Medicaid expansion altogether. As a result, as of March of 2015, residents in only 28 states and the District of Columbia have gained access to Medicaid under the ACA's original design of expanded eligibility. More troublingly, 43% of persons living with HIV live in the remaining 22 states that have elected not to expand Medicaid.

Ongoing judicial challenges to the ACA post-*Sebelius* continue to destabilize the law's implementation and impact its efficacy for the very populations it was designed to benefit. The *King v. Burwell* suit before the Supreme Court this term may jeopardize access to premium tax credits and other financial assistance for the seven million women across the country currently eligible for assistance in federally facilitated Marketplaces. Approximately half of these women are of color, including women who are Latina (1.8 million), Black (1.1 million), Asian (250,000), and Native American (106,000). In this unstable environment, low and moderate income WLHIV will continue to require gap-filling HIV services administered through Ryan White.

### Coverage Gap

For states that have not expanded Medicaid in the wake of the *Sebelius* decision, many low-income PLHIV have fallen into the "coverage gap." This is true in regions such as the Deep South, which is most severely affected by the epidemic. This gap in coverage affects people who live in non-expansion states, where Medicaid eligibility is limited to specific low-income groups. To qualify for financial assistance in a state marketplace in 2014, individual adults must make at least \$11,670 per year. Currently, in most non-expansion states, single adults without a disability are ineligible. Therefore, single adults making less than \$11,670 per year fall into the "coverage gap:" they cannot qualify for Medicaid, but they do not make enough money to access financial assistance to purchase a marketplace plan.<sup>23</sup>

## The Continued Importance of Ryan White in our Current ACA Environment

### Benefits of Ryan White

Ryan White continues to be necessary in a significantly unsettled ACA environment. Ryan White's unique services, designed to effectively engage clients at each stage of the care continuum, serves an important gap-filling function for PLHIV who lack insurance, or who have insurance but still cannot reasonably afford all necessary aspects of care and medications in our current medication tiering and cost-sharing system. Furthermore, Ryan White-funded providers have extensive knowledge in caring for PLHIV - aimed at engaging and retaining people in care as well as facilitating education and prevention efforts for communities most impacted by HIV. Under the ACA, Ryan White

providers should remain the primary clinicians, social support, and prevention and education service providers for PLHIV, so as to ensure that culturally-relevant care is delivered.

The majority of people receiving care under Ryan White are low-income: in 2012, 67% of Ryan White clients were at or below the federal poverty limit.<sup>24</sup> Ryan White services have a major impact on communities of color: 72% of Ryan White clients in 2012 were people of color.<sup>25</sup>

Ryan White funding is distributed in sections, or "parts." Ryan White services are comprehensive in scope; they are designed to meet the multiple needs of PLHIV. Each part of Ryan White is complementary in that parts provide primary care and wraparound services to ensure that PLHIV have continuous, uninterrupted care.

Part A of Ryan White allocates funds to Eligible Metropolitan Areas (EMA) and Transitional Grant Areas (TGA), which are regions severely affected by HIV/AIDS that require emergency grant assistance. These funds are designed to fund primary care and support services that facilitate access and retention in care. Importantly, Part A includes community consumers and providers of Part A services as important decision-makers in the administration of programs, by carving out an integral role for them on Ryan White planning councils. Participation of consumers and providers on decision-making committees allows for the identification of special populations in grantee jurisdictions and enhances collection of data that increases understanding of unique service delivery challenges for those populations.

Part C of Ryan White provides comprehensive primary care in an outpatient setting for PLHIV, including home healthcare, hospice care, and home- and community-based services. Part C is designed to address a client's health needs at various stages of their lives, as well as the services required to maximize access and usage of care. For example, in addition to funding health insurance premiums and cost-sharing for low income clients, Part C allocates funding for transportation to medical appointments, and provides translation services (including for the hearing-impaired). Part C also serves the dual function of ensuring that clients receive sexual health and HIV education after

diagnosis, as well as making outreach and prevention available in high-risk communities.

### Prescription Drug Coverage

Part B of Ryan White allocates funds to states to provide prescription drug assistance. That funding, awarded through state AIDS Drug Assistance Programs (ADAPs), ensures that low-income PLHIV have access to HIV-related prescription medication via co-pays or coverage of medication costs. Many ADAPs include medications for other comorbidities in their lists of prescription drug medications available. The ACA was enacted with the intention of increasing access to care, including prescription drugs

with HIV, in the form of case management, outreach, and family-centered direct medical services; services that are all directly focused on promoting the health and development of women with HIV to lead long lives.

The services provided to women and youth through Part D funds are community-based, culturally relevant, and family-centered. Grantees receiving Part D funds work through collaborative care models to ensure that women with HIV are receiving the care and services that they need to live long, healthy, and dignified lives. This care can take the form of comprehensive reproductive health services, mental health services, or health education services. Part D-funded services, such as transportation to and from medical appointments, provide essential support that enables women to engage and remain in HIV care. Services funded through Part D, like case management services and peer support services, exist to ensure that women receive the services they need to be in treatment. All of these services aim to meet the particular needs that women face when

*The standards created within Part D services can serve as models for the ACA.*

through Medicare and Medicaid, uninsured and underinsured people. But discriminatory pricing of HIV medications has created a significant hurdle to increasing access for PLHIV. Even without discriminatory pricing, PLHIV may be left with unmet medication coverage. ADAPs can continue to play a vital role in ensuring that PLHIV are engaged and retained in care by providing coverage of medication costs. Thus, ADAPs provide critical medication assistance to people who otherwise would have limited or no access to HIV-related medication.

they are living with HIV. The ACA does not currently provide for any social support services or case management services that are structured to meet the particular needs of women living with HIV or keep them engaged and retained in care. The standards created within Part D services can serve as models for the ACA, and can be incorporated into ACA implementation when addressing the needs of high-need populations like WLHIV.

The role of ADAPs in the lives of people living with HIV cannot be understated: ADAP services are far-reaching and impactful. In June 2013, ADAPs extended medication coverage to 152,487 people living with HIV nationwide, and filled 457,640 prescriptions. (KFF ADAP fact sheet April 2014). A significant portion of people utilizing ADAP services were Black (34%) and Latino/a (27%).<sup>26</sup> Approximately 21% of people using ADAP services have identified as female.<sup>27</sup>

### Funding for Women and Youth

Part D of Ryan White specifically allocates funding for women, children, and youth living with HIV. Part D services are culturally relevant: offering family-centered medical care and support services that are specific to the needs of women and youth. These services work to support women

### Spotlight on Ryan White in Georgia and the Deep South

This brief has identified some of the key ways that PLHIV are impacted by ongoing judicial, legislative, and administrative obstacles that have arisen during the process of ACA implementation. Access to healthcare in our post-ACA environment continues to be in flux for low-income WLHIV, necessitating continued support and protection of healthcare safety net programs such as Ryan White. The ACA's vision of greater inclusiveness in this country's healthcare system, regardless of race, gender, income level, disabilities, and pre-existing health conditions, has proven to be a complicated mission to realize. As the brief has discussed, the benefits of the ACA are out of reach for PLHIV who fall into the "coverage gap" in states that have refused to expand Medicaid, which include the nine Deep South states

affected more severely than any other region in the nation. For individuals who do qualify for coverage in federally facilitated Marketplaces, many plans have had a discriminatory impact on low-income PLHIV, as a consequence of drug price tiering arrangements, the prohibitively high drug costs associated with this system, as well as prohibitively high premiums, deductibles, and co-payments. The case of Georgia illustrates the unique challenges for PLHIV in the Deep South facing these very challenges. This spotlight on Georgia highlights the disempowering reality that has resulted from the failure to expand Medicaid as intended under the ACA, and the continued need for Ryan White.

### HIV/AIDS Trends in Georgia

Like most states in the Deep South, Georgia lacks a robust healthcare infrastructure. With nearly two million uninsured individuals in a population of 9.9 million, the state has one of the most dismal coverage records in the country, and is among the 22 jurisdictions that has not expanded Medicaid.<sup>28</sup> As a result, the individuals most impacted by HIV rely on “coverage gap”-filling Ryan White funding for the provision of core medical and support services. The importance of health coverage in relation to health outcomes is magnified for PLHIV because of the heightened risk of opportunistic infections and other chronic illnesses and comorbidities.

The demographic trends that characterize the most impacted states in the Deep South are clearly reflected in the case of Georgia. Georgia is among the most severely and disproportionately affected by HIV/AIDS in the nation. Metro Atlanta has a concentrated amount of HIV cases in Georgia, and has among the highest rates of HIV/AIDS prevalence nationally. Georgia has the fifth highest number of new HIV diagnoses among all U.S. states, and the fifth highest number of HIV-related deaths in the nation.<sup>29</sup> The Black community is, by far, the racial group most impacted by HIV/AIDS in Georgia. HIV has been among the top 5 causes of death for Black individuals between ages 20 and 54 over the past 5 years.<sup>30</sup> While 62% of Black individuals in Georgia are linked to care within 3 months, only 38% are virally suppressed.<sup>31</sup>

The most affected sub-groups in Georgia are Black women and young Black men who have sex with men (MSM). Black heterosexual women constitute *75% of all women living with HIV in the state*.<sup>32</sup> New diagnoses are increasing for Black women over 55, and Black women are 12.2 times more likely to contract HIV than white women.<sup>33</sup> In Metro

Atlanta, the rate of HIV acquisition for Black women is 14 times that of white women.<sup>34</sup> Black men in Georgia constitute 60% of all men living with HIV, and new diagnoses are increasing among the youngest groups of Black men (13–24 and 25–34.)<sup>35</sup> Despite findings that Black MSM engage in less unprotected sex than whites, predominating factors such as lack of health insurance among Black MSM and a tendency of Black MSM to have sex within same-race sexual networks are linked to increased risk.<sup>36</sup>

### Operation of Ryan White in Georgia

In 2010, Georgia received a total of \$137 million in federal funding for HIV/AIDS grants from the federal government through the following agencies: the Ryan White HIV/AIDS Program, funded through the Department of Health and Human Services-Health Resources and Services Administration, the Centers for Disease Control and Prevention (CDC), Housing Opportunities for Persons with AIDS (HOPWA), and the Substance Abuse and Mental Health Services Administration (SAMHSA). Ryan White contributed the lion's share of funding, at \$104,160,792, equivalent to over 75% of total HIV federal funding awarded to the state.<sup>37</sup>

Implementation of the ACA in Georgia means that more people qualify for coverage, but because Georgia has not expanded its Medicaid program, an estimated 6,000 uninsured Georgians will continue to rely primarily on Ryan White to fund their HIV services.<sup>38</sup> In 2011, 22,089 people in Georgia received services through the Ryan White Program, equaling approximately 65% of Georgia's total population of PLHIV.<sup>39</sup> Among these clients, 68% were living below the poverty line. In 2013, Georgia received a total of \$94 million Ryan White funds, and approximately one-third of this sum funded HIV/AIDS medications through Ryan White's AIDS Drug Assistance Program (ADAP).<sup>40</sup>

Ryan White is designed to provide equitable assistance along the entire continuum of HIV care, which is of particular importance in Georgia, and the Deep South as a whole, due to protracted barriers in social determinants of health, including high poverty rates, widespread lack of health insurance, and structural racial inequity. In addition to the stress of identifying funding sources for HIV care and antiretroviral medications, many PLHIV struggle with the psychological and emotional toll of regularly grappling with the reality of the virus as a prominent facet in their lives. Ryan White's services for treatment adherence, case management, and referrals for support services, are thus extremely important for PLHIV to realize optimal physical

and mental health along the continuum of care. The importance of Ryan White's continuum of care framework and its gap-filling function is heightened now more than ever, and it must be protected in order to meet the healthcare and support needs of the most impacted subgroups of PLHIV, especially Black women and young Black MSM in Georgia and across the Deep South.

### **The ACA, Medicaid, and Ryan White: Experiences on the Ground**

The post-ACA landscape in Georgia is a complicated one for WLHIV, clinicians, and support services providers to navigate. Jacqueline Muther has worked in HIV advocacy since the start of the HIV/AIDS epidemic in the mid-1980s and currently directs HIV public policy, grants, and contracts at the Grady Hospital Infectious Disease Program, housing one of the highest traffic and highest disparity HIV clinics in the South and the United States overall. In regards to the complicated healthcare landscape for PLHIV in Georgia, she remarks candidly: *"The ACA isn't working in Georgia. It will not work in states that don't expand Medicaid. That's the core of the thing."* Muther explains that many patients at the clinic either cannot afford insurance on federal exchanges, or they do not have incomes low enough to qualify for un-expanded Medicaid. The clinic is consequently forced to "pick up the tab," much of which is done through Ryan White, in addition to other funding sources.

Part D of Ryan White is indispensable for women, infants, and youth in heavily impacted areas like Metro Atlanta. Muther explains that for Black women and young Black MSM in Atlanta, who bear a disproportionate share of HIV/AIDS cases and new diagnoses in Georgia, "Part D of Ryan White has been a Godsend to take care of the uninsured, in addition to Parts A, B, and C." The need for Ryan White is compounded because the ACA eliminated funds that the clinic previously received based on its high disparity case-load. The ACA eliminated this type of funding based on the assumption built into the ACA that all states would expand Medicaid.

Many WLHIV in Georgia are bearing the brunt of the fall-out from post-ACA obstacles to full implementation. Masonia Traylor is a 28-year old sexual and reproductive health advocate for women and youth who conducts direly needed sexual health education and HIV awareness trainings in Georgia and across the US. In addition to building her well-recognized career in health advocacy, Traylor has been working as a pharmacy technician for the past 8 years in order to support her children and pay for her ed-

ucation. As a technician, she makes below ten dollars an hour, which translates to earnings below \$1000 monthly, and below \$10,000 per year. Her employers cap her hours at 30 per week, effectively barring her from access to greater employee benefits. She recognizes the importance of her degree in her local economic context, explaining that it is virtually impossible for a retail employee without an undergraduate degree to earn over \$12,000 annually. Just a few months shy of completing her degree and on the cusp of beginning a new health advocacy job, Traylor shares that she treasures her family, including her two young children (ages eleven and three), and her career in advocacy. Traylor remarks: "I'm your statistical African American, HIV-positive woman, but I don't appear to be so."

Traylor is intimately familiar with the barriers to healthcare access in Georgia. Traylor was 23 years old and five weeks pregnant when she received her HIV-positive diagnosis. While enrolled in Medicaid during her pregnancy, she achieved viral suppression, and gave birth to her HIV-negative daughter, Maya. Currently, Traylor is keenly aware that her current care under Medicaid is in imminent jeopardy due to an upcoming health advocacy position she is slated to begin. Although her current monthly income qualifies her for Medicaid, this healthcare coverage will be terminated when she begins her part-time employment position because it would incrementally increase her income. However, even with this increase, she would *not* qualify for private insurance or Marketplace coverage under the ACA, but she *would* earn over the amount necessary to qualify for un-expanded Medicaid in Georgia. Thus, she will likely have to rely on alternative sources of local healthcare services, many of which rely on gap-filling healthcare safety nets such as Ryan White. The prospect of changing physicians is unsettling for Traylor, especially after having been treated by the same physician for as long as she has been living with HIV. She explains that the cultural competency and life experiences of her physician – who is also a woman of color and a mother – greatly influence Traylor's healthcare experience and her ability to achieve positive physical and mental health outcomes. As is the case for most PLHIV, Traylor's comfort level, familiarity, and trust with a culturally competent physician is a prime factor influencing her retention in care, treatment adherence, and viral suppression. The positive doctor-patient relationship Traylor has built with her physician for the past five years is now in imminent jeopardy because of the marginal shift in income she will gain with her new job.

She describes many situations in Georgia's healthcare and social services system as "catch-22s," and explains that for

young, single-income household mothers, access to social services assistance for basic survival needs (i.e. food, housing, healthcare, etc.) is contingent on one being extremely poor; if the same person is fortunate enough to advance even incrementally, their social supports have a high likelihood of being terminated. With regard to primary physical healthcare, Traylor observes the irony in the fact that, as a pharmacy technician, her mission is to ensure that clients receive the medicines necessary for their wellbeing, and yet she is precluded from the affordable healthcare coverage that would afford her the same medical necessities. This array of double binds for Traylor illustrates the way in which ACA implementation is frustrated by the failure to expand Medicaid, and highlights the continued need for Ryan White as a healthcare payer of last resort.

Traylor's and Muther's experiences both exemplify the complex challenges in Georgia for WLHIV and the providers who serve them. Upon close analysis of the stark HIV health disparities and severe impact of the epidemic in Georgia and the Deep South generally, it is clear that without Ryan White, the health resources available for WLHIV in Georgia are gravely inadequate to match widespread healthcare needs. While WLHIV in all regions of the US are impacted by HIV/AIDS, the case in Georgia and the Deep South make it absolutely clear that Ryan White must continue to be supported, especially in regions bearing a disproportionately severe burden of the HIV epidemic.

## Recommendations

There is much more left to do to fully realize the benefits of the ACA for WLHIV and Ryan White will continue to play an essential role in meeting women's sexual and reproductive health needs. Consistent access to treatment, without interruptions in delivery of care, is imperative to ensuring that people living with HIV can lead long, healthy lives. Three recommendations follow that aim to ensure accessible, consistent, and affordable healthcare coverage is available for people living with HIV.

First, robust enforcement of the ACA's nondiscrimination requirements regarding prescription drug benefits is a necessary step. The government has provided guidance to help end some of these discriminatory practices in its *Notice of Benefit and Payment Parameters for 2016* (79 FR 70673, Nov. 26, 2014). The guidance states, for instance, that a practice in which an insurer's drug formulary excludes preferred, commonly prescribed single tablet ther-

apies violates the ACA's nondiscrimination mandate. Additionally, plan formularies that place most or all drugs used in the treatment of a certain condition in the same class on the highest cost-sharing tier also violate the ACA's nondiscrimination mandate.

In ongoing discussions around ACA implementation and Ryan White reauthorization, advocacy will be the driving factor in ensuring that HIV medications are affordable and accessible. Advocates should target efforts to monitor instances of discriminatory medication practices. Advocates can structure their efforts on: identifying instances of pricing discrimination, identifying instances of medication coverage discrimination, and any resultant disruptions to care. Any advocacy around discriminatory practices of coverage and pricing of HIV-related medication should also examine the role of ADAPs, and Ryan White generally, in meeting the needs of people living with HIV.

Second, advocates can be instrumental in ensuring that the needs of WLHIV addressed in Part D are preserved and expanded. Social support services, such as transportation assistance and family-centered case management, are part of a comprehensive system that works to assure women are engaged and retained in HIV care. Additionally, incorporating a trauma-informed care framework in Ryan White clinics and other healthcare settings, holds great promise to enhance health outcomes and quality of life for women with HIV.

Third, Ryan White services and funding should remain stable as ACA implementation progresses. Considering that we are currently in the early stages of ACA implementation, and 19 states are not expanding Medicaid under the ACA, a decision not to reauthorize Ryan White, or to take it apart piecemeal, as has been proposed in recommendations to consolidate Part D into Part C, would be premature. High premiums, imbalanced pricing structures for HIV medications, and the absence of social support services that keep women and youth engaged and retained in HIV care are the early indicators of a new healthcare system that does not adequately meet the needs of people living with HIV.

The Ryan White Program continues to ensure that PLHIV whose healthcare needs remain unmet through insurance plans or insurance marketplaces alone, are receiving comprehensive, culturally-relevant HIV-related health services. Government officials can ensure that the healthcare needs of all high-need populations are met by applying the Ryan White Program's comprehensive healthcare delivery framework as a model for ACA implementation.

**(Endnotes)**

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