



UPDATING THE RYAN WHITE HIV/AIDS PROGRAM FOR A NEW ERA: KEY ISSUES & QUESTIONS FOR THE FUTURE

APRIL 2013

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EXECUTIVE SUMMARY

The Ryan White HIV/AIDS Program (Ryan White) is at a critical juncture. First enacted in 1990, the program has grown to become a critical part of the HIV health care delivery system in the United States, providing care and services to more than half a million people with and affected by HIV each year. It is the largest HIV-specific grant program in the U.S., and the third largest source of federal funding for HIV care. Federal funding for the Ryan White program has increased over time, although it has not necessarily kept pace with need; when adjusted for inflation, FY 2012 Ryan White funding is approximately at the same level as it was a decade ago, despite an increase in the number of people living with HIV by 33% during that time.¹

The program has been reauthorized four times, most recently in 2009. Since its last reauthorization, there have been several significant changes to the health care environment and new knowledge about HIV which, taken together, significantly alter the environment in which the program operates. These include:

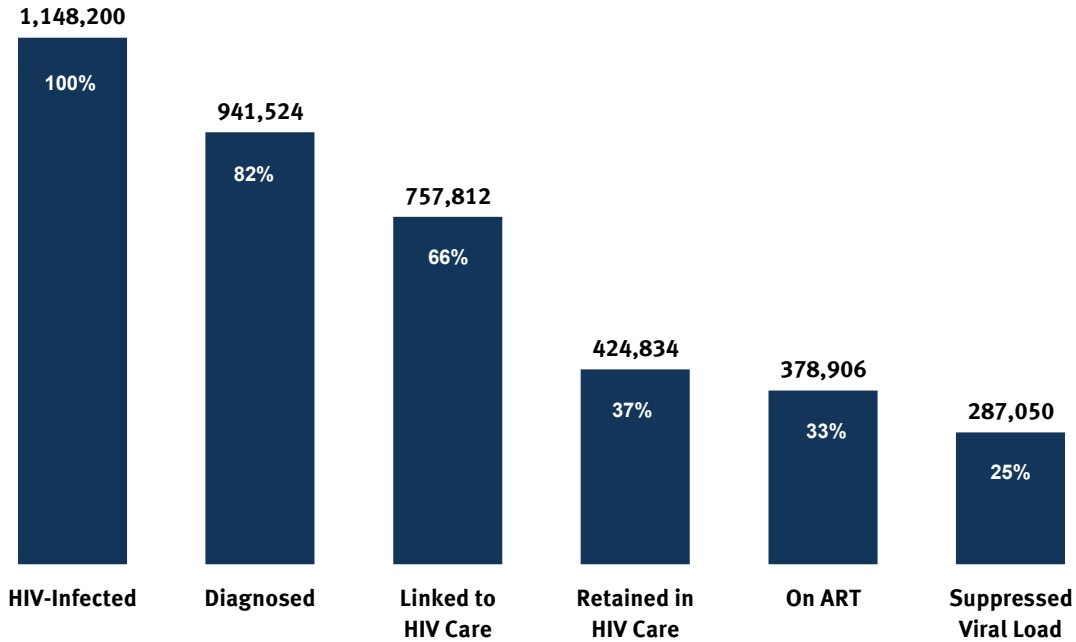
- New scientific evidence demonstrating that antiretroviral treatment (ART) not only provides tremendous clinical benefit, it can also significantly reduce the risk of HIV transmission², prompting calls, for the first time, to work toward achieving an “AIDS Free Generation”³;
- The passage of the Affordable Care Act (ACA), which will significantly increase access to health insurance coverage for millions of people, including people with HIV; and,
- The release of the first-ever comprehensive National HIV/AIDS Strategy⁴ for the U.S., with the goals of reducing HIV incidence, increasing access to care, and reducing HIV related health disparities.

Yet current data indicate that ART coverage and viral suppression in the U.S. are quite low – only 33% of people with HIV are estimated to be on ART and only 25% are virally suppressed.^{5,6} Assessment of national performance along the HIV “treatment cascade”, or care continuum⁷, reveals significant drops at each stage of the cascade, particularly between linkage to and retention in care (see Figure 1). This has raised questions about how best to target resources and programs, including the Ryan White program, to increase coverage and work toward achieving an AIDS Free Generation.

With the Ryan White program’s current authorization set to expire on September 30, 2013, discussions about how best to structure the program in this new environment, including the timing of any changes, have already begun. Some have even questioned whether Ryan White will be necessary after the ACA is implemented or what level of funding will be warranted. Yet most Ryan White clients today (70%) have insurance coverage⁸ and rely on the program to supplement limits in their coverage or help with co-pays, indicating that insurance coverage, on its own, does not necessarily protect against the high cost of HIV care or provide the range of services needed to keep people with HIV engaged in care and on treatment.

Given that the ACA will not supplant critical Ryan White services, including linkage, retention and adherence supports, the program is expected to continue to be a critical part of the HIV care system in the U.S. going forward.^{4,9,10,11} Moreover, as increased attention is directed to getting more people with HIV retained in care, the demand for the Ryan White program’s services could surpass current levels, even if more people have public or private insurance coverage; at the same time, expanded insurance coverage could also serve to ease pressure on some parts of the Ryan White program in the future.

Figure 1: The HIV Treatment Cascade



Source: Adapted from CDC "HIV in the United States—The Stages of Care" July 2012.



The experience in the state of Massachusetts is instructive for informing a future role for the Ryan White program. Even though the state began implementing significant health reforms more than a decade ago, and has achieved near universal health coverage, it has seen a continued and critical role for the Ryan White program, which has shifted a larger share of its resources to purchasing health insurance, assisting with co-payments, and investing in needed support services that enable care engagement and treatment adherence. Notably, the state has found a decrease in new HIV diagnoses over the period, and very high levels of viral suppression, which it attributes to the combination of expanded insurance coverage, ART access, and an extensive HIV community care network, including Ryan White providers.¹²

To help inform discussions about the future of the Ryan White program, this policy brief identifies key issues and questions facing the program and explores a range of potential program changes for policymakers and other stakeholders to consider going forward. These fall into four, broad, intersecting areas and are detailed in Table 1:

- 1. Supporting People with HIV at Each Stage of the Treatment Cascade, from Diagnosis to Viral Suppression.**
- 2. Building HIV Care Networks in Underserved Communities.**
- 3. Integrating HIV Care Expertise into the Mainstream Health Care System.**
- 4. Effectively and Fairly Allocating Ryan White Resources**

Ultimately, the issues and potential changes examined here are intended to initiate a discussion on how to build on a legacy of success of the Ryan White program in saving and improving the lives of people living with HIV, and they offer a pathway for how Ryan White, coupled with expanded health coverage due to the ACA, can best strengthen engagement in care and access to treatment, and achieve greater population-level viral suppression by people with HIV.

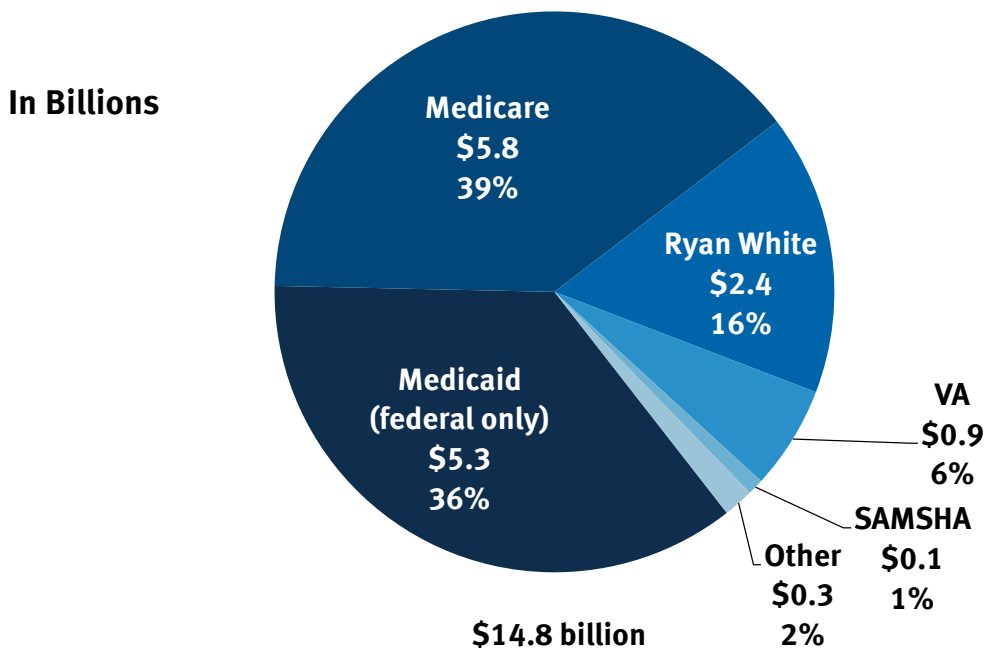
Table 1: Summary of Key Issues & Questions for the Future of the Ryan White HIV/AIDS Program

<p>1. Supporting people with HIV at each stage of the treatment cascade, from diagnosis to viral suppression</p> <ul style="list-style-type: none"> • Focus on supporting the maximum number of people along the treatment cascade • Streamline and strengthen jurisdictional planning • Integrate HIV prevention and care planning • Measure HIV clinical indicators and performance along the cascade • Update the 75/25 rule
<p>2. Building HIV care networks in underserved communities</p> <ul style="list-style-type: none"> • Re-tool Ryan White to better reach the most marginalized populations • Strengthen the Ryan White program's focus on gay and bisexual men • Consider new programs for high cost cases or especially vulnerable populations • Integrate people living with HIV and affected communities into care networks to provide testing, linkage, and retention services • Support CBO planning for re-tooling, coordination and consolidation
<p>3. Integrating HIV care expertise into the mainstream health care system</p> <ul style="list-style-type: none"> • Address payer of last resort limitation during coverage transitions • Enhance Ryan White's ability to help individuals navigate insurance transitions • Consider new service models to remove barriers to continuous care • Work with other parts of the health system to strengthen the quality of HIV care • Strengthen collaboration and coordination between Ryan White medical and support services providers • Support HIV providers and the HIV workforce
<p>4. Effectively and fairly allocating Ryan White resources</p> <ul style="list-style-type: none"> • Reconsider funding formulas and allocation mechanisms • Allocate funding to Parts A and B for both services and other program functions • Expand or modify the SPNS program to encourage investigator-driven innovation • Simplify grantee application and reporting procedures

INTRODUCTION

The Ryan White HIV/AIDS Program is at a critical juncture. First enacted in 1990 as an emergency response to a burgeoning public health crisis, the program has grown to become a critical part of the HIV health care delivery system in the United States, providing care and services to more than half a million people with and affected by HIV each year¹³ who are uninsured or underinsured. It is the largest, HIV-specific, grant program in the U.S., and the third largest source of federal funding for HIV care, after Medicaid and Medicare¹⁴ (see Figure 2).

Figure 2: Federal Spending for HIV Care, FY 2012

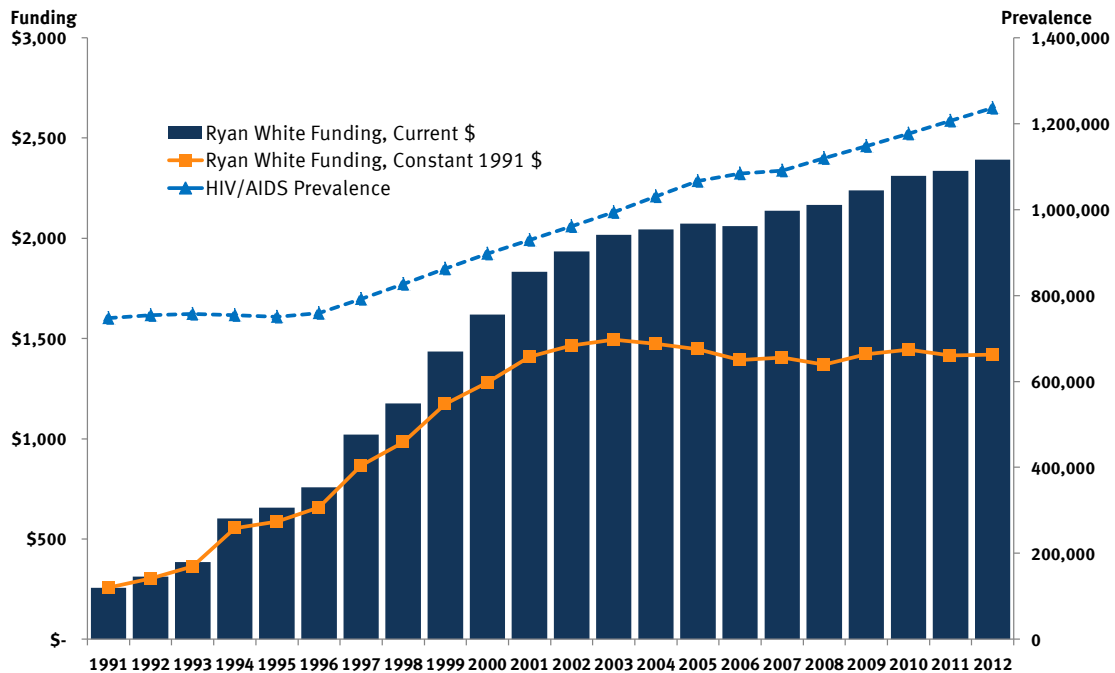


Source: Kaiser Family Foundation analysis of data from OMB, CBJs, and appropriations bills.



Federal funding for Ryan White has risen significantly over time, from \$257 million in FY 1991 (the program's first year) to \$2.4 billion in FY 2012. However, as a discretionary grant program dependent on annual appropriations by Congress, funding has not necessarily kept pace with need. When adjusted for inflation, FY 2012 Ryan White funding is approximately at the same level as it was a decade ago, despite an increase in the number of people living with HIV by 33% during that time.¹⁵ (See Figure 3).

Figure 3: Federal Ryan White Funding (adjusted for inflation) and HIV Prevalence, 1991-2012



Notes: The Consumer Price Index (CPI) from the Bureau of Labor Statistics (BLS) was used to adjust for inflation. HIV prevalence data are estimates based on analysis of data from CDC. Sources: Funding amounts based on Kaiser Family Foundation analysis of data from OMB, CBJs, appropriations bills, and CRS; Prevalence based on data from CDC; U.S. Department of Labor, Bureau of Labor Statistics.



The program has been reauthorized by Congress four times, most recently in 2009. Since its last reauthorization, there have been several new developments which, taken together, significantly alter the environment in which the program operates. These include:

- New scientific evidence demonstrating that ART, which works to suppress the virus in people living with HIV, not only provides tremendous clinical benefit, it also can significantly reduce the risk of HIV transmission², prompting calls, for the first time, to work toward achieving an “AIDS Free Generation”³;
- The passage of the ACA, which will significantly expand health insurance coverage for millions of people in the U.S., including people with HIV; and
- The release of the first-ever comprehensive National HIV/AIDS Strategy for the U.S., with the goals of reducing HIV incidence, increasing access to care, and reducing HIV related health disparities⁴.

Yet current data indicate that ART coverage and viral suppression in the U.S. are quite low – only 33% of people with HIV are estimated to be on ART and only 25% are virally suppressed – some are not yet diagnosed, but others are not yet linked to care or fall out of care.⁵ As a result, there has been an increased emphasis on the role of programs like Ryan White for helping to link, engage, and re-engage people with HIV in care.

With the Ryan White program's current authorization set to expire on September 30, 2013, discussions about how best to structure the program in this new environment, including the timing of any changes, have already begun. Some have even questioned whether the Ryan White program will be necessary after the ACA is implemented or what level of funding will be warranted. Yet, most Ryan White clients today (70%) have public (e.g., Medicaid, Medicare) or private insurance coverage.⁸ This suggests that insurance coverage, on its own, is often insufficient to protect against the high cost of HIV care or to provide the range of services needed to keep people with HIV engaged in care and on treatment. Given that the ACA will not supplant critical Ryan White services, including linkage, retention and adherence supports, the program is expected to continue to be a critical part of the HIV care system in the U.S. going forward.^{4,9,10,11} Moreover, as increased attention is directed to getting more people with HIV diagnosed and linked to care, the demand for Ryan White services could surpass current levels, even if more people have public or private insurance coverage; at the same time, expanded insurance coverage could also serve to ease pressure on some parts of the Ryan White program in the future. Given Ryan White's unique role in the HIV response, the program is likely to act as the fulcrum of efforts to help turn the vision of an AIDS-free generation into a reality in this country.¹⁶

Indeed, the Ryan White program has helped to create a "medical home" model^{17,18} for people with HIV and is likely to play a fundamental role in helping to maintain continuity and quality of care for people with HIV as the health care system changes.¹⁶ Continuity of care is particularly important for people with HIV, for whom even short interruptions in care could have significant negative implications for their health and for the transmission of new HIV infections.¹⁹ Recent data from a national probability study of people with HIV in care, for example, found that those with no or lapsed insurance were less likely to achieve viral suppression.²⁰ A study of the implementation of the Medicare Part D drug benefit found an association between implementation and ART treatment interruptions among a hard to reach population of people with HIV, with most respondents citing increased cost sharing as a primary barrier.²¹

This policy brief identifies key issues and questions facing the Ryan White program and explores a range of potential program changes for policymakers and other stakeholders to consider going forward. Background on the history, structure and funding of the Ryan White program is provided in an appendix.

A NEW CONTEXT: MAJOR CHANGES SINCE THE LAST REAUTHORIZATION

Since the last reauthorization of the Ryan White program in 2009, there have been several significant changes to the health care environment and new knowledge about HIV that alter the landscape in which the program operates. These include the following:

- **New Science and "Treatment as Prevention":** This is a particularly important time in AIDS research, with exciting progress being made on several fronts. In recent years, we have learned of new discoveries in vaccine science, made progress toward the development of safe and effective microbicides, and observed new hope for the development of long-acting treatment regimens. Research advances in two critical areas, however, are especially relevant to the future of the Ryan White program. Results from the NIH-sponsored "HPTN 052" randomized trial found that early versus delayed initiation of ART reduced the risk of HIV transmission from an HIV positive to negative partner by 96%.² In addition, studies demonstrate that early and uninterrupted ART also significantly delays the progression of HIV disease and reduces the occurrence of adverse health events and death.^{22,23,24,25,26} Therefore, while initiation of ART must always be voluntary, getting more people with HIV on treatment soon after they become infected can keep them healthy and reduce onward transmission. As a result of this study, federal HIV treatment guidelines were recently

updated to recommend initiation of ART immediately after HIV diagnosis in the U.S., regardless of CD4 count²⁷ (a marker of immune system health).

In addition, researchers have begun to popularize the concept of an HIV “treatment cascade” which depicts the continuum of HIV care, from initial diagnosis of HIV through to maximal viral suppression.⁷ The treatment cascade provides a useful framework for assessing the biggest drop offs, or “cliffs”, along the care continuum and thus helps to identify opportunities for intervention, including for services and supports that not only are designed to diagnose HIV, but to help people with HIV navigate and access the health system, initiate ART, and remain adherent to therapy. The latest estimates, however, indicate that there are significant drop offs at each stage of the cascade (see Figure 1). Of those living with HIV in the U.S., approximately 82% have been diagnosed, 66% have been linked to care, and only 37% retained in care. As a result of these cliffs, only 33% of people with HIV in the U.S. are on ART and only 25% are fully virally suppressed.⁵ The biggest cliff occurs between linkage to and retention in care – more than 300,000 people with HIV are lost between these stages of the continuum. This suggests that while policy attention is needed at each stage of the cascade, increasing the share of people with HIV who are retained in regular care is a critical intervention point for scaling up ART coverage and maximizing public health and clinical benefits. As such, more efforts are needed not just to get a newly diagnosed individual to a single medical appointment, but to more systematically ensure that people with HIV are supported throughout the care continuum, including by establishing a trusted partnership with a medical provider or medical system that will offer ongoing care, a role that is currently played almost uniquely by Ryan White providers.

- **The Affordable Care Act (ACA):** The ACA, signed into law by President Obama in 2010 (Public Law 111-148), will expand insurance coverage, and therefore access to care, for millions of people in the U.S., including people with HIV. Some of the ACA’s provisions went into effect soon after the law was passed, but the most far reaching take effect in 2014. While nearly all of them have some impact on people with HIV or their care, several are of particular relevance.²⁸ These include: the elimination of pre-existing condition exclusions and of annual and lifetime caps on coverage; the creation of “health insurance marketplaces” with options for individuals to purchase coverage from competing health plans through state-based health insurance exchanges; a new emphasis on and incentives to provide prevention services, including HIV screening; and, perhaps most significantly, the creation of a new mandatory Medicaid eligibility category as of 2014 for citizens and eligible legal residents with incomes up to 138% FPL, thereby removing the categorical eligibility requirement, such as disability, which had been a barrier to many people with HIV - eligibility for this new group is based solely on income. Prior to the ACA, low-income, non-disabled adults without dependent children were excluded from Medicaid by federal law (states wishing to cover them had to use state-only dollars or obtain a federal waiver to do so). The ACA also provides states with an enhanced federal matching rate for the Medicaid expansion population. These provisions offer significant opportunity to scale up ART coverage in the U.S., and achieve greater public health and clinical benefit.

A ruling by the U.S. Supreme Court in June 2012, however, while upholding the Medicaid expansion (as well as the rest of the ACA), limited the Secretary’s enforcement authority over the mandatory Medicaid expansion.^{29,30} Therefore, it is uncertain whether and when all states will comply with this requirement, making it hard to assess the extent to which people with HIV will benefit from Medicaid expansion. Much like the HIV coverage landscape today, coverage will likely continue to vary significantly across the country, with some finding themselves in states that do expand, and others in states that do not. In states that do expand Medicaid, financial pressure on the Ryan White program, including its AIDS Drug Assistance Program (ADAP), is likely to ease, allowing Ryan White funding to go further or to be used in different ways (e.g., shifting from buying medications to assisting with cost-sharing that can be a barrier to care). In states that do not expand Medicaid, Ryan White will need to

fill a bigger relative gap. Indeed, those states that have faced strains in their Ryan White programs in the past tend to be those without coverage of low income, non-disabled adults under Medicaid.²⁸ This could lead to further disparities in access across the country for people with HIV. It also raises difficult policy questions about whether federal Ryan White funding should compensate states that do not expand Medicaid; providing such enhanced financing could lessen health disparities, but it could also heighten tensions among states over the equitable distribution of resources or be seen as rewarding states that do not expand Medicaid.

In addition, while expanded insurance coverage, as provided by the ACA, is an important starting point for getting people with HIV engaged in care, it is not necessarily sufficient. For example, a recent 15-state study found that just 21% of Medicaid patients with HIV had been linked to appropriate care within one year of their diagnosis.³¹ The experience of Massachusetts is also instructive for the progress that is possible, as well as the range of supports needed to build on Medicaid, Medicare, or private insurance coverage.^{12,32} Starting more than ten years ago, the state expanded Medicaid to low-income people and in 2007 implemented other reforms to get to near universal access to coverage. These changes facilitated a transformation in how Ryan White resources were used in the state. Once the state's broader health reforms were enacted, a larger share of Ryan White resources were used to purchase insurance continuation coverage, assist individuals with co-payments for prescription drugs and other health services that can be a barrier to care, and to invest in needed support services that enable people to engage in care and support adherence to treatment. The state has observed a decline in new HIV diagnoses and has achieved very high levels of viral suppression, which it attributes to the combination of expanded insurance coverage, ART access, and an extensive HIV community care network, including Ryan White providers. This experience suggests that while the ACA is critically important to improving access to health care for people with HIV, it will not address all HIV care needs and there will be a continued need for Ryan White to supplement – and complete – health coverage for people with HIV, as well as to provide care to those who have no other source of coverage, including undocumented persons living with HIV or legal residents with HIV who are not yet eligible for public coverage.³³ It also will be needed to continue to build and support the community infrastructure and HIV care expertise that are critical to addressing the HIV epidemic going forward.

- **The National HIV/AIDS Strategy (Strategy):** Soon after the ACA's passage, the White House released the first comprehensive National HIV/AIDS Strategy for the U.S. which is a 5-year plan for aligning the efforts of all public and private stakeholders responding to the epidemic around a core set of priority actions steps. The Strategy has three primary goals – reduce the number of new infections, increase access to care, and reduce HIV related health disparities.⁴ It calls for greatly enhanced efforts to create a seamless system to immediately link people to continuous and coordinated quality care as soon as they are diagnosed, a longtime focus of the Ryan White program, but one that has been challenging and will likely continue to be so within a transforming health system. The Strategy specifically notes the critical importance of the Ryan White program in helping to reach the Strategy's three primary goals both now and after the ACA is fully implemented, stating that, "[g]aps in essential care and services for people living with HIV will continue to need to be addressed along with the unique biological, psychological, and social effects of living with HIV. Therefore, the Ryan White HIV/AIDS Program and other Federal and State HIV-focused programs will continue to be necessary after the law is implemented."³⁴

Taken together, these developments create a very new environment for people living with HIV. They also suggest a continued and important, but changing, role for the Ryan White program in the future.

KEY ISSUES & QUESTIONS FOR THE RYAN WHITE PROGRAM GOING FORWARD

Given these changed circumstances, and with Ryan White's current authorization set to expire on September 30, 2013, discussions about reauthorization, and whether and what changes might be needed to improve the program and ensure stability and quality of care for people with HIV, have already begun.³⁵

Yet, while some of the ACA's provisions have already gone into effect, the most far reaching changes will not occur until 2014, after Ryan White is due to be reauthorized. Importantly, it is still unknown how many states will choose to expand their Medicaid programs and which states will have their health exchanges up and running, decisions that will have a significant impact on people with HIV and the Ryan White system. This has raised questions about the timing of reauthorization, including whether reauthorization should be delayed until sometime after 2014 – while funding for the program continues through annual appropriations – and, if legislative changes are needed to ensure stability of care and mitigate disruptions in access for people with HIV in the short term, during the transition to ACA, whether appropriations legislation could be used to provide such program flexibility.

Recent experience in the state of California illustrates the challenges that can arise, at least in the short-term. In 2010, the state received federal approval to expand its Medicaid program (Medi-Cal), in preparation for 2014. In developing its expansion program, the state assumed that people with HIV receiving Ryan White services would continue to receive their care through Ryan White.^{36,37} As soon as the expansion went into effect, however, Ryan White's payer of last resort³⁸ requirement no longer allowed the program to pay for services for individuals who had an entitlement to them through Medi-Cal, a policy clarified by the Health Resources Services Administration (HRSA) which administers the Ryan White program, and the Centers for Medicare and Medicaid Services (CMS), which administers the Medicaid program, as counties were beginning to set up their programs. This forced state and other stakeholders to quickly come up with a remedy to protect continued access to critical services. It also led to concerns about continuity of HIV care during the transition, the capacity of counties to serve people with HIV, differences between Ryan White and Medi-Cal payment rates, and other issues.³⁹ More broadly, the California experience has raised questions about whether Ryan White, at present, has sufficient statutory authority to respond nimbly as issues arise during the ACA implementation period.

Going forward, there are several key issues and questions, as well as strategies and opportunities, for policymakers and other stakeholders to consider for the Ryan White HIV/AIDS program in a new environment. While not meant to be an exhaustive list, this policy brief examines four, broad, intersecting areas:

1. **Supporting People with HIV at Each Stage of the Treatment Cascade, from Diagnosis to Viral Suppression:** How can the Ryan White Program best be configured to support people at each step of the cascade and create a more seamless continuum across these distinct pillars?
2. **Building HIV Care Networks in Underserved Communities:** What is Ryan White's continuing role in building HIV care networks in underserved communities? Can partnerships between health care providers and community based organizations be strengthened?
3. **Integrating HIV Care Expertise into the Mainstream Health Care System:** How can Ryan White help to integrate HIV care and expertise into the mainstream health care system and support quality HIV care in both public and private settings?

4. **Effectively and Fairly Allocating Ryan White Resources:** Are there ways to improve upon how Ryan White resources are allocated to increase impact, equity, and efficiency, to make smarter investments going forward?

Beyond these questions, it will be important to monitor additional technical or other issues that may arise during ACA implementation that could affect access to care for people with HIV.

1. SUPPORTING PEOPLE WITH HIV AT EACH STAGE OF THE TREATMENT CASCADE, FROM DIAGNOSIS TO VIRAL SUPPRESSION

1. Supporting people with HIV at each stage of the treatment cascade, from diagnosis to viral suppression

- Focus on supporting the maximum number of people along the treatment cascade
- Streamline and strengthen jurisdictional planning
- Integrate HIV prevention and care planning
- Measure HIV clinical indicators and performance along the cascade
- Update the 75/25 rule

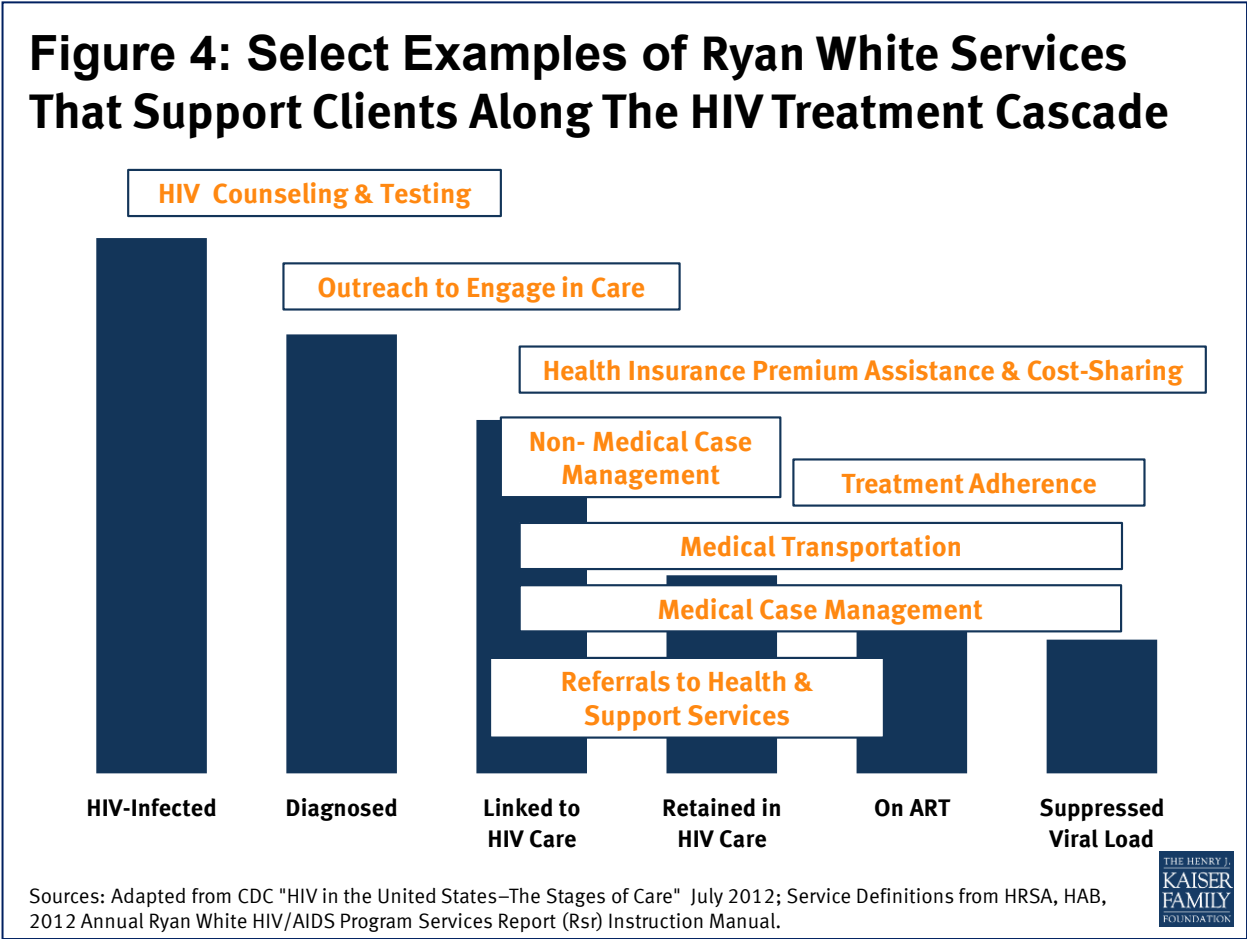
The treatment cascade provides a useful framework for assessing how the Ryan White program and the rest of the health system are performing and may suggest to policymakers, and local program planners and implementers, where efforts are most needed. This could include considering how to more strategically use Ryan White resources to increase the share of people with HIV who are diagnosed, linked to and retained in care, and helping to achieve population-level impact. Research into trends in treatment initiation and viral suppression over time suggest that, while still low, the percentage of people with HIV in the U.S. achieving maximal viral suppression is improving, likely due, in part, to more effective medications with simplified dosing regimens, as well as to other factors including having adequate support systems.^{40,41} At the same time, after controlling for individual-level factors that affect treatment initiation and viral suppression, one recent study observed state-level variation in the timely initiation of antiretroviral therapy, suggesting that system-level factors – such as differences in access to Medicaid and Ryan White – may be at play.

HRSA, as well as some state and local Ryan White grantees, have already taken initial steps to use the treatment cascade for understanding the Ryan White system's performance, efforts that can serve as an important starting point for beginning to monitor care as the ACA is implemented.^{42,43,44,45} HRSA's preliminary estimates, for example, indicate that Ryan White clients perform better on the treatment cascade than people with HIV overall. For example, once linked to care, Ryan White clients were more likely to be retained in care than people with HIV overall (76% compared to 56%).⁴² In addition, a recent analysis of HIV care in an urban clinic, which primarily served low-income uninsured and underinsured people with HIV, found significant improvement in and engagement in care over time, including ART coverage and reductions in viral load, and attributed this impact in part to Ryan White funding, which enabled the clinic to provide quality services to those with financial and other barriers to care.⁴⁶

Today, some people count on Ryan White as their primary or only source for medical care. This includes non-citizen legal residents who are not yet eligible for other forms of public assistance and undocumented residents who are barred from accessing most other non-emergency health care programs. Because of the compelling public health need to provide treatment to minimize further HIV transmission and avoid preventable health care costs, Ryan White has always permitted this type of assistance. Most Ryan White clients (70%), however, have public

insurance coverage (i.e. Medicaid or Medicare) or private insurance⁸, and rely on Ryan White to supplement, or complete, this coverage by providing critical services not covered or insufficiently covered by other programs and to assist with cost sharing that could be a barrier to care. In the future, both types of Ryan White clients will continue to exist, although the balance may shift so that even more people with HIV use Ryan White to supplement other coverage.

Given that three-quarters of people with HIV are not achieving sustained viral suppression, it is likely that supplemental, targeted efforts by Ryan White will still be needed in the future to complement insurance coverage and help reach national HIV treatment goals. Ryan White already covers a range of services that can support individuals along the care continuum, at each step of the cascade (see Figure 4), including services currently defined as “core medical services” but also many defined as “support services”⁴⁷ (see discussion below and Table 2).



Given that the cascade is a relatively new tool for understanding and assessing the HIV care continuum, however, HRSA does not currently measure grantee performance along the cascade. In addition, further research is needed to assess and identify those interventions that are most scalable and cost-effective; to assess what is known about when and why people with HIV fall out of care during coverage transitions; and to identify models of collaboration for bridging HIV care programs with public and private insurance programs and for strengthening collaboration between HIV medical and support service providers. Issues that could be examined include:

- **Focus on supporting the maximum number of people along the treatment cascade**

The overall goal of the Ryan White program, as stated in legislation, is “to improve the quality and availability of care for individuals and families with HIV disease”⁴⁸ by providing funding to states, cities, and other organizations to provide care and support services. While a focus on individuals remains important, there has been an increasing emphasis on affecting impact at the community or population level. Using the treatment cascade as a guide, the emphasis could be shifted from individual-level impact to creating new accountability mechanisms for getting the largest number of people with HIV diagnosed, linked and retained in care, supported in successfully staying on HIV treatment, and ultimately achieving viral load suppression. This could include an increased focus on achieving specific goals tied to each step of the cascade. For example, HRSA could set targets tied to improving performance along the cascade. It could also engage in increased collaboration with CDC which has already been working to monitor population impact along the treatment cascade for the nation and in different communities. Finally, policymakers could also consider including performance-based bonus payments or withholds to drive improvements. The ACA includes new initiatives to test performance-based payment, including the Medicare hospital value-based purchasing program⁴⁹, which may provide lessons for how to adopt such a system within Ryan White.

- **Streamline and strengthen jurisdictional planning**

The National HIV/AIDS Strategy calls for streamlining the planning and targeting of resources to the areas of greatest need. With federal agencies charged with moving in this direction, there are several opportunities to consider related to Ryan White planning and resource allocation procedures. Such opportunities could take fuller advantage of the recent availability of the treatment cascade as a new tool and more explicitly respond to the new science about HIV, which underscores the importance of early access to HIV treatment for both clinical and public health outcomes.

Currently, Ryan White grantees engage in multiple and extensive planning processes, a hallmark of which has been the engagement of people living with HIV, other affected community members, and public health officials to reach agreements on the most pressing needs for services and the best strategies and approaches to meet those needs within a given state or community. While such planning processes have provided a mechanism for making evidence-based decisions about service needs and gaps in affected communities, they also have been criticized for producing uneven results, with some jurisdictions showing a high fidelity to epidemiological data, while others diverge from it when specific groups have been better represented in the decision making process.^{50,51} Policy guidance from HRSA provides a general outline for how plans should be organized and asks grantees to address new developments (e.g., the current policy guidance from HRSA asks grantees how they plan to address the Strategy), but it does not provide metrics or specific guidance on how to address the treatment cascade or prioritize certain services to achieve the greatest impact. Further, HRSA has limited tools to ensure consistency across jurisdictions.

Given many of the changes described above, this is an important juncture for assessing whether the planning structures in place meet current needs. When Ryan White was enacted, there were no effective treatments, and fewer “right” answers with respect to which services should be prioritized. Today, science has provided better insights into which services are most urgently needed and which interventions are most effective. If the Strategy calls for reducing HIV-related disparities, one approach to meeting this goal would be for HRSA to provide further guidance or more active engagement in working with grantees to ensure that state and local plans are evidence-based, consistent with epidemiological data, and align with national priorities. At the same time, there remains an important role for state and local planning and new mechanisms could be considered that would ensure that people living with HIV and other important stakeholders remain engaged. The role of community engagement may shift in emphasis,

however, if HRSA were to give more clear guidance about what steps individual jurisdictions need to take to improve their performance on the cascade. The planning process could become more narrowly focused on “how” to be maximally effective in a given state or community.

There are existing models outside of the Ryan White context that may offer suggestions for the way forward. One such model is the “Country Operating Plans” (COPs) of the President’s Emergency Plan for AIDS Relief (PEPFAR), the U.S. global HIV program.⁵² COPs are used to document “annual investments and anticipated results” and serve as “the basis for Congressional notification, allocation, and tracking of budget and targets and as an annual work plan for the USG”. The plans are developed by U.S. country teams, reviewed by an interagency team in DC, and approved by the U.S. Global AIDS Coordinator. COP guidance identifies key priorities and is designed to assist countries in prioritizing among competing activities. For example, PEPFAR has identified specific countries that are expected to scale up treatment. While not all aspects of the COP process likely could or should be adopted within Ryan White, it may offer lessons to policymakers when considering how HRSA could become more actively engaged, how to use multi-sectoral review panels that include federal and state officials and community stakeholders to review numerous grantee plans using the same principles and standards, and how to ensure that plans are actively supporting the best evidence for maximizing impact.

- **Integrate HIV prevention and care planning**

A related issue to streamlining planning and one potential way for developing better plans would be to integrate HIV prevention and care planning within a state or local jurisdiction. Indeed, many jurisdictions already have unified prevention and care planning processes, but differing administrative guidance and other barriers between CDC and HRSA (and the laws under which their programs operate) have limited the ability of jurisdictions to move in this direction. Further, differences in programmatic goals and other factors mean that planning for prevention services may differ in some ways with care planning. Nonetheless, as more people see treatment as prevention, and as the overlap increases between high priority care and prevention interventions, such as increased linkage and retention services, it is becoming increasingly important for federal and state officials, along with community stakeholders, to work together to smartly bring our prevention and care investments more closely in line with each other to increase impact. Further, the prevention system has resources that can improve the effectiveness of care services. For example, some jurisdictions have begun using their HIV surveillance data (the national HIV surveillance system is funded and overseen by CDC) to identify people who have fallen out of care, in order to re-engage them in care. While such programs must be implemented in ways that foster community trust and support, this type of effort offers new potential to get more people with HIV engaged or re-engaged in care.

- **Measure HIV clinical indicators and performance along the cascade**

In March 2012, a committee of the Institute of Medicine commissioned by the White House Office of National AIDS Policy issued a report with recommendations for core clinical HIV care indicators. These included nine standardized measures for tracking performance along the treatment cascade and five measures for mental health, substance abuse, and supportive services. Separately, HHS has undertaken a cross-agency initiative to standardize reporting on a related set of core metrics. HRSA already tracks some of these indicators⁵³, but more flexibility may be needed if statutory definitions inhibit the ability of the agency to align the indicators and definitions of terms to ensure comparability across federal programs and across health insurance systems.

Consideration could be given, for example, to having HRSA provide a short annual public report on local, state, and national performance along the cascade with recommendations for priority actions for improving future performance. As mentioned above, HRSA and some local

jurisdictions have already begun to analyze national Ryan White client-level data along the cascade. Moving forward, HRSA, perhaps with the assistance of CDC, could work more closely with grantees to help them to begin calculating their own performance along the cascade (overall and for specific populations within their jurisdictions), and setting specific benchmarks in order to actively use core measures to monitor clinic-level performance.

- **Update the 75/25 rule**

The Ryan White program permits grantees to fund a range of medical and non-medical services that are critical to supporting people with HIV. In the 2006 reauthorization, the Congress established a policy called the 75/25 rule that requires that 75% of the grant award under Parts A and B, and early intervention services under Part C be applied to core services⁴⁷, which are largely medical services (see Table 2).

Table 2: Ryan White Core Medical & Support Services	
<p>Core medical services:</p> <ul style="list-style-type: none"> • Outpatient/ambulatory medical care • AIDS Drug Assistance Program (ADAP) • Local AIDS pharmaceutical assistance (APA) • Oral health care • Early intervention services (counseling; testing; referral; other clinical, diagnostic periodic medical evaluation; therapeutic services) • Health Insurance premium and cost-sharing assistance • Home health care • Home and community-based health services • Hospice services • Mental health services • Medical nutrition therapy • Medical case management, including treatment adherence • Substance abuse (outpatient) 	<p>Support Services:</p> <ul style="list-style-type: none"> • Case management (non-medical) • Child care services (for children of HIV positive clients attending medical or other services) • Pediatric developmental assistance and early intervention services • Emergency financial assistance • Food bank/home-delivered meals • Health education/risk reduction • Housing services (short-term, emergency, temporary or transitional housing to enable family or individual gain or maintain medical care) • Legal services • Linguistic services (as part of HIV service delivery) • Medical transportation services • Outreach services (to identify undiagnosed HIV) • Permanency planning • Psychosocial support • Referral for care/support services • Rehabilitation services • Respite care • Substance abuse services (residential) • Treatment adherence counseling

Sources: HRSA, HAB, 2012 Annual Ryan White HIV/AIDS Program Services Report (Rsr) Instruction Manual and Public Law 109-415, December 19, 2006.

The policy was put in place to ensure that limited federal resources are being used for those services most likely to have an impact. At the same time, it has also raised challenges in some jurisdictions, with concerns being raised that it makes inappropriate distinctions between core and non-core services – especially in light of the new understanding of the continuum of services that may be needed to keep people engaged in care. Some jurisdictions have also said that the rule does not recognize variations in service delivery systems from state to state or community to community. In addition, with coverage expected to expand significantly under the ACA, there is

concern that the 75/25 rule could pose new challenges to Ryan White grantees who may increasingly find that they need to provide supplementary, non-medical services to people with HIV to support their transition to new coverage, and their access to and retention in care. Still, jurisdictions are already able to seek waivers of this policy^{47,54} on an annual basis if they are able to demonstrate that there are no ADAP waiting lists and that core medical services are otherwise available to people with HIV who rely on Ryan White.

While the current waiver process remains available for addressing challenges presented by the 75/25 rule, there may be other approaches to consider for updating the rule to adapt to the new science and new environment, including:

- **Reconsidering the definition of core and non-core services:** To a large extent, the existing definition of core and non-core services tracks a distinction between medical care and support services. Given that in the future many Ryan White clients will have greater access to medical care through expanded insurance coverage, a greater focus for Ryan White resources may be on support or “wrap-around” services that help complete coverage and allow individuals to remain in care (such as assisting with premiums, co-pays, and deductibles, as was the experience in Massachusetts). As described above, many of the services needed to improve performance along the treatment cascade are currently defined as “support services” (non-core) under Ryan White. At the same time, not all support services are equally important and policymakers may still wish to prioritize certain services or exclude coverage for certain services. Given the new attention to the treatment cascade, Congress could re-define core and non-core services to track the treatment cascade. Under this scenario, core services could be those directly tied to supporting individuals at each step of the cascade, and some services currently classified as non-core services could be moved into the core group, such as treatment adherence counseling or non-medical case management, given their potential importance at keeping people engaged in care. Non-core services would remain those services that are beneficial to individuals with HIV, but that are more indirectly associated with diagnosis, linkage, retention in care and access and adherence to ART. Such services could still be covered, but in a more limited fashion.
- **Replacing or altering the waiver process with a more tailored approach for each grantee:** Given the uncertainties about ACA implementation and resulting changes in the care and delivery environment, grantees could be allowed to apply for waivers on a rolling or more frequent basis than the current annual process only. In addition, Congress could consider modifying the criteria needed to obtain a waiver to allow for flexibility at the local level; for example, one could imagine the desire to permit funding for non-core services (as currently defined) that support retention in care, even in cases where there is a waiting list for drug services.

2. BUILDING HIV CARE NETWORKS IN UNDERSERVED COMMUNITIES

2. Building HIV care networks in underserved communities

- Re-tool Ryan White to better reach the most marginalized populations
- Strengthen the Ryan White program’s focus on gay and bisexual men
- Consider new programs for high cost cases or especially vulnerable populations
- Integrate people living with HIV and affected communities into care networks to provide testing, linkage, and retention services
- Support CBO planning for re-tooling, coordination and consolidation

Part of what has made the Ryan White program effective is that it is deeply grounded in a community response. Ryan White was built over many years to serve as a stand-alone, community-based health system that operated, to some extent, independently of the mainstream health system. Even at a time when there is an enhanced focus on integrating Ryan White with the rest of the health system, there are core aspects of Ryan White that policymakers may wish to preserve.^{16,17,46} One such role of the program is to build and sustain HIV care networks in underserved communities. Indeed, given the diversity of affected populations, and the concentration of the epidemic among underserved populations and within geographically underserved areas, the program has always had to be proactive about building the capacity to meet the health care and support needs of specific communities of people living with HIV. This has included making sure that there was the capacity to provide medical care where such capacity did not exist, as well as supporting a network of community-based organizations (CBOs) to provide testing, counseling, case management, linkage and retention and other critical services. Going forward, it will be important to assess what and where the biggest gaps in capacity are and how Ryan White can have the biggest impact in supporting networks of HIV care in communities across the country.

As policymakers think in new ways about how to support the Ryan White program in complementing the mainstream health system, consideration may need to be given to bolstering the program's focus on targeting the most underserved populations, supporting CBOs serving these populations, and strengthening partnerships between CBOs and medical clinics to increase their impact. Issues to consider could include:

- **Re-tool Ryan White to better reach the most marginalized populations**

Reaching marginalized and underserved populations continues to be a particular challenge to the HIV response in the U.S. Racial and ethnic minority communities tend to have less access to HIV prevention and care services and poorer health outcomes.^{55,56} Young gay men of all races are among those at highest risk for HIV infection in the U.S. and the only group for whom HIV incidence is increasing⁵⁷, but models of care for serving them are generally in short supply. Further, while increased attention and resources have focused on improving health outcomes for women with HIV in recent years, more focused efforts are still needed to reach Black women and Latinas, who are disproportionately impacted and may face unique obstacles to staying in care. Transgender women, and people who inject drugs, while relatively small populations, are also groups at very high risk for HIV infection, and more efforts are needed to improve their engagement with the health system and their performance along the treatment cascade.^{58,59}

While the Ryan White program has played a unique and important role in reaching underserved populations, there may be opportunities to strengthen this engagement going forward by more systematically assessing which populations are most underserved (including, for example, through population-specific treatment cascade modeling), further developing the evidence-base for model interventions, evaluating their effectiveness, and promulgating best practices.

While services funded under various parts of Ryan White support HIV care networks for underserved populations, three programs stand out for their potential collaborative role in developing evidence-based models for intervening to improve clinical outcomes for targeted populations. They are the Minority AIDS Initiative (MAI), which provides dedicated funding through Ryan White and other HHS programs to respond to the disproportionate impact of HIV in communities of color, the Part D program which is focused on serving women, infants, children, and youth, and the AIDS Education and Training Center (AETC) program, which is funded to train medical providers to provide HIV health care services.

- **Strengthen the Ryan White program's focus on gay and bisexual men**

As mentioned above, gay and bisexual men, particularly those who are young and are racial and ethnic minorities, continue to be at significant risk of HIV infection in the U.S. and are the only group for whom new infections are increasing. Currently, Ryan White does not have a mechanism that directly targets gay and bisexual men, analogous, for example, to its existing programs that more broadly target racial and ethnic minorities (the MAI) and women, infants, children, and youth (Part D). At the same time, the National HIV/AIDS Strategy calls for better targeting of resources to the hardest hit populations, including gay and bisexual men of all races/ethnicities. Going forward, consideration could be given to enhancing Ryan White's emphasis on addressing HIV among gay and bisexual men across the program's current Parts and/or within the MAI and Part D structures.

- **Consider new programs for high-cost cases or especially vulnerable populations**

In virtually any health system, a small segment of the population is responsible for a large share of overall health spending. Whereas Ryan White has been more focused than most programs on targeting efforts to reach specified populations, the program has not focused on special approaches to serving high cost or especially vulnerable clients. As the ACA more tightly integrates care and as Ryan White adapts to supplement gaps in coverage, policymakers could focus more Ryan White resources and attention on the small share of the HIV population that has disproportionate needs. This could include, for example, individuals with co-occurring diagnoses of HIV, mental illness, and addiction disorders. Policymakers could authorize HRSA to test new benefit categories for high need individuals, such as intensive case management, housing and other supports that would not be available to other Ryan White clients.

- **Integrate people living with HIV and affected communities into care networks to provide testing, linkage, and retention services**

As policymakers consider ways to increase the engagement in HIV care along the treatment cascade, people living with HIV and members of affected communities are a critical resource that could be more fully integrated into broader systems of care. In various Ryan White-supported programs across the country, popular models for improving linkage and retention in care and adherence to treatment have been developed that are built around having trained individuals from affected communities conduct outreach and engage people in care, and to help individuals navigate the health system and troubleshoot with them as problems arise. In many cases, people living with HIV are perceived to be particularly effective because they are able to create a relationship of trust by sharing their own experiences with the care system and with stigma and discrimination. Studies have shown that Ryan White-funded patient navigator models help to improve engagement in care.¹⁸ While many policymakers express support for this type of effort, there have been few systematic efforts to integrate peers and evaluate their effectiveness as part of a strategy to improve performance along the treatment cascade. Policymakers could consider ways to standardize and bring to scale training and credentialing programs for peer outreach workers. They could also evaluate and promulgate evidence-based approaches for effectively integrating peer support into current HIV programs, which could also help strengthen such capacity in the post-ACA health care environment.

- **Support CBO planning for re-tooling, coordination and consolidation**

While Ryan White has made major contributions to building community infrastructure, in many communities, there are simply more CBOs than available public and charitable resources can

support. During the economic downturn, many CBOs had to close their doors and more will likely do so in the coming years. Some organizations are better equipped than others to work within the new health system. If only the strongest organizations survive, however, this may lead to even greater gaps in access to services within specific communities. Therefore, federal policymakers could consider new ways to help CBOs adapt to changing roles, including through technical assistance and by supporting peer outreach or other interventions to assist with engagement and retention in care and to strengthen coordination between CBOs and medical providers within a given community. A part of this function could be to pro-actively plan for potential CBO consolidation in order to preserve as much community infrastructure as possible. This could include allowing Part A and B grantees to dedicate a portion of their grants for planning activities or providing certain flexibilities to mitigate service interruptions and to prevent new gaps in access to services from arising during potential closings of CBOs or consolidation of providers, especially within marginalized communities for whom there may already be a limited supply of experienced and culturally competent providers.

3. INTEGRATING HIV CARE EXPERTISE INTO THE MAINSTREAM HEALTH SYSTEM

3. Integrating HIV care expertise into the mainstream health system

- Address payer of last resort limitation during coverage transitions
- Enhance Ryan White's ability to help individuals navigate insurance transitions
- Consider new service models to remove barriers to continuous care
- Work with other parts of the health system to strengthen the quality of HIV care
- Strengthen collaboration and coordination between Ryan White medical and support services providers
- Support HIV providers and the HIV workforce

While policymakers may want to consider how best to retain some of the unique aspects of Ryan White, it will also be important to find ways to integrate Ryan White into the mainstream health system. In addition to expanding coverage, the ACA seeks to improve the quality of care by making different parts of the system work together and use scientific methods to evaluate and implement best practices. The vision for a new and improved health system also includes a greater emphasis on prevention and health promotion. Given the current experience with the mainstream health care system, however, it is expected that Ryan White will need to continue to play a central role in serving people with HIV, and that it may be uniquely situated to do so.¹⁶ As noted in a recent Institute of Medicine report, "The Ryan White HIV/AIDS Program is an example of an effective integrated model of care for PLWHA. Primary and specialty care as well as psychosocial services are coordinated within a single "medical home." Therefore, the Ryan White HIV/AIDS Program model of care helps to overcome challenges posed by the fragmented health care system that may impede retention in care for many PLWHA."⁶⁰ In fact, the ACA does not specifically address many of the barriers that cause people with HIV to fall off of the treatment cascade and the ACA's reforms did not contemplate taking on Ryan White's current responsibilities for supplementing public and private insurance coverage for people with HIV. Therefore, policymakers may wish to consider how to ensure that Ryan White and the mainstream health system interact in ways that lead to less duplication, greater efficiency, and higher quality care.

Such consideration could be aided by recent HHS regulations and guidance defining "essential community providers" under the ACA, for purposes of ensuring network adequacy in state health insurance marketplaces, to include Ryan White providers.^{61,62} In addition, the new law calls for the creation of "Navigators" and "Patient-Assistors"^{63,64} to help people eligible for insurance in state insurance marketplaces learn about their options and assist them with enrollment, a role Ryan White providers may be particularly well suited for. Given the broad need for such services for the general population, however, it is unlikely that such funding will be sufficient to assist all

people with HIV. Therefore, HRSA could work to educate Ryan White providers about these opportunities and ensure that Ryan White resources are complimentary and non-duplicative.

Ryan White already extensively interacts with and supplements Medicaid, Medicare, and private insurance coverage. For example, under ADAP, states are permitted to use ADAP funds to purchase private insurance or continue coverage instead of purchasing drugs directly. Ryan White is also perhaps more focused on removing barriers to care than some insurance programs. It often pays cost sharing for drugs or services required by other programs or pays for transportation and other services that enable people to stay in care. Case management is a particularly important service for managing HIV. Yet, too frequently, public and private insurers either do not cover this service or limit coverage.

Issues and potential approaches to consider for working to integrate HIV care expertise into the mainstream health system include:

- **Address payer of last resort limitation during coverage transitions**

Many people with HIV have lower incomes that place them near the income cutoffs for Medicaid and state health insurance marketplace coverage. Therefore, some individuals will gain and lose eligibility for different programs as they gain or lose jobs, move from place to place, or face other life transitions. This could cause a fair amount of movement from exchange coverage into and out of Medicaid. Each of these insurance transitions creates the possibility for care to be interrupted. Unlike other people for whom short interruptions in care may not be problematic, however, it is important to maintain people with HIV on continuous ART and minimize gaps in access to other health care services. Just as Ryan White supplements coverage for these other programs, policymakers may wish to consider whether and how to permit Ryan White to prevent or minimize gaps in care. This could involve working to ensure that Ryan White providers are included in both Medicaid and state health insurance marketplace networks and that Ryan White payer of last resort requirements, intended to prevent cost-shifting to Ryan White, do not affect continuity of care. As mentioned above, in the case of California, the payer of last resort requirement presented unforeseen challenges as the state sought to move people with HIV into new coverage. One way to address this would be to temporarily permit HRSA to waive enforcement of the payer of last resort requirement in emergency situations, such as to ensure uninterrupted access to ART. This could include, for example, promoting the use of “pay and chase models,” already used by some Ryan White grantees and providers, wherein Ryan White would guarantee temporary pharmacy benefits at the point-of-sale for individuals who are eligible for other coverage, but are unable to receive benefits during an insurance transition. These grantees could then seek retroactive reimbursement from the other source of coverage.

- **Enhance Ryan White’s ability to help individuals navigate insurance transitions**

Consideration also could be given to prioritizing access to educational, case management, and legal services to help individuals navigate insurance transitions and coverage disputes. While Ryan White can cover such services now, past legislative and administrative guidance may have signaled to grantees that such activities should be a low priority. In the new coverage landscape where a greater focus is on accessing available insurance coverage, however, grantees could be directed to ensure that such services are available to prevent or resolve insurance eligibility and access to services issues. As mentioned above, the ACA’s creation of navigators and patient-assistors may provide an additional avenue for Ryan White providers to help manage insurance transitions for people with HIV.

- **Consider new service models to remove barriers to continuous care**

While Medicaid, Medicare, and private insurance coverage will cover the basic elements of medical care, not all of these programs will provide comprehensive coverage for the services and supports needed to ensure that people are diagnosed, linked, and retained in care, or that are needed to support adherence to ART. As noted above, a central role of Ryan White in the new health system will likely be to support supplemental coverage for some of these services. While Ryan White supplements insurance coverage today, policymakers could consider a number of new Ryan White service categories to improve performance along the treatment cascade, such as linkage and retention services or other services designed to integrate preventive care with primary care, or that are designed not just to work alongside insurance coverage, but to be integrated into Medicaid and health insurance marketplace plan networks developed as part of the ACA.

Additionally, research has demonstrated the value of access to stable housing for supporting people with HIV in staying in care and staying adherent to ART.^{65,66} Among the range of HIV service needs, housing supports is one area with perhaps the biggest persistent shortages in supply.⁶⁷ Although Ryan White funding can currently be used to support short-term, emergency housing services, some stakeholders have advocated for expanding Ryan White housing policy to include longer-term housing assistance. Others have argued that doing so falls outside of the jurisdiction of a health program operated by HHS and Ryan White's primary goal of providing medical care and related health care services to people with HIV.⁶⁸ HRSA and the Department of Housing and Urban Development (HUD), which is the department responsible for housing assistance including the Housing Opportunities for People with AIDS (HOPWA) program, have begun collaborating on ways to integrate Ryan White and HOPWA-funded services more directly. An examination of these efforts could be conducted to determine if new policies are warranted.

- **Work with other parts of the health system to strengthen the quality of HIV care**

Medicaid, Medicare, and private insurance are the dominant payers for HIV health services and this will only increase once the ACA is implemented. Yet HIV care comprises only a very small share of spending within these other programs. Consequently, these programs may have limited expertise, capacity, and incentive to focus on HIV quality. Therefore, it may be important for policymakers to consider how best to support the transfer and integration of the experience and expertise held by Ryan White grantees and providers to the rest of the health system. One approach would be to permit grantees to fund staff time for working on policy development outside of Ryan White. In CDC's current funding announcement for HIV prevention for health departments, for example, policy development to align public policies to optimize HIV prevention, care and treatment is now considered a core prevention function.⁶⁹ Similarly, policymakers could permit Ryan White grantees to engage in policy development to increase the quality and consistency of HIV care. For example, HRSA program staff and Ryan White grantees could enhance collaboration with CMS and private insurers on implementing current standards of HIV care so that policy decisions made in these other programs support quality HIV care. Or, state grantees could increase efforts to work with their Medicaid programs, their state insurance commissioners, and private plans to educate them about standards for HIV clinical care and evidence-based approaches to managing services for people with HIV. To be maximally effective, however, consideration may also be needed to be given regarding how best to incentivize Medicaid programs, the exchanges, and private health plans into actively working with HIV providers and experts.

- **Strengthen collaboration and coordination between Ryan White medical and support services providers**

In addition to thinking through how Ryan White will collaborate with other parts of the health system, it is also important to consider ways to strengthen collaboration between Ryan White medical care and support services providers. In many instances, medical and support services providers may receive funding from one part of Ryan White, with limited mechanisms to ensure strong and consistent coordination of services, especially when multiple grantees are providing services to the same clients. Policymakers could establish new requirements to ensure that support service providers have formalized relationships with and are sharing relevant data with the medical providers treating their clients. Additionally, in the context of improving linkage and retention in care, new mechanisms could be considered to ensure that these important support functions are more integrally connected to the medical care system.

- **Support HIV providers and the HIV workforce**

Providing quality HIV medical care is complex, and requires expertise and experience, as well as time. Payment rates for HIV providers, especially non-specialty primary care providers, may be insufficient for most HIV providers within both public and private insurance programs. Moreover, there are projected shortages in the HIV workforce.⁷⁰ To address these challenges, policymakers could consider new ways to ensure adequate reimbursement for HIV care providers or to further bolster workforce capacity. This may include supplementary payments for expanded medical consultation services to account for the specialty care they are providing and to accommodate the extended time that is often required for HIV medical visits. One recent step in this direction is the final regulations issued by the federal government on a provision of the ACA designed to give Medicaid providers higher reimbursement rates for a temporary period.^{28,71} As many in the HIV community had recommended, the final rule includes primary care specialists in the definition of providers who will receive enhanced reimbursement.⁷² Since many HIV specialists meet this definition, it is one mechanism for supporting adequate payment for HIV care. Ryan White could build on this effort to help support access to HIV medical providers not only in Medicaid, but also in Medicare and private insurance plans. In addition to payment incentives, various other mechanisms for increasing workforce capacity have been suggested, including greater use of task shifting, co-management, and integrated delivery systems; and the broader adoption of interdisciplinary care teams in the provision of HIV care.⁷⁰

4. EFFECTIVELY AND FAIRLY ALLOCATING RYAN WHITE RESOURCES

4. Effectively and fairly allocating Ryan White resources

- Reconsider funding formulas and allocation mechanisms
- Allocate funding to Parts A and B for both services and other program functions
- Expand or modify the SPNS program to encourage investigator-driven innovation
- Simplify grantee application and reporting procedures

Implementing the ACA and updating the Ryan White program is an enormous opportunity to strengthen the HIV care delivery system, but the ability to implement many of these policies turns on ensuring adequate and appropriately targeted resources. The National HIV/AIDS Strategy emphasizes the imperative to ensure that the money follows the epidemic. Resource allocation within Ryan White, however, has been a challenge for the program since it was established.⁷³ Unlike Medicaid and Medicare where funding increases with increased need, and where unexpected developments such as increased enrollment or the availability of new technologies

(such as more effective treatments or improved diagnostics) automatically lead to increased funding, Ryan White is a discretionary program whose annual funding is determined through the federal appropriations process. This means that tension over how to allocate funding is complicated by limited funding in the face of significant unmet need.

Ryan White currently uses a mix of formula funding and competitive funding for States through Part B of Ryan White and local jurisdictions through Part A, as well as direct funding of clinics and health care organizations, through Parts C, D, and F (see the appendix for additional details). Each funding approach serves a different purpose. Most program funding has historically been awarded on the basis of a formula, which creates a sense of fairness if the public recognizes that the money follows the epidemic and that the largest factor determining the level of funding their state or community receives is based on living HIV/AIDS cases. The program has already worked through difficult transitions moving from a formula that counted only historical AIDS cases, including people who are no longer living, to counting living AIDS cases, but not HIV, to now basing formula awards on living HIV/AIDS cases.

In addition to formula-based funding, because of significant variations in the burden of the HIV epidemic, per capita income, the availability of charity and other private sector resources, and the reach of Medicaid and other parts of the safety net, competitive supplemental funding provides an opportunity to respond to the areas and communities with the greatest demonstration of need. On top of this, the Part C and D programs directly fund medical clinics or other entities, and this enables federal officials to target investments to underserved geographic areas and to specific underserved populations within a community. Over the years, there has been broad support for using these different funding approaches to respond to different visions of equity within a very unequal and diverse national health system.

Despite all of this, some stakeholders still believe that funding is not allocated as fairly or as efficiently as it should be. Some have argued that the way that in which Parts A and B are funded creates advantages for states that receive funding from both Parts. Past reauthorizations have sought to partially remedy this through changes to the Part B formula, without ever completely eliminating such disparities. Still others have said that grantees under Part D are more generously funded relative to Part C. Beyond issues specific to different parts of the program, virtually all Ryan White grantees have argued that the administrative burden associated with applying for and receiving Ryan White funding is unreasonable and detracts from their ability to effectively serve people living with HIV.

While policymakers may wish to preserve the different funding approaches for the program, issues to be considered to simplify the allocation of funding, increase transparency, better target where needs are greatest, and minimize grantee burden could include:

- **Reconsider funding formulas and allocation mechanisms**

As noted above, the formulas used to allocate funding across the country have changed over time as concerns have been raised about equity. Given that such concerns continue and in light of the significant changes to the health care system that will occur as a result of the ACA, policymakers may want to assess whether further changes in the formula are warranted. Historically, there has been a competition for resources between metropolitan areas and states. Today, most parties recognize that both types of jurisdictions have critical roles to play in responding to HIV. At the same time, some have continued to question whether allocating Part A funding separately from Part B has led to both inequities in the per person level of funding available for services and pressure to add more Part A grantees simply to bring in more federal resources to a state.

One approach to addressing these concerns could be to allocate Part A and B funding using a single formula providing funding for states, a part of which is then allocated for EMAs and TGAs.

This would be consistent with the CDC's new resource allocation of HIV prevention funds to state and local health departments.⁷⁴ In such a scenario, a state's allocation would be based on their share of HIV cases nationally, and EMAs and TGAs would receive a proportional share of their state's federal allocation. The remainder of funding would go to the state to provide the same level of support for services for people with HIV in the rest of the state. This could ensure that resources better track where the epidemic is, and minimize inequities between states and within a state between EMAs and TGAs and non-EMA/TGA parts of the state. A related issue that could be considered is whether to merge the ADAP earmark into this new single formula or retain a separate allocation, or provide flexibility for states to transfer ADAP funds to other services if it can be demonstrated that such flexibility will have a positive impact on getting more people to access medications.

Another issue that could be explored is the relationship between Parts C and D. Both programs give HRSA broad discretion to fill gaps in service capacity across the nation and fulfill a compatible purpose within the Ryan White program. The Part D program is more narrowly focused on women, infants, children and youth. While these are vulnerable populations that need focused attention, some have argued, however, that they are not the only vulnerable populations and other groups suffer by not having a program dedicated to their needs, such as gay and bisexual men. Further, some have asserted that the Part D program has been more generously funded than the Part C program that serves a broader share of the HIV population. A related issue is that Part D can support a broader range of services than Parts A, B and C. Therefore, clients of the small number of Part D clinics can receive services unavailable to other Ryan White clients, raising questions of fairness. To increase both equity across populations and to maximize the impact and reach of the program that directly funds medical clinics in underserved communities, policymakers could consider merging the Part C and Part D programs, so that current grantees of both programs would remain eligible for funding, but there would be one set of covered services and HRSA would apply one standard for allocating grant awards.

- **Allocate funding to Parts A and B for both services and other program functions**

In the new health system, Ryan White's primary role will be to provide services for uninsured individuals with HIV and to fill in gaps in insurance coverage. As discussed previously with respect to improved integration of the HIV care system with the mainstream health system, an important enhanced function of the program may be to serve as a resource for the rest of the health system by monitoring HIV care, evaluating best practices, disseminating best practices, and working with insurers, federal agencies, and state insurance commissioners and others to continually evaluate and improve HIV care delivery. Given other competing demands for time and attention within the rest of the health system, on their own, most health insurers will not have sufficient expertise to devote adequate attention to HIV care. Reauthorization may create an opportunity to ensure that resources are available for these increasingly critical functions.

One way to provide support for these new functions at the state and local level would be to create a separate allocation for services and a smaller share for other state and local functions. Under this scheme, the law could designate a percentage of the Part A and B appropriation for services provided through the formula and the competitive supplemental process, and a separate percentage for other state and local functions. Whereas funding for services would remain a priority, this represents a new paradigm wherein Ryan White may have a bigger impact on access and quality of care by using a dedicated portion of its funding for monitoring, evaluation, policy development, and dissemination of best practices outside of Ryan White.

- **Expand or modify the SPNS program to encourage investigator-driven innovation**

The Special Projects of National Significance (SPNS) program plays an important role in allowing HRSA to take a national view and fund demonstrations to address important policy issues. SPNS

has done important work. Policymakers could consider establishing a complimentary investigator-driven component of SPNS that permits existing grantees or other entities providing HIV care and services at clinics or CBOs to apply for funding to test and evaluate new models for improving care delivery. In this way, front line medical and non-medical services providers would have new opportunities to apply their experience with their clients to inform policy development and the development of improved models of services delivery.

- **Simplify grantee application and reporting procedures**

As mentioned above, in identifying potential strategies for working toward increasing the share of people with HIV who are virally suppressed, federal officials could be given new powers to hold grantees accountable for improving performance along the treatment cascade and strengthening program accountability. Achieving these goals, however, likely requires a fresh approach to grants management procedures. At present, the burden on all types of Ryan White grantees is potentially a barrier to their efforts to maximize program outcomes. In a recent GAO report on the MAI program, for example, it was found that prospective grantees indicated that they did not apply for MAI funds despite having a severe need for the funding because of the administrative burden associated with the application process. The Strategy calls for streamlining of data collection and simplification of the grantmaking process. An IOM report also recommended such streamlining and reduction of grantee reporting burden¹⁰, and HHS has recently undertaken a process do so.⁷⁵

Policymakers could consider further streamlining the legislative provisions of the law or grant the Secretary new authority to waive requirements of the law in order to improve the efficient management of the program. This may include examining approaches to simplifying application requirements, reducing the periodicity requirements for financial and other reporting, and permitting the Secretary to change requirements in law in order to align the definition of clinical and financial metrics with other federal programs.

CONCLUSION

The key issues and questions raised here are intended to build on a legacy of success of the Ryan White program at saving and improving the lives of people living with HIV. At a moment when the National HIV/AIDS Strategy, the Affordable Care Act, and other policy and research developments create so much optimism for the possibility of moving towards an AIDS-free generation, it is sobering to recognize that just a third of all people with HIV are on ART and only one in four is virally suppressed. The Ryan White program is uniquely situated to support the rest of the health system and lead the way in getting many more people with HIV engaged and retained in care and, ultimately, fully virally suppressed. It is hoped that the range of ideas presented here demonstrate the possibilities for adapting this critical program to ensure its relevance and success in the future.

APPENDIX

BACKGROUND ON THE RYAN WHITE PROGRAM

First enacted in 1990, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act was named after a teenager with hemophilia who was diagnosed with HIV in 1984. After facing incredible stigma and discrimination in his own community, he became an early and prominent advocate for all people with HIV. Ryan White died of AIDS at the age of 18, a few months before the enactment of the CARE Act. The program is administered by the Health Resources and Services Administration (HRSA) at the Department of Health and Human Services.⁷⁶

The original purpose of the Ryan White CARE Act was to:

[T]o provide emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease (P.L. 101-381).

It grew out of an increasing recognition by policymakers and others of the toll the epidemic was taking on people with HIV and their families, as well as the growing financial burden faced by states and cities in trying to meet their care needs.⁵¹ There were several precursor federal grant programs, including an “AZT Drug Reimbursement” program (created in 1987) to help states afford treatment and AIDS Service Demonstration Grants, which provided funding to four hard hit cities. The CARE Act consolidated and expanded these different efforts. It created formulas for allocating funding to states and cities and, in recognition of the need for a strong community and consumer role by people with HIV and the diverse nature of the HIV epidemic in the U.S., gave significant discretion to grantees for designing their programs. Due to divergent needs and varying levels of public health and health care infrastructure, Ryan White varies considerably across the country.

Over the course of its more than 20 year history, the program, as well as the environment in which it operates, has changed. For example, there has been a significant shift in the delivery of HIV care, from hospital-based support (the law has always prohibited Ryan White from paying for inpatient care) to outpatient care and, increasingly, chronic care management. This is due primarily to the development of effective combination ART and to Ryan White itself which was designed to build-up outpatient, community-based capacity to serve people with HIV. In addition, the surveillance of HIV disease has improved over time, allowing public health officials and others to move from only being able to track AIDS cases, the most advanced form of HIV disease, to tracking HIV cases (including those who have advanced to an AIDS diagnosis) and obtain a fuller measure of the epidemic’s burden. As a result, federal funding formulas for Ryan White, and other HIV-specific programs, have also been revised to reflect some of these changes.

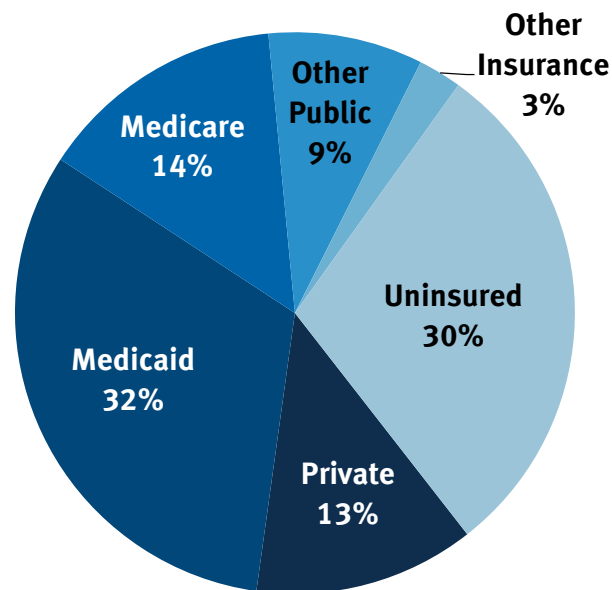
Each of the program’s four reauthorizations has also brought changes. For example, at the time of the program’s first reauthorization in 1996, just after the emergence of successful combination antiretroviral therapy. Congress created an AIDS Drug Assistance Program (ADAP) “earmark” for the first time, providing for a separately funded line item for ADAPs as part of Ryan White. Congress also provided new requirements for prioritizing funding for women, infants, children and youth. In 2000, Congress first initiated a process for incorporating counts of HIV cases, in addition to AIDS, which began the longer shift toward using living HIV/AIDS cases when determining funding allocations. It also put a renewed emphasis on early intervention services, in order to help people with HIV learn their status and get into care. The 2006 reauthorization, the

last comprehensive reauthorization of the program, made numerous changes including requiring that 75% of most funding be used for a defined set of “core medical services” (also known as the “75/25 rule”) and requiring the Secretary of HHS to develop a list of antiretrovirals to serve as a “minimum formulary” for ADAPs. It also included a “sunset provision” that would have repealed the legislation in September 2009, a provision that was eliminated when the program was reauthorized in 2009. This last reauthorization, while not making major changes, did include provisions designed to strengthen Ryan White’s role in helping to identify undiagnosed people with HIV and established a new annual national HIV testing goal.

RYAN WHITE TODAY

The Ryan White program is the third largest source of federal financing for HIV care in the U.S., after Medicare and Medicaid. It fills gaps in the health system by providing services to uninsured and underinsured individuals with HIV, functioning as the “payer of last resort” for persons who have no other source of coverage or who face coverage limits. Most Ryan White clients actually have insurance coverage, but rely on Ryan White to supplement limits in their coverage (e.g., limits in the number of prescription drugs per month) or assist them with cost-sharing. In 2010, HRSA estimates that 70% of Ryan White clients had some other form of insurance, primarily Medicaid, while 30% were uninsured altogether (see Figure 5). In addition, about six in ten Ryan White clients (59%) had household incomes at or below the Federal Poverty Level (FPL).⁸

Figure 5: Ryan White Clients by Payer, 2010

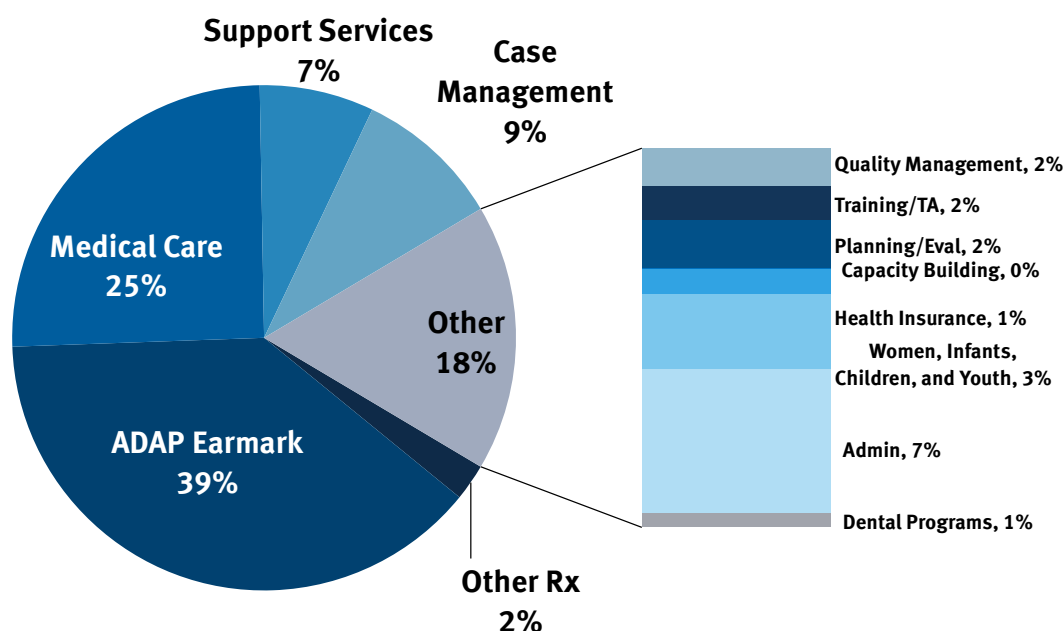


Notes: Based on those with reported insurance status (duplicated number of clients, N=764,163).
Source: HRSA, HAB, <http://hab.hrsa.gov/stateprofiles/index.htm>.



A primary role of the program continues to be to expand the availability of HIV health services, especially in underserved or marginalized communities. Most Ryan White resources are spent on primary care, including medical care services, ADAP and other prescription drug spending (see Figure 6).

Figure 6: Ryan White Program Spending, 2009



Source: HRSA.gov, Grantee Allocations & Expenditures, 2009, accessed August 2012.



The Ryan White program funds various governmental, academic, and community-based entities to achieve its mission. The program is organized into several “Parts” (see Figure 7, and Table 3 for additional details):

- **Part A:** Eligible metropolitan areas (EMAs), which are communities with a population of at least 50,000 people that have had more than 2,000 AIDS cases in the past five years, and beginning in 2006, transitional grant areas (TGAs), which are communities with at least 1,000, but fewer than 2,000 AIDS cases in the past five years;
- **Part B:** States and territories, including the largest component of Ryan White, the AIDS Drug Assistance Program (ADAP);
- **Parts C and D:** Directly funded medical clinics and other entities; and,
- **Part F:** The AIDS Education and Training Center (AETC) Program, the Dental Program, the Minority AIDS Initiative (MAI) Program, and the Special Projects of National Significance (SPNS) Program.

Figure 7: The Current Structure of The Ryan White HIV/AIDS Program

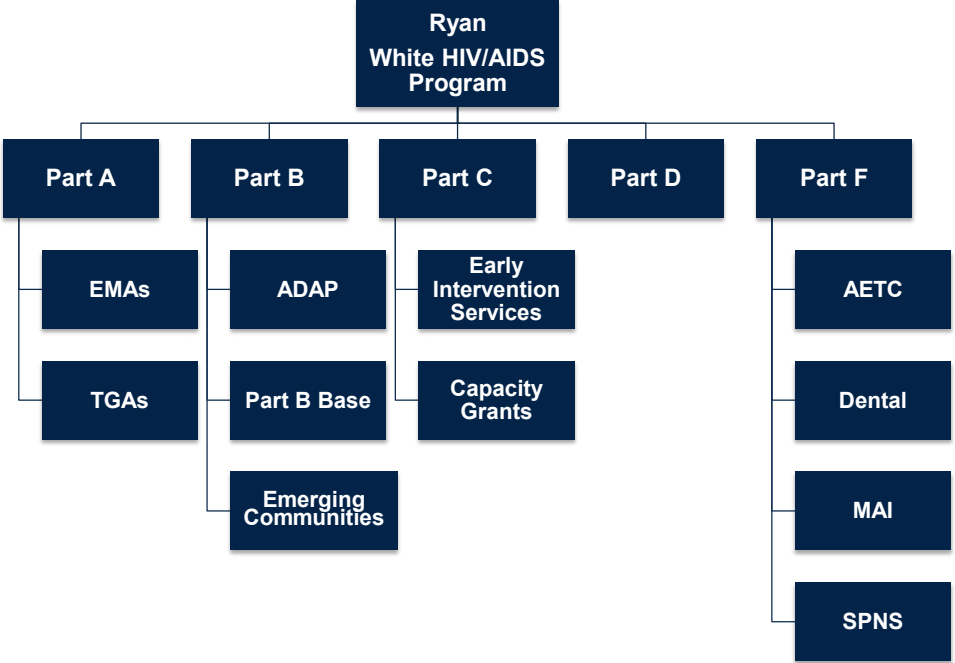


Table 3: Overview of the Ryan White HIV/AIDS Program		
FY 2012 Funding (\$ in Millions)	Funding Recipients	Purpose
Part A		
\$666.1	24 EMAs and 28 TGAs	Provides funding to heavily impacted metropolitan areas to support a continuum of care (medical and support services) to people living with HIV.
Part B		
\$1,360.8 (\$933.3 is for ADAP)	All states, DC, and US territories	Provides funding to all 50 States, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and the five U.S. Pacific Territories to support the same medical and support services as Part A. Most states provide some services directly or through sub-grantees, while others work with HIV Care Consortia, which are associations of public and nonprofit health care and support service providers and community-based organizations, to deliver support services. The majority of Part B funding supports medications through the AIDS Drug Assistance Program (ADAP).
Part C		
\$215.1	367 grantees; ~270 HIV medical clinics	Provides grants directly to medical clinics and other entities to support outpatient HIV early intervention services and ambulatory care. Also funds capacity development and planning grants that support organizations in more effectively delivering HIV care.
Part D		
\$77.2	114 grantees (CBOs, state and local governments, and tribes)	Provides funding for family-centered primary medical care involving outpatient or ambulatory care for women, infants, children, and youth with HIV/AIDS. The range of medical and support services is broader than in other parts of Ryan White. Also supports activities to improve access to clinical trials and research for these populations.
AIDS Education and Training Center (AETC) Program (Part F)		
\$34.5	5 national centers, 11 regional centers, and 130 local affiliated sites, most at academic institutions	Provides funds for targeted, multidisciplinary education and training programs for health care providers treating people with HIV, to increase the number of health care providers who are effectively educated and motivated to counsel, diagnose, treat, and medically manage people with HIV disease, and to help prevent high-risk behaviors that lead to HIV transmission.
Dental Program (Part F)		
\$13.5	56 DRPs and 12 CBDPP	Provides funding for the Dental Reimbursement Program (DRP) that assists institutions with accredited dental or dental hygiene education programs by defraying their unreimbursed costs for serving people with HIV, and the Community-Based Dental Partnership Program (CBDPP) that increases access to oral health care services for people with HIV while providing education and clinical training for dental care providers, especially those in community-based settings.
Minority AIDS Initiative (MAI) Program (Part F)		
\$160.7	Grantees of Parts A, B, C, D, and the AETC program	Provides support for a range of activities to address HIV care needs among African-Americans, Latinos and other disproportionately impacted minority communities.
Special Projects of National Significance (SPNS) Program (Part F)		
\$25.0 (funded from Public Health Service Act evaluation set-aside)	87 grantees	Provides funding for demonstration programs to develop innovative models of HIV treatment and funds projects to develop standard electronic client information data systems to improve the ability of Ryan White grantees and provider organizations to report client-level data.

Sources: HRSA.gov and HRSA FY 2013 Budget Justification, available at <http://www.hrsa.gov/about/budget/budgetjustification2013.pdf>; and KFF RW Fact Sheet. Notes: EMA = Eligible Metropolitan Area, TGA = Transitional Grant Area, and CBO = community based organization.

Funding for the program is allocated through a mix of formula funding, competitive supplemental funding to jurisdictions that demonstrate significant unmet need, and direct federal funding to HIV medical clinics and other institutions. Under Part A, Congress appropriates funds for EMAs and TGAs, with two-thirds of funds awarded by a formula based on living HIV/AIDS cases, but the eligibility requirements for both EMAs and TGAs rely on cumulative AIDS cases. The remaining third of Part A funds are awarded through competitive supplemental grants on the basis of need, and one-third of the weighting for the competitive awards is based on success at increasing knowledge of HIV serostatus.

Under Part B, Congress appropriates funds for the Part B program and earmarks a specific portion for ADAP. In FY 2012, ADAP funding formed 68% of Part B funding. Two-thirds of the Part B base funding (that which is left after the ADAP earmark and a \$5 million appropriation for the Emerging Communities program⁷⁷) is allocated by a formula and one-third of new funds through a competitive supplemental funding process. The formula allocates 75% of funds using a state's proportion of total national living HIV/AIDS cases, 20% is allocated based on the state's proportion of HIV/AIDS cases outside of Part A-funded EMAs and TGAs, and 5% is based on the state's proportion of living HIV/AIDS cases in states with no Part A funding. The combined Part B based funds and ADAP earmark must be matched by state funds (at an escalated match rate for states representing 1% or more of the nation's AIDS cases⁷⁸). Most (95%) ADAP funds are allocated using a formula based on living HIV/AIDS cases, with 5% of ADAP funds reserved for competitive supplemental grants based on a demonstration of severe need, and with states meeting a matching requirement. In addition, in FY 2010, the Obama Administration provided "emergency funding" to address ADAP waiting lists and other unmet ADAP needs in some states, by reprogramming other funds, and in fiscal years 2011 and 2012, the Congressional earmark for ADAP included funding to specifically address such shortages.

Under Parts C and D, the Congress appropriates specific amounts of funding for each part, identifies eligible types of grantees, but gives HRSA discretion in making grant awards to respond to the areas of greatest need. The law directs that eligible entities under Part C must serve underserved populations and directs HRSA to give preference to qualified applicants that are "experiencing an increase in the burden of providing services regarding HIV/AIDS," indicated by factors such as the number of cases, the rate of increase in cases, the lack of availability of early intervention services, and the number of cases of other conditions such as sexually transmitted diseases (STDs) and tuberculosis, rates of drug abuse, and the number of hepatitis B and C cases. HRSA must also consider the availability of primary care from other providers and the distance between the applicant's area and the nearest area with adequate availability of HIV-related services. In giving preference to applicants, the law requires an equitable allocation between urban and rural areas. The Part D program provides grants for providing family-centered care for women, infants, children, and youth with HIV/AIDS. The Part D program is not subject to the 75/25 rule and it is permitted to fund a broader range of services than the core and non-core services that are funded by Parts A, B, and C (early intervention services).

Part F includes a number of components. One is the AIDS Education and Training Center (AETC) program that seeks to increase the number of health care providers who are educated and able to effectively counsel, diagnose and treat people with HIV. They target services to providers serving minority populations, people who are homeless, individuals who are incarcerated and rural communities. In addition, Part F supports oral health for people with HIV through a Dental Reimbursement Program (DRP) and a Community-Based Dental Partnership Program (CBDPP).

Lastly, Part F includes a portion of funding for the Minority AIDS Initiative (MAI) program, which was first created in 1998 in response to growing concern about the impact of HIV on racial and ethnic minorities in the U.S. In addition to funding through Ryan White, the MAI includes funding through other several DHHS agencies and programs.

In recognition of the varying and changing nature of the HIV epidemic, grantees under Parts A and B have broad discretion in making decisions about services to be provided and which entities

to fund, but must obtain community input in the planning process. Under Part A, local “Planning Councils” are tasked with assessing the need for and gaps in services in a given area, setting priorities for resource allocations, and developing comprehensive plans for providing services within an area. By law, all of these planning activities are required to be grounded in epidemiological data. Under Part B, States must also engage in a consultative planning process, which they can do through a “Consortia” (associations set up to plan for and deliver HIV care) or other planning body.

As mentioned above, when Ryan White was reauthorized in 2006, the Congress enacted a core medical services spending requirement, called the 75/25 rule. This applies to Parts A and B (and to Part C with slightly different requirements⁷⁹) and requires that at least 75% of funding for services be spent on core medical services. Non-core support services (up to 25% of funding) must be linked to medical outcomes and may include services such as outreach, medical transportation, referrals for health care and other support services, case management, and substance abuse residential services. The law also established a process for grantees to request waivers to permit more than 25% of grant awards to be allocated to support services if there is no waiting list for treatment under the state’s ADAP program and if core medical services are available to all individuals eligible for services under the grant; currently, grantees are permitted to apply for a waiver on an annual basis.

ENDNOTES

¹ Kaiser Family Foundation analysis. See Figure 3 and endnote #15.

² Cohen MS et al. (2011). “Prevention of HIV-1 Infection with Early Antiretroviral Therapy.” *N Engl J Med*, 365(6):493-505. Available at www.nejm.org/doi/full/10.1056/NEJMoa1105243#t=articleTop.

³ Hillary Rodham Clinton, “Remarks on “Creating an AIDS-Free Generation”, National Institutes of Health, November 8, 2011. Available at <http://www.state.gov/secretary/rm/2011/11/176810.htm>.

⁴ White House (2010). *National HIV/AIDS Strategy for the United States*. Available at <http://www.whitehouse.gov/administration/eop/onap/nhas>.

⁵ CDC. (2012). *Fact Sheet: HIV in the United States—The Stages of Care*. Available at <http://www.cdc.gov/nchhstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.

⁶ Viral suppression is when an HIV positive person’s viral load has been reduced to an undetectable level. See, *AIDSinfo* glossary. Available at <http://aidsinfo.nih.gov/education-materials/glossary>.

⁷ Gardner EM et al. (2011). “The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection,” *Clin Infect Dis*. 52 (6): 793-800. Available at <http://cid.oxfordjournals.org/content/52/6/793.short>.

⁸ HRSA. *Ryan White HIV/AIDS Program, 2010 State Profiles*. Available at: <http://hab.hrsa.gov/stateprofiles/2010/states/us/Client-Characteristics.htm#chart6>.

⁹ Martin E, Schackman R. (2012). “What Does US Health Reform Mean for HIV Clinical Care?”, *J Acquir Immune Defic Syndr*, Vol 60 (1): 72-76.

¹⁰ Institute of Medicine. (2012). *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press. Available at <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States.aspx>.

¹¹ Kathleen Sebelius, Remarks at White House World AIDS Day Event, November 29, 2012. Available at <http://www.hhs.gov/secretary/about/speeches/sp20121129.html>.

¹² Cranston K et al. (2012). “Controlling the Massachusetts HIV Epidemic: Triangulated Measures of Care Access and HIV Incidence”, 19th International AIDS Conference: Abstract no. TUPE212. Available at <http://www.iasociety.org/Abstracts/A200746937.aspx>.

¹³ HRSA, About the Ryan White HIV/AIDS Program, <http://hab.hrsa.gov/abouthab/aboutprogram.html>.

¹⁴ Kaiser Family Foundation analysis of data from OMB, Congressional Budget Justifications, and Congressional appropriations bills.

¹⁵ The Consumer Price Index (CPI) from the Bureau of Labor Statistics (BLS) was used to adjust for inflation; 1991 was used as the base year. HIV prevalence data are estimates based on analysis of data from the following CDC sources: CDC, “Prevalence of Undiagnosed HIV Infection Among Persons Aged ≥13 Years — National HIV Surveillance System, United States, 2005–2008,” *MMWR*, Vol. 61, June 15, 2012 and CDC, “Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 U.S. dependent areas—2010, HIV Surveillance Supplemental Report 2012, Vol. 7;

Funding amounts are based on Kaiser Family Foundation analysis of data from OMB, Congressional Budget Justifications, appropriations bills, and the Congressional Research Service.

¹⁶ Gallant JE et al. (2011). "Essential Components of Effective HIV Care: A Policy Paper of the HIV Medicine Association of the Infectious Diseases Society of America and the Ryan White Medical Providers Coalition". *Clin Infect Dis*. Available at <http://cid.oxfordjournals.org/content/early/2011/10/20/cid.cir689.full>.

¹⁷ Saag MS. (2009). "Ryan White: An Unintentional Home Builder", *AIDS Reader*, Vol.19:166-168. Available at <http://www.theaidsreader.com/display/article/1145619/1408105>.

¹⁸ Mugavero MJ. et al. (2011). "Health Care System and Policy Factors Influencing Engagement in HIV Medical Care: Piecing Together the Fragments of a Fractured Health Care Delivery System", *Clin Infect Dis*, Vol. 52(S2): S238-246. Available at http://cid.oxfordjournals.org/content/52/suppl_2/S238.long.

¹⁹ Mayer K. (2011). "Introduction: Linkage, Engagement, and Retention in HIV Care: Essential for Optimal Individual- and Community-Level Outcomes in the Era of Highly Active Antiretroviral Therapy", *Clin Infect Dis*. 52 (S2): S205-S207. Available at http://cid.oxfordjournals.org/content/52/suppl_2/S205.full.

²⁰ Quinn K, Skarbinksi J. (2013). "Health Insurance Coverage and Type Predict Durable Viral Suppression among HIV+ Adults in Care: US, Medical Monitoring Project, 2009", Tuesday, March 5, 2013. Available at: <http://www.retroconference.org/2013b/Abstracts/45596.htm>.

²¹ Das-Douglas M et al. (2009). "Implementation of the Medicare Part D Prescription Drug Benefit is Associated with Antiretroviral Therapy Interruptions", *AIDS Behav*, Vol. 13(1):1–9. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3591735/>.

²² HPTN. (2012). *Press Release: Expanded Analysis of HPTN 052 Study Results Show Cost-Effectiveness of Early Treatment of HIV*, July 27. Available at <http://www.hptn.org/web%20documents/IndexDocs/PR052CostBenefitsEB27Jul12.pdf>.

²³ Thompson MA et al. (2012). "Antiretroviral Treatment of Adult HIV Infection: 2012 Recommendations of the International Antiviral Society—USA Panel," *JAMA*; 308(4): 387-402. Available at <http://jama.jamanetwork.com/article.aspx?articleid=1221704>.

²⁴ Zolopa A, Andersen J, Powderly W, et al. (2009). Early antiretroviral therapy reduces AIDS progression/death in individuals with acute opportunistic infections: a multicenter randomized strategy trial. *PLoS One*; 4(5):e5575. Available at: <http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0005575>.

²⁵ Kitahata, MM et al. (2009). "Effect of early versus deferred antiretroviral therapy for HIV on Survival." *N Engl J Med*; 360(18):1815-26. Available at www.nejm.org/doi/full/10.1056/NEJMoa0807252.

²⁶ Mugavero, MJ et al. (2011). "Viremia Copy-Years Predicts Mortality Among Treatment-Naive HIV-Infected Patients Initiating Antiretroviral Therapy," *Clin Infect Dis*, 53(9): 927-35. Available at <http://cid.oxfordjournals.org/content/53/9/927.abstract>.

²⁷ Department of Health and Human Services, Panel on Antiretroviral Guidelines for Adults and Adolescents (2013). *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*, February 12, 2013. Available at <http://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/0/>.

²⁸ Crowley J, Kates J (2012). *The Affordable Care Act, the Supreme Court, and HIV: What Are the Implications?* Washington, DC: Kaiser Family Foundation. Available at <http://www.kff.org/hiv/aids/8363.cfm>.

²⁹ The Supreme Court's decision in the case of *National Federation of Independent Business v. Sebelius* is available at <http://www.supremecourt.gov/opinions/11pdf/11-393c3a2.pdf>

³⁰ Kaiser Family Foundation. (2012). *A Guide to the Supreme Court's Affordable Care Act Decision*. Available at <http://www.kff.org/healthreform/8332.cfm>.

³¹ Johnston SS et al. (2013). "Patterns and correlates of linkage to appropriate HIV care after HIV diagnosis in the US Medicaid population", *Sexually Transmitted Diseases*, Vol. 40(1):18-25.

³² Kevin Cranston, Personal communication, January 22, 2013.

³³ Legal residents are subject to a five-year waiting period for Medicaid, although states may choose to eliminate this waiting period for children and pregnant women. Undocumented immigrants are ineligible for Medicaid and state-based health exchanges.

³⁴ White House (2010). *National HIV/AIDS Strategy for the United States*, page ix.

³⁵ The Ryan White program was initially created, and subsequently modified, through authorizing legislation and it is funded annually through appropriations legislation. Authorizing legislation establishes or continues a federal agency or program, establishes the terms and conditions under which they operate, authorizes appropriations for them, and specifies how appropriated funds are to be used. Appropriations legislation provides annual funding for an agency or program. Changes to a program's legislative requirements or conditions can only be made through legislation. Typically, such changes are made to a program's authorizing language, although under some circumstances they can also be enacted through annual appropriations bills. A program, however, does not need to be reauthorized to continue, and Congress may choose to appropriate funds for a program even if its authorization has expired, as is the case for some other federal programs (see, for example, <http://www.cbo.gov/publication/42858>), except if an authorization contains a "sunset" provision, a date after which the law ceases to have effect unless further legislative

action is taken; this was the case for Ryan White's 2006 reauthorization, but is not the case for its current reauthorization. At the same time, having an authorization does not guarantee an appropriation.

³⁶ Harbage P, Ledford King M. (2012). *A Bridge to Reform: California's Medicaid Section 1115 Waiver*. Oakland: California Healthcare Foundation. Available at <http://www.chcf.org/publications/2012/10/bridge-to-reform>.

³⁷ San Francisco AIDS Foundation and Project Inform (2012). *Health Care Reform: CA Lessons Learned*. Available at <http://www.sfaf.org/policy-center/policy-library/healthcare-reform-ca-lessons-learned.pdf>.

³⁸ The legislation states that Ryan White funds cannot be used to make payments for any item or service "to the extent that payment has been made, or can reasonably be expected to be made" by another payment source. See, <http://hab.hrsa.gov/about/hab/careactcompilation.html>.

³⁹ San Francisco AIDS Foundation, Testimony to the California Assembly Budget Sub-Committee on "Low Income Health Programs and People with HIV", March 26, 2012. Available at <http://www.sfaf.org/policy-center/policy-library/lihp-low-income-health-programs-testimony-compilation-2012-mar.pdf>.

⁴⁰ Hanna DB et al. (2013). "Trends and disparities in antiretroviral therapy initiation and virologic suppression among newly treatment-eligible HIV-infected individuals in North America, 2001-2009", *Clin Infect Dis*. Vol. 56(8): 1174-1182.

⁴¹ Yehia BR et al. (2012). "Sustained Viral Suppression in HIV-Infected Patients Receiving Antiretroviral Therapy", *JAMA*, 308(4):339-342. Available at <http://jama.jamanetwork.com/article.aspx?articleid=1221693>.

⁴² Doshi R et al. (2013). "Continuum of HIV Care among Ryan White HIV/AIDS Program Clients: US, 2010", Paper #1031a, March 4, 2013, Available at <http://www.retroconference.org/2013b/Abstracts/47995.htm>.

⁴³ Benbow N et al. (2012). "Linkage, retention, ART use and viral suppression in four large cities in the United States", 19th International AIDS Conference: Abstract no. MOPDC0303. Available at <http://www.iasociety.org/Abstracts/A200746148.aspx>.

⁴⁴ Los Angeles County (2012). Program Brief: HIV Prevention through Care and Treatment. Available at <http://publichealth.lacounty.gov/aids/reports/TLCBrief4-12.pdf>.

⁴⁵ District of Columbia, Department of Public Health (2013). Ending the Epidemic: The District of Columbia HIV/AIDS Implementation Plan. Available at http://doh.dc.gov/sites/default/files/dc/sites/doh/publication/attachments/DC%20HIV%20Implementation%20Plan%20FINAL%20DRAFT_07%20MAR%202013.pdf.

⁴⁶ Moore RD et al. (2012). "Improvement in the health of HIV-infected persons in care: reducing disparities", *Clin Infect Dis*. (2012) 55 (9): 1242-1251. Available at <http://cid.oxfordjournals.org/content/55/9/1242.long>.

⁴⁷ Public Law 109-415, December 19, 2006.

⁴⁸ Public Law. 101-381, August 18, 1990.

⁴⁹ CMS (2011). *Fact Sheet: Hospital Value-Based Purchasing Program*. Available at http://www.cms.gov/outreach-and-education/Medicare-Learning-Network-MLN/MLNProducts/downloads/Hospital_VBPurchasing_Fact_Sheet_ICN907664.pdf.

⁵⁰ IOM (2004). *Measuring What Matters: Allocation, Planning, and Quality Assessment for the Ryan White CARE Act*, Washington, DC: The National Academies Press. Available at <http://www.iom.edu/Reports/2003/Measuring-What-Matters-Allocation-Planning-and-Quality-Assessment-for-the-Ryan-White-CARE-Act.aspx>.

⁵¹ IOM (2005). *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White*, Washington, DC: The National Academies Press. Available at http://www.nap.edu/catalog.php?record_id=10995.

⁵² PEPFAR, FY 13 Country Operational Plan (COP) Guidance, Available at <http://www.pepfar.gov/documents/organization/198957.pdf>.

⁵³ HRSA, FY 2013 Congressional Budget Justification. Available at <http://www.hrsa.gov/about/budget/index.html>.

⁵⁴ HRSA (2008). *Policy Notice 08-02, Uniformed Standard for Waiver of Core Medical Services Requirements for Grantees Under Parts A, B, & C*. Available at <http://hab.hrsa.gov/manageyourgrant/pinspals/uniformstandard0802.html>.

⁵⁵ CDC (2013). *HIV among African Americans*. Available at <http://www.cdc.gov/hiv/topics/aa/index.htm>.

⁵⁶ Kaiser Family Foundation (2013). *Fact Sheet: Black Americans and HIV/AIDS*. Available at <http://www.kff.org/hiv/aids/6089.cfm>.

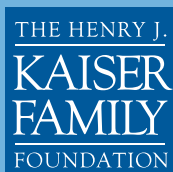
⁵⁷ CDC (2013). *HIV among Gay and Bisexual Men*. Available at <http://www.cdc.gov/hiv/topics/msm/index.htm>.

⁵⁸ CDC (2011). *HIV among Transgender People*. Available at <http://www.cdc.gov/hiv/transgender/index.htm>.

⁵⁹ CDC (2007). *Drug-Associated HIV Transmission Continues in the United States*, Available at <http://www.cdc.gov/hiv/resources/factsheets/idu.htm>.

⁶⁰ Institute of Medicine. (2012). *Monitoring HIV Care in the United States: Indicators and Data Systems*. Washington, DC: The National Academies Press, p. 27.

-
- ⁶¹ Federal Register, Vol. 57(9), March 27, 2012. Patient Protection and Affordable Care Act; Establishment of Exchanges and Qualified Health Plans; Exchange Standards for Employers, Available at <http://www.gpo.gov/fdsys/pkg/FR-2012-03-27/pdf/2012-6125.pdf>.
- ⁶² CMS. *Affordable Exchanges Guidance*, March 1, 2013. Available at <http://cciio.cms.gov/resources/files/issuer-letter-3-1-2013.pdf>.
- ⁶³ Public Law 111-148.
- ⁶⁴ Enroll America (2013). *Fact Sheet: Navigator & In-Person Assistance Programs*. Available at http://files.www.enrollamerica.org/best-practices-institute/enroll-america-publications/Navigator_and_IPA_factsheet_Jan2013.pdf.
- ⁶⁵ Wolitski RJ et al. (2010). "Randomized trial of the effects of housing assistance on the health and risk behaviors of homeless and unstably housed people living with HIV", *AIDS and Behavior*, Vol. 14(3):493-503.
- ⁶⁶ Holtgrave DR et al. (2012). "Cost-utility analysis of the Housing and Health Intervention for homeless and unstably housed persons living with HIV", *AIDS and Behavior*, Epub, May 16.
- ⁶⁷ Department of Housing and Urban Development (2012). *FY 2013 Congressional Budget Justification*. Available at http://portal.hud.gov/hudportal/HUD?src=/program_offices/cfo/reports/2013/main_toc.
- ⁶⁸ White House. (2010). "Blog: Responding to Concerns Over Ryan White Emergency Housing Policy". Available at <http://www.whitehouse.gov/blog/2010/02/10/responding-concerns-over-ryan-white-emergency-housing-policy>.
- ⁶⁹ CDC (2012). *CDC'S New High-Impact Approach to HIV Prevention Funding For Health Departments: Advancing the National HIV/AIDS Strategy*. Available at <http://www.cdc.gov/hiv/topics/funding/PS12-1201/resources/factsheet/foa-partner.htm>.
- ⁷⁰ Institute of Medicine (2011). *HIV Screening and Access to Care: Health Care System Capacity for Increased HIV Testing and Provision of Care*, Washington, DC: The National Academies Press. Available at <http://www.iom.edu/Reports/2011/HIV-Screening-and-Access-to-Care-Health-Care-System-Capacity-for-Increased-HIV-Testing-and-Provision-of-Care.aspx>.
- ⁷¹ HHS (2012). *Press Release: Health care law increases payments to doctors for primary care*, May 9, 2012. Available at <http://www.hhs.gov/news/press/2012pres/05/20120509b.html>.
- ⁷² Federal Register (2012). *Medicaid Program; Payments for Services Furnished by Certain Primary Care Physicians and Charges for Vaccine Administration Under the Vaccines for Children Program*. Vol. 77, No. 215 / Tuesday, November 6, 2012. Available at <http://www.gpo.gov/fdsys/pkg/FR-2012-11-06/html/2012-26507.htm>.
- ⁷³ See, for example, GAO, *Ryan White: Opportunities to Enhance Funding Equity*, GAO/T-HEHS-00-150, July 2000; GAO, *Changes Needed to Improve the Distribution of Ryan White CARE Act and Housing Funds*, GAO-06-332, February 2006; Buehler J, Holtgrave D, Challenges in defining an optimal approach to formula-based allocations of public health funds in the United States, *BMC Public Health*, 2007, Vol. 7:44.
- ⁷⁴ CDC (2011). *Funding Opportunity Announcement (FOA) PS12-1201: Comprehensive Human Immunodeficiency Virus (HIV) Prevention Programs for Health Departments*, attachment, <http://www.cdc.gov/hiv/topics/funding/PS12-1201/pdf/Attachment-X.pdf>.
- ⁷⁵ AIDS.gov (2012). *HHS seeks input on streamlining HIV data collection, reducing reporting burden for HIV grantees*, August 22, 2012, <http://blog.aids.gov/2012/08/hhs-seeks-input-on-streamlining-hiv-data-collection-reducing-reporting-burden-for-hiv-grantees.html>.
- ⁷⁶ HRSA, *Ryan White Timeline*, available at http://hab.hrsa.gov/livinghistory/timeline/toward_passage.htm.
- ⁷⁷ The 2006 reauthorization established the Emerging Communities program, for which \$5 million is appropriated annually for grants to states to assist metropolitan areas with a cumulative total of at least 500, but fewer than 1,000, cases of AIDS during the most recent period of 5 calendar years for which such data are available.
- ⁷⁸ NASTAD (2009). *Fact Sheet: Ryan White Program Part B State Matching Requirements*. http://www.nastad.org/Docs/032601_State%20Match%20Factsheet%2009.pdf.
- ⁷⁹ By law, for Part C early intervention services, at least 75% of the balance remaining, after subtracting administrative costs and clinical quality management, must be used for core medical services.



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