

ISSUE BRIEF No. 01

2015

REIMAGINING THE
RYAN WHITE
HIV/AIDS PROGRAM

JUNE 2015

PROTECTING THE LEGACY — IMPROVING HIV HEALTH OUTCOMES



ALIGNING

THE RYAN WHITE
HIV/AIDS PROGRAM
WITH INSURANCE
COVERAGE

JUNE 2015

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This issue brief was developed independently of, but informed by an expert consultation held in Washington, DC in September 2014 of approximately 50 diverse stakeholders, including people with HIV, HIV medical and non-medical providers, Ryan White grantees, and federal HIV policy and program staff. The project is guided by an advisory group consisting of:

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THE RYAN WHITE POLICY PROJECT

seeks to generate and evaluate ideas for adapting the Ryan White HIV/AIDS program to be maximally effective in a changing health system.

Some might question whether we need a dedicated HIV care and treatment program now that the Affordable Care Act (ACA) has prohibited discrimination on the basis of health status and expanded access to insurance coverage.

Yes. Continuing the Ryan White HIV/AIDS program is necessary to maintain twenty-five years of investment that has saved lives and improved HIV health outcomes. It has yielded a nationwide system of clinical and non-clinical providers equipped to meet the complex and specialized needs of people with HIV in a manner that is culturally relevant and effective. In addition, the Ryan White program provides an extraordinary example of the effectiveness of an integrated care model in decreasing the morbidity and mortality of what would otherwise be a terminal illness.

While the Ryan White program was created in the early years of the epidemic as an “exceptional” response to a national crisis, this focused response to HIV remains important because of the continuing serious public health aspects of HIV. If we do not address the care and treatment needs of people with HIV, the epidemic will spread and increase the costs it imposes on the Nation. The Ryan White program sits alongside other programs such as those that serve people with mental health and substance abuse disorders at the Substance Abuse and Mental Health Services Administration (SAMHSA), programs for people with developmental disabilities and seniors within the Administration for Community Living, and special eligibility options for specific populations within certain Federal programs. All of these were designed by past Congresses and Administrations to provide cost-effective responses to specific health threats facing the American people.

People with HIV who are in care, on treatment, and virally suppressed are unlikely to transmit HIV to others. Recent data indicate that more than 60% of HIV transmissions in the United States occur among people with HIV who have been diagnosed, but are not in regular care compared to fewer than 10% of

transmissions among people diagnosed and in care (*JAMA*, Skarbinski, 2015). The Ryan White program supports people to remain engaged in care. New analyses from CDC and HRSA show that uninsured people with HIV receiving Ryan White services are more likely to be virally suppressed than people with HIV who have insurance, but no access to Ryan White services (CROI 2015 Abstract 1064, Bradley). Further, the same study found that people with HIV with private insurance or Medicaid who receive supplemental coverage from Ryan White were more likely to be prescribed antiretroviral therapy (ART) and people with HIV in Medicaid and Medicare with supplemental coverage from Ryan White were more likely to be virally suppressed than if they did not receive supplemental Ryan White services. In 2010, more than 70% of Ryan White program clients had Medicaid, Medicare, or private insurance, yet they turned to the Ryan White program because insurance, on its own, does not meet all of their health care needs. Moreover, some people with HIV remain ineligible for insurance coverage.

Early experience with the ACA coverage expansions demonstrates that gaps remain. For example, many health plans have placed all HIV medications in the highest cost tiers. A study in 12 states found that when people with HIV enrolled in these plans, their costs were three times higher than in plans with different formulary structures. Even factoring in lower premiums and the annual out-of-pocket limit, researchers concluded that persons enrolled in such plans paid about \$3,000 more each year than if they had enrolled in a plan with a different formulary structure (*NEJM*, Jacobs and Sommers, 2015). The Ryan White program serves as the essential backstop payer of last resort for HIV health services.

For background on the Ryan White HIV/AIDS Program, see the Kaiser Family Foundation issue brief developed as a collaboration between the Foundation and the O’Neill Institute: *Updating The Ryan White HIV/AIDS Program For A New Era: Key Issues & Questions For The Future*. (Available at kff.org)

This is a time of remarkable opportunity for improving the Nation's response to the care and treatment needs of people living with HIV. Taking action to ensure access to HIV medical care and improve engagement in HIV care has the potential to enable all people with HIV to lead long and healthy lives and reduce the number of new HIV infections.

The Ryan White HIV/AIDS Program, the largest and most significant public investment in HIV care specifically targeted to people living with HIV, has been and will continue to be the primary mechanism for supporting engagement in care and moving the health system toward ending the HIV epidemic in the United States. The Ryan White program was an early innovator in the development of a medical home model.¹

Going forward, as the health system seeks to test new approaches to integrating care to improve outcomes and reduce health spending, the program is poised to remain at the forefront of these reform efforts, providing lessons for better serving not only people with HIV, but also other populations of people with disabilities and chronic conditions.

The convergence of the first comprehensive domestic National HIV/AIDS Strategy defining a roadmap for collective action, a period of nearly unprecedented scientific advances [leading the federal government in 2012 to recommend immediate initiation of HIV antiretroviral therapy (ART) as soon as individuals are diagnosed with HIV],² and the expansion in access to insurance coverage resulting from the Affordable Care Act (ACA) has produced new excitement that we can make a leap forward in how we respond to the HIV epidemic in the United States. With many people living with HIV gaining access to reliable and comprehensive insurance coverage for the first time (both through Medicaid and private insurance plans), adapting the Ryan White program to operate effectively in this new environment is crucial.

The Ryan White program always has worked with both public and private insurance programs. Though it was conceived as a standalone program intended to relieve the mainstream health system of the overwhelming burden of responding to a new and growing epidemic, over time the Ryan White program has evolved to supplement other health care coverage. Structuring the Ryan White program so that it can effectively supplement and support insurance coverage has taken on increasing urgency now that most individuals are required to have insurance. Importantly, the Ryan White program operates, by law, as the ‘payer of last resort’, which means that eligible individuals must enroll in and access insurance benefits first, and Ryan White funds can be used to supplement those benefits or to cover services not covered by insurance.

The Ryan White program has always existed in the context of a changing epidemic and a dynamic health system. All of these recommendations should be considered in the context of where the program is today and reasonable steps that can be made in the near future to better align and integrate the Ryan White program with the insurance system. We are not proposing to set the course for the program for all time, but rather make it most effective at responding to the current epidemic and facilitate new collaborations with other actors in the health system.

Moving forward, the Ryan White program may need to strike a new balance between flexibility and accountability for improving outcomes along the HIV care continuum that spans from HIV diagnosis to effective viral suppression. This may require greater uniformity in service capacity and implementation of best practices across the country. At the same time, the program has always functioned as an overlay onto a diverse and unequal health system. Therefore, as we adapt the program for the future and reduce significant disparities across the country, we must be mindful of the need to retain flexibility to respond to local needs and different contexts based on geography, unique needs across the lifespan, and the specific communities served.

We anticipate that the Congress will revisit the Ryan White program and consider changes as we learn from the initial experience following the recent insurance expansions. Concurrently, the Health Resources and Services Administration (HRSA) that administers the Ryan White program is continually adapting its administrative practices and guidance to grantees.

We present ideas for consideration that we hope describe a path forward and identify immediate actionable recommendations.

While broader changes to the Ryan White program should be considered, with regard to re-defining the relationship between the Ryan White program and the insurance system, this brief attempts to address three primary goals:

1

GETTING THE MOST

from insurance and further integrating Ryan White grantees with the mainstream insurance system

2

IDENTIFYING HIV SERVICES

not fully addressed by insurance benefits packages

3

EXPANDING CAPACITY

of the health system to deliver high quality HIV care

GETTING THE MOST FROM INSURANCE AND FURTHER INTEGRATING RYAN WHITE GRANTEES WITH THE MAINSTREAM INSURANCE SYSTEM

Gaining access to insurance increases health security.^{3,4,5,6} The Ryan White program, for example, is prohibited by law from covering inpatient hospital care so the availability of this benefit through insurance is an important component of health security for both HIV care and general health-related concerns. Further, insurance provides access to specialty care for non-HIV related issues not covered by Ryan White. Whether it is Medicaid, Medicare, or private insurance, people are better off with a defined benefits insurance plan—that appropriately meets their needs. Previously, unless they had access to group health insurance through their jobs, people with HIV were largely excluded from affordable or comprehensive insurance coverage. A 2001 study by the Kaiser Family Foundation created hypothetical people with a range of health conditions from minor problems such as hay fever to serious conditions such as HIV and attempted to purchase actual individual market insurance coverage for these individuals.⁷ Coverage applications were submitted to a total of 60 individual market plans in eight communities across the country. This study found that the person with HIV was denied coverage every single time. People with HIV have had greater access to group health insurance than individual coverage, but even here they have been underrepresented compared to their share of the population. Medicaid and Medicare are disproportionately responsible for serving people living with HIV, but prior to 2014, beneficiaries of these programs predominately qualified for coverage only once their conditions progressed to

an AIDS diagnosis thereby making them eligible on the basis of disability. While many people with HIV now have greater access to insurance in states that have expanded Medicaid, thousands of low-income people with HIV live in states that have not expanded Medicaid. Further, a majority of people living with HIV with insurance still requires supplemental help to meet their health care needs.

While insurance is important—and people with HIV often have been well served by private and public insurance—there are consistent gaps in coverage that undermine access to quality HIV care. Addressing these gaps is a primary role of the Ryan White program, along with providing primary medical care for persons with HIV who lack access to insurance coverage. A challenge for policymakers is to bolster the scope and quality of insurance coverage for people with HIV to maximize the services that insurance will cover (to minimize the need for Ryan White services) and to ensure that essential Ryan White services remain available and are efficiently and effectively integrated with insurance.⁸

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

EDUCATE

INSURERS ON HIV STANDARDS OF CARE

In many communities, HIV prevalence is low and many health plans may have limited experience with HIV care. While HRSA and others have created an extensive body of work to define HIV service needs, the primary audience for much of this work has been the existing network of Ryan White grantees and providers. Many health plans appear unaware of the current HIV standard of care. Parts A and B could be authorized to allocate funding for more than services and allow Part A and B funds to support health department activities that help the health system function more effectively. This could include, for example, establishing training opportunities and other partnerships with Medicaid programs, health centers, marketplaces, and health plans to improve the quality and efficiency of HIV care. It also could serve to educate about Ryan White services and how to effectively wrap these services around insurance benefits to maximize engagement in care.

TEST

NEW MODELS TO PAY INSURERS TO IMPROVE HIV OUTCOMES

The Ryan White program often has served as a supplemental wrap around program to extend and complete insurance coverage for individuals. If the future of health care delivery is moving toward greater integration, however, people with HIV will not benefit if their primary options for obtaining care remain in bifurcated systems. The next phase of innovation in HIV care could use Ryan White funding to work with insurers to test and evaluate new insurance models of more integrated HIV care, including 'pay for performance' models that are being applied in other areas. These models could be designed to create incentives for health plans to contract with experienced HIV providers and support health plan networks to improve their performance on critical HIV clinical care indicators.

DEVELOP

SERVICE PACKAGES THAT RYAN WHITE GRANTEEES CAN MARKET TO INSURERS

The trust built in affected communities, the cultural competency, and the deep knowledge of how to support engagement in care are hallmarks of the Ryan White community. Just as we propose that policymakers consider developing new models for health plans to develop new integrated care models, a corollary and equally important activity for the next phase of Ryan White could be for the program to authorize grantees to use grant funds to develop, price, market, and bill for service packages that health plans and Medicaid programs would purchase from Ryan White providers, such as the development of community-based retention in care or re-engagement in care programs.

Health plans will understand the impact that Ryan White providers have when they document how they impact standardized health quality metrics.

Ryan White grantees and providers need to do a better job of making their business case to health plans.

POLICY RECOMMENDATIONS FOR OUTSIDE OF THE RYAN WHITE PROGRAM

CONSIDER

INDUCEMENTS AND
REQUIREMENTS FOR
HEALTH CENTERS
TO PROVIDE MORE
COMPREHENSIVE
HIV CARE

There is a diversity of health centers across the country and they respond to a variety of community needs. Many HIV organizations have transitioned into health centers in recent years strengthening their sustainability and improving their ability to meet community needs. In many communities, however, health problems other than HIV have been prioritized and health centers have presumed that the Ryan White network was sufficient to meet their community's HIV care needs. HRSA or the Congress could consider strategies to expand routine HIV screening in all health centers and incentivize health centers either to build their capacity to deliver quality HIV care or partner with existing Ryan White grantees to provide such care.

STRENGTHEN

THE ENFORCEMENT OF
ACA'S NON-DISCRIMINATION
REQUIREMENTS

Section 1557 of the ACA applies civil rights protections to the newly established marketplaces.

This prohibits discriminatory insurance practices, including plan benefit designs that discourage enrollment of persons with significant health needs, such as people with HIV. There is an emerging pattern of health plans placing all ART medications on the highest cost specialty tiers.^{9,10} In addition to harming affected individuals, the presence of such benefit designs has the effect of inappropriately shifting insurable expenses onto the Ryan White program. While HHS has stated, in general terms, what constitutes discrimination, further federal action may be needed to comprehensively prevent such discriminatory practices. Further, much discrimination faced by people living with HIV may be expressed as anti-LGBT bias. Therefore, further work is needed to ensure that this section of the law is enforced to also protect against discrimination on the basis of sexual orientation and gender identity.

WORK

WITH MEDICAID PROGRAMS
AND MARKETPLACES TO
DEFINE BENEFIT STANDARDS
THAT ARE ATTUNED TO THE
CURRENT HIV STANDARD
OF CARE

In the mid-1990s when managed care programs were initially being developed to serve people with HIV and other health conditions, there were clear patterns of poor quality HIV care from health plans ill-equipped to serve these individuals effectively. Over time, several policy interventions were developed to create effective models of managing HIV care in a capitated environment, some of which were supported through the Ryan White Special Projects of National Significance (SPNS) Program. Additionally, the George Washington University developed model purchasing specifications for Medicaid programs including specifications specifically related to HIV.¹¹ Ryan White, Medicaid, and marketplaces could establish collaborative efforts to review these specifications in light of significant innovation in HIV care, in order to develop evidence-based standards for all health plans.

IDENTIFYING HIV SERVICES NOT FULLY ADDRESSED BY INSURANCE BENEFITS PACKAGES

In addition to primary care, people with HIV often have distinct needs that must be met to retain them in care over their lifetimes and to address the public health aspects of the HIV epidemic. This often has presented a challenge for the health system, which at times has resisted dealing with the social context in which people live their lives and access health care. We have a real world example of what progress can be made if the health system is re-oriented toward supporting engagement in care and if the Ryan White program is more tightly focused on integrating with the insurance system. More than a decade ago, Massachusetts broadly expanded access to Medicaid for people with HIV, followed by later reforms that further expanded access to private insurance. The state continues to receive funding from the Ryan White program, and how they deploy these resources provides a road map for the Nation. Once insurance coverage was more readily available, Massachusetts was able to make bigger investments in services that support engagement in care and adherence to treatment. Also, the state substantially increased its investment in financial support for premiums, co-payments and cost sharing so that the financial burden associated with accessing prescription medications and needed services does not become a barrier to care. Researchers have tied these reforms to declines in HIV transmission and the state has documented declines in HIV incidence.¹² The role of the Ryan White program in the new health system should include supporting:

CRITICAL PUBLIC HEALTH FUNCTIONS: Health departments have a mandate to protect the public health. This means that they are organized and responsible for assessing and responding to health issues affecting whole populations. By contrast, health plans sign contracts wherein they make commitments to manage the health of individuals by providing them a defined set of benefits. Services to help people with HIV avoid transmitting infection to others may be a high priority for public health officials, but a low priority or out of the scope of contract for individual health plans. Similarly, routinizing HIV screening at all clinical encounters may be an important strategy

for health departments to identify persons with HIV who do not perceive themselves at risk, but health plans may think this is a costly endeavor whose only outcome is the identification of new costly beneficiaries so they may not prioritize scaling up routine screening initiatives. An important role for the Ryan White program must be to retain a population health focus as more of the services received by people with HIV are covered by insurance. This could mean establishing standards for health plans to deliver specific services in a manner that helps to achieve public health goals.

ENGAGEMENT SERVICES: The social context in which people with HIV live and their experience of HIV-related stigma and discrimination create barriers to stable, ongoing engagement in care. The complexity of the medical management of HIV often comes when HIV providers have to manage HIV in the context of other medical conditions, such as mental health and substance abuse, while also dealing with social and structural barriers to care associated with a history of trauma, higher levels of poverty, and social marginalization. Critical services provided by the Ryan White program to improve HIV clinical outcomes include care coordination and case management services needed to coordinate medical care and social services; public benefits and insurance navigation services needed to reduce or eliminate barriers to care; transportation services that facilitate access to medical and other appointments; legal services to help individuals and families access health care, income supports, housing, and enforce workforce right, address discrimination, and obtain immigration relief; adherence supports; and active efforts to identify and re-engage people who have stopped receiving regular medical care.

MENTAL HEALTH, SUBSTANCE ABUSE, AND ORAL HEALTH SERVICES: Providers in virtually every part of the country highlight the high levels of unmet need for mental health care, substance abuse treatment, and oral health care for people with HIV. The Ryan White Part F Dental Program operates critical programs to build the capacity to delivery

oral health services to people with HIV, but the reach of this program can be limited. Further, Ryan White already pays for mental health and substance abuse treatment, and mental health parity legislation, and programs operated by the Substance Abuse and Mental Health Services Administration (SAMHSA) all support important programs. Nonetheless, practitioners cite these services as the areas with the greatest remaining unmet need. Significantly, even in Massachusetts, which is ahead of the rest of the nation in many respects, ensuring access to adequate mental health, substance abuse and oral health services can be a challenge. Further, as greater efforts are made to engage in care people with HIV not currently in regular care, this population often has a high need for mental health, substance abuse, and oral health care services. Therefore, bolstering Ryan White's capacity to prioritize access to these services nationwide may be important.

INSURANCE NAVIGATION AND TROUBLE-

SHOOTING: Because the health system is so complex, even the most sophisticated individuals often get lost. Claims denials, re-certification requirements, and other factors can cause needed services to be declined. Since continuous, uninterrupted access to care is so important, insurance navigation services play an increasingly important role in the Ryan White program. While health plans should be required to support many of these functions, it is sometimes necessary for individuals to get assistance outside of their plan. This generally consists of public benefits eligibility counseling and enrollment assistance conducted by HIV services organizations (with access to legal services for complex cases) to file grievances and appeals and/or troubleshoot around issues that impact access to care. Since persons enrolled in marketplace health plans have the option to switch plans annually and the best plan for an individual may change from year to year, this type of assistance may be more important now than in the past.

ENHANCED MANAGEMENT OF PERSONS WITH HIGH COST CONDITIONS AND EXCEPTIONAL NEEDS: Policymakers have recognized that

people with multiple co-occurring conditions or other significant challenges need more assistance navigating the health system and remaining engaged in care. Health administrators also acknowledge that beneficiary populations are not uniform and costs are often concentrated in a small subset of individuals. A key role for the Ryan White program in a more integrated health system is to identify which individuals have unique and exceptional needs and develop initiatives to address them. Ryan White grantees also likely have a role in working with hospitals and other facilities to avoid unnecessary readmissions to keep costs down. While research may be needed to comprehensively identify specific populations, providers often identify the following groups that need tailored interventions and more intensive services: persons with HIV and co-occurring mental health or substance use issues, people who have been incarcerated, and people who have been homeless. Further, within any delineated population, a greater emphasis should be placed on assessing acuity and preserving intensive case management, housing supports, legal services, and other services for persons with the greatest needs.

COST-SHARING ASSISTANCE: Assisting with cost sharing is one of the most important steps that can be taken to keep people with HIV engaged in care. Even when programs such as Medicaid and the Medicare prescription drug program have reduced cost-sharing for low-income populations, these programs may offer inadequate protection for people with HIV given the higher than average use of prescriptions and other services and the typically very low incomes of many people with HIV. Further, many persons enrolled in marketplace health plans have selected high deductible plans, emphasizing the need for assistance for people with HIV to ensure continuity of care until the deductible is met. Therefore, ensuring that Ryan White resources through the AIDS Drug Assistance Program (ADAP) and other parts of the Ryan White program are used to provide cost-sharing assistance and remove cost as a barrier to essential services is likely to become even more important in the future.

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

RETAIN

THE CAPACITY TO
ENSURE ACCESS TO
PRIMARY CARE FOR
PEOPLE WITHOUT
ACCESS TO INSURANCE
COVERAGE

This brief focuses on people with insurance, but as policymakers consider new guidance for grantees to better integrate services within insurance systems, consideration also should be given to maintaining capacity to deliver primary care to uninsured people with HIV. This could include consideration of guidance for Ryan White grantees on minimal capacity standards to prevent all Ryan White resources from being devoted to only supplementing other coverage and it could include maintaining robust support for directly funded clinics.

REQUIRE

GRANTEES TO
DEMONSTRATE THAT
THESE PUBLIC HEALTH AND
FACILITATIVE SERVICES
ARE AVAILABLE IN THEIR
COMMUNITIES

To date, the emphasis in the Ryan White program has been on flexibility for grantees to decide how to set priorities and allocate resources for services. In the next phase of the program, there may be a need to require grantees to demonstrate that at least minimal levels of engagement services are available, including case management, public benefits and insurance navigation, other legal services, transportation assistance, and medical adherence supports. To the extent that such services are provided by community-based organizations, a greater emphasis is needed on integrating the delivery of such services with the client's health care team.

DEDICATE

SOME PORTION OF RYAN
WHITE FUNDS TO SUPPORT
THE TESTING OF INNOVATIVE
APPROACHES TO IMPROVING
POPULATION-LEVEL HIV
HEALTH OUTCOMES

An important role for the Ryan White program is likely to continue to push forward models of innovation. While the Special Projects of National Significance (SPNS) is an important component of the Ryan White program and has supported several important initiatives over the years, it is relatively small and its funding has been stagnant for many years. Policymakers could consider whether other parts of Ryan White, perhaps in conjunction with the Centers for Medicare and Medicaid Services (CMS), could more directly support innovation in HIV care, such as through funding demonstration programs that test and evaluate new approaches for more integrated HIV care. As the epicenter of the HIV epidemic in the United States is now among young gay men, especially young Black gay men, developing new and better models for engaging these men in care is a critical priority. Additionally, as people with HIV are living longer, understanding how HIV interacts with other health conditions associated with aging and developing better models for supporting older people with HIV is also a topic that warrants further attention.

POLICY RECOMMENDATIONS FOR OUTSIDE OF THE RYAN WHITE PROGRAM

EXPAND

MEDICAID HEALTH HOMES FOR PEOPLE LIVING WITH HIV

The Ryan White program was one of the pioneers of the concept of the medical home, which offers comprehensive and coordinated care for physical and mental health services needed by people with HIV. The Medicaid Health Home Demonstration Program offers an important opportunity to greatly expand access to Medicaid health homes for people with HIV. In fact, HRSA funded an HIV Medical Homes Resource Center to provide technical assistance to entities that were considering health homes for people with HIV. Policymakers could consider ways to broaden access to Medicaid Health Homes for people with HIV in more states.

ESTABLISH

NEW MARKETPLACE NETWORK ADEQUACY STANDARDS FOR HIV PROVIDERS

A premise of a competitive marketplace is to give health plans flexibility in plan operations in order to develop new and more attractive and efficient plan designs. At the same time, the new marketplaces have minimum benefit requirements including requiring health plans that do not provide sufficient HIV care to offer a contract to at least one Ryan White grantee in their network. Since there is a diversity of Ryan White grantees and some serve only specific sub-populations, these network adequacy standards do not consistently ensure access to qualified HIV care. Policymakers could consider new approaches to protecting network adequacy for HIV providers among all plans that would guarantee to all enrollees in a health plan access to qualified HIV providers with experience treating people with HIV.

The public and private insurance systems depend on the Ryan White program not only to supplement benefits, but also to develop and promulgate clinical care standards, support clinics and providers providing HIV specialty care, and to monitor population-level HIV health outcomes.

EXPANDING CAPACITY OF THE HEALTH SYSTEM TO DELIVER HIGH QUALITY HIV CARE

Delivering effective, efficient and high quality health care requires data and using that data to establish systems of care that promote evidence-based practices, support innovation and continual improvement, and hold providers and others accountable for improving health outcomes. The Ryan White program and the CDC's National HIV surveillance system, and important HIV data sets such as CDC's medical monitoring project (MMP), the AHRQ-supported HIV Research Network, and the NIH-supported North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD) all contribute to our knowledge of the care experience of people living with HIV in the United States. In 2012, the Institute of Medicine issued two reports that offered recommendations on how to better integrate and utilize data from these and other public and private data sets to better monitor HIV clinical care.^{13,14} One report also provided recommendations for a core set of HIV clinical and non-clinical care indicators that have been adopted (with minor modifications) by the Department of Health and Human Services (HHS) to streamline and align HIV indicators collected across

federal HIV programs. One of the more exciting new developments in HIV care is the growing trend by health departments to use their HIV surveillance data, often in partnership with HIV clinics and community based organizations to identify and target services for individuals who have stopped engaging in care.

As more services are provided by insurance, however, there is the potential for health departments to lose access to critical client-level data that is needed to effectively monitor the epidemic and achieve population-level improvements in care. And this data sharing must go both ways...for health plans to effectively re-engage people in care, they often need access to surveillance and other data held by health departments. Work remains to be done to enhance collaboration and information sharing between health plans, health care providers, and health departments, while protecting the confidentiality of sensitive medical information.

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

ESTABLISH

TARGETS FOR
INDIVIDUAL GRANTEES
TO IMPROVE HEALTH
OUTCOMES ALONG THE
CARE CONTINUUM:

Because of the large disparities in health system capacity across the country, it is likely not feasible to establish nationwide performance standards for Ryan White grantees. What is needed instead is to create a culture throughout the Ryan White program that supports effective monitoring of population-level outcomes and pushes grantees to continually improve quality and measurable health outcomes. For community-based providers, this likely means enhanced collaboration with HIV medical, mental health, and substance abuse treatment providers. Policymakers could consider new tools for HRSA to set individualized, enforceable targets and authorize HRSA to demand programmatic changes to ensure that programs fund best practices and prioritize resources likely to have the largest impact.

FUND

DEMONSTRATION PROGRAMS
FOR DATA SHARING
COLLABORATIONS BETWEEN
HEALTH DEPARTMENTS AND
HEALTH PLANS

Health departments, health plans, and consumers benefit when agreements are in place to share client-level information, with adequate privacy protections. The move toward integration with insurance could undermine the ability of public health officials to effectively monitor the HIV epidemic unless new approaches are established to ensure health departments have access to critical health plan data. Policymakers could consider establishing demonstrations to test approaches to data management that address privacy concerns, promote the adoption of interoperable electronic medical records, establish reimbursement for data sharing, and grapple with rules for the handling of both sensitive and proprietary information.

ENCOURAGE

MUCH GREATER INTEGRATION
AND COLLABORATION AT THE
COMMUNITY LEVEL BETWEEN
CLINICAL AND NON-CLINICAL
PROVIDERS

Clinical and non-clinical organizations both have been critical in achieving the many successes of the Ryan White program. Sometimes there has been competition and too little collaboration between these different providers. Policymakers could consider new strategies to align incentives and require formalized relationships to foster greater patient-centered collaboration and streamline the management of people with HIV with clear responsibilities of each party.

The Ryan White program produces very effective models of care. The next iteration of the program may need to focus more on scaling up effective models, creating clear and enforceable targets for grantees, and giving HRSA more authority to enforce standards that will increase the quality of care nationwide.

POLICY RECOMMENDATIONS FOR OUTSIDE OF THE RYAN WHITE PROGRAM

EXPAND

HIV OUTCOME MEASURES MONITORED BY NATIONAL QUALITY MONITORING PROGRAMS

It is often said that what is measured is what matters. While we recognize that many health plans struggle under the weight of too many quality indicators, the absence of meaningful HIV clinical care indicators (except an HIV testing indicator) further marginalizes HIV within the broader health system. Policymakers could consider adopting HIV quality indicators, such as for viral load suppression, time to entry into HIV care, and time to initiation of treatment following diagnosis that would be reported by all health plans nationwide. As an example, CMS and America's Health Insurance Plans (AHIP) are creating a joint set of HIV and Hepatitis C quality metrics, based on HRSA and National Quality Forum endorsed metrics. Further, NCQA HEDIS® should include HIV care quality metrics as part of their set of required indicators for health plans.

REQUIRE

DATA SHARING BETWEEN HEALTH PLANS FUNDED BY MEDICAID AND MARKETPLACES WITH HEALTH DEPARTMENTS

Just as the Ryan White program can facilitate data sharing between health departments and health plans, broader efforts are also likely needed. Further, the sharing of client-level data is not exclusively an HIV issue. Therefore, policymakers could consider new efforts within Medicaid and marketplaces to establish requirements and procedures for sharing client-level data of public health importance, so that a more comprehensive system is developed that facilitates the smooth and consistent sharing of information between health plans and providers and health departments regarding information on a variety of infectious diseases and other conditions of public health concern.

CONCLUSION

Ensuring that the Ryan White HIV/AIDS program becomes better aligned and integrated with the insurance system is only one of the important topics that policymakers should consider as they set the course for the next phase of the program. To build on the rich legacy of the Ryan White program, we need to take bold, yet practical steps now to support innovation and new forms of collaboration between Ryan White grantees and providers and the public and private insurance systems.

These changes should not turn the program upside down, as the Ryan White program has served people with HIV and affected communities well, and the program offers a safe haven of stability with so many changes in health care financing occurring nationwide. But, with the broader health system innovating, we cannot afford for HIV care delivery models to be left behind.

The opportunity at hand is to look for incentives and supports to channel and direct the passion, creativity, and deep expertise of the Ryan White provider base to keep moving us forward to build sustainable systems of care that are accountable for better supporting all people with HIV to remain engaged in care and lead long and healthy lives.

ENDNOTES

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RYAN WHITE WAS AN INDIANA TEENAGER



with hemophilia who was diagnosed with HIV in 1984. He was an object of fear and he faced extreme discrimination when he attempted to attend school in the early years of the HIV epidemic. He was one of the first people that the Nation came to know as living with HIV and he was a prominent champion for an inclusive response toward all persons living with the virus. Ryan died of AIDS in 1990 before he was able to complete

high school. His mother, Jeanne White Ginder continues to advocate for HIV/AIDS issues and educate the public about the impact of this disease.

Later in 1990 when the Congress enacted the first comprehensive national response to HIV, pulling together a few smaller and more targeted initiatives, they named the law the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The program has had bipartisan support and has been reauthorized in 1996, 2000, 2006, and 2009. Today, the program works with cities, states, and local community-based organizations to provide services to an estimated 536,000 people living with HIV.

The passion, perseverance, and dedication to providing a caring response to all people in the United States living with HIV as embodied by the Ryan White HIV/AIDS Program is a lasting legacy of Ryan White and the many other people living with HIV and their friends, families, and care providers over the course of the epidemic. Twenty-five years later, the program has become the indispensable linchpin in the Nation's response to the HIV epidemic in the United States.