

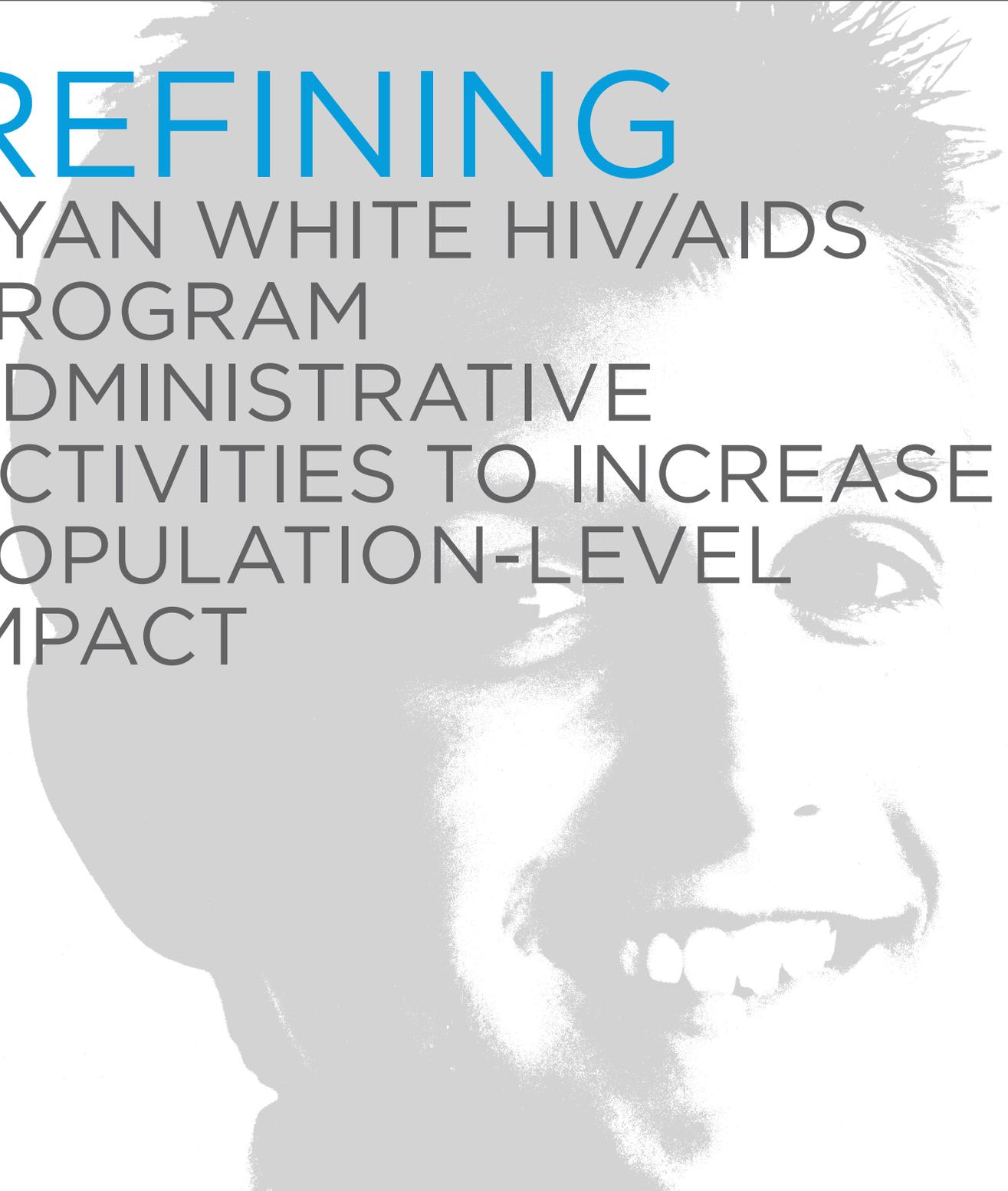
ISSUE BRIEF No. 02

2015

REIMAGINING THE
RYAN WHITE
HIV/AIDS PROGRAM

JUNE 2015

PROTECTING THE LEGACY – IMPROVING HIV HEALTH OUTCOMES



REFINING

RYAN WHITE HIV/AIDS
PROGRAM
ADMINISTRATIVE
ACTIVITIES TO INCREASE
POPULATION-LEVEL
IMPACT

JUNE 2015

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This issue brief was developed independently of, but informed by an expert consultation held in Washington, DC in November 2014 of approximately 30 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)

We have come so far in how we respond to HIV that it is possible to not know or forget about the time when the Ryan White HIV/AIDS program was created before effective treatments were available. It was an outgrowth of several earlier programs, but it was the first attempt to build a truly national response to the care and treatment needs of people living with HIV.

At a time when AIDS mortality was high and increasing numbers of people with HIV were seemingly crowding our hospitals and clinics, the Ryan White program sought to build a community-based response that acted in parallel to the rest of the health system.

Especially because of who was most affected by HIV—gay men, people of color, people who use drugs—all people marginalized or poorly served to some extent by the mainstream health system—building a response within affected communities and leveraging the caring and understanding of these communities was a masterstroke that has contributed greatly to the program’s many successes.

A guiding principle of the Ryan White program always has been to bring together a diversity of resources to weave together a comprehensive response to meet the HIV care needs of the community. State and local health departments have a central role in administering HIV health services. People living with HIV and affected communities also must be at the forefront of responding to HIV and guiding the development of the

Ryan White program. The program was created when there were no effective treatments and there was not an evidence base for prioritizing some services over others. Today, however, with clear evidence on the need to diagnose all people with HIV, get them in care and on treatment as soon as possible, and support people to remain engaged in care, the program may need to consider placing more emphasis on scaling up best practices and demanding greater accountability for improving population-level health outcomes. All of these issues are playing out as the program is becoming more tightly aligned with the public and private insurance systems.

The Ryan White HIV/AIDS program has always looked and acted differently than other components of the US health system. Its community orientation has been a great source of strength and has fostered continual innovation in how we effectively reach and serve communities heavily impacted by HIV.

As we adapt the program, we need to retain the program’s passion for ensuring that all people with HIV are well supported in systems of care that enable them to lead long and healthy lives.

In order to consider how to uphold core principles of leadership and inclusion of people with HIV, and collaborative planning and monitoring, this brief considers opportunities for using the next phase of the Ryan White program to increase its emphasis on three important goals:

1

BUILDING HIV DATA SYSTEMS

that are integrated with the insurance system to produce reliable population and patient-level outputs

2

DEVELOPING MORE USEFUL

and comprehensive state and local plans for improving HIV health outcomes

3

MOVING BEYOND PLANNING

to effective monitoring and program improvement

BUILDING HIV DATA SYSTEMS THAT ARE INTEGRATED WITH THE INSURANCE SYSTEM TO PRODUCE RELIABLE POPULATION AND PATIENT-LEVEL OUTPUTS

Another brief in this series considers issues related to better aligning the Ryan White program with the insurance system. It discusses new challenges for health departments that are tasked with increasing population health and protecting the public health when more health care services are provided through insurance. While access to insurance is important and beneficial for people with HIV, new arrangements need to be established between the Health Resources and Services Administration (HRSA) that administers the Ryan White program, the Centers for Disease Control and Prevention (CDC), Medicaid, Medicare, the Department of Veterans Affairs health programs, marketplaces, health plans and state and local health departments to share data and work collaboratively.

This requires a significant re-orientation of the role of health departments vis à vis other parts of the health system and the integration of HIV surveillance and clinical care data systems. This work has begun with both HRSA (through the implementation of its client-level data system and related data and monitoring activities)¹ and the CDC (through its Data to Care program)² launching important new initiatives in this area.

While state and local health departments have long had responsibility for collecting and managing HIV surveillance and other data, there is great variation in the capacity of health departments to effectively collect data, use it to inform policy development at the clinic, local, state, and national levels, as well as to work collaboratively with health plans.

Many health departments may embrace this expanded role, but are constrained by limited resources available for these functions. Therefore, in the next phase of the Ryan White program, policymakers may want to consider prioritizing the role of health departments in using data in strategic ways to support efficient health care delivery and improve rates of HIV viral suppression across the population. The purpose would be to enable health departments to provide tangible support for individual providers, clinics, and health plans who stand to benefit from timely information on population-level indicators and individual clients that can inform the care and services they provide. While using federal resources to fund services will likely remain the primary function of the Ryan White program, there may be a need to rethink limitations on spending for administrative functions and specifically permit a portion of Ryan White funding under Parts A and B to be allocated to hire staff to expand the data management capacity of health departments.

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

BUILD

NEW HEALTH DEPARTMENT CAPACITY TO COLLECT, MANAGE, USE AND SHARE PATIENT ENCOUNTER DATA

There are numerous and exciting examples of health departments and other entities using data in smart ways to improve access to care and support engagement in care for people with HIV.³ The Louisiana Public Health Information Exchange (LaPHIE) is an often-cited example of how health department leadership working in a meaningful way with people with HIV, health care providers and health systems, and other stakeholders has built a novel system for using HIV data to support engagement and re-engagement in care.⁴ Similarly, local health departments, such as San Francisco have pioneered neighborhood-based approaches to monitoring where HIV infections are occurring, where HIV viral suppression is highest and lowest, and other data points to strategically target resources to increase impact.⁵

What is needed now is to fund health departments to build more uniform capacity across the country to implement these types of innovative practices and programs. This could be achieved in a number of ways, such as prioritizing resources within the Ryan White Special Projects of National Significance (SPNS) program for demonstration projects and further expanding HRSA-supported capacity building grants. To achieve the level of scale needed to meaningfully build this capacity within all health departments, however, more far reaching change may be needed, such as adjusting current caps on administrative expenses or specifically allocating a share of the Part A and B grants to be devoted to monitoring and data management issues. Greater coordination between HRSA and CDC is also needed as both agencies make important investments to strengthen the collection, analysis, and dissemination of timely data.

CONTINUE

EFFORTS TO STANDARDIZE AND STREAMLINE CORE HIV CLINICAL AND NON-CLINICAL INDICATORS

Collecting more data does not automatically lead to better use of data. In some cases, standardizing and reducing the number of indicators Ryan White grantees must report on and taking other concrete steps to minimize reporting burden may improve the quality of data and facilitate its use in informing policy. In 2012, pursuant to a project commissioned by the White House, an Institute of Medicine (IOM) panel made recommendations for a core set of HIV clinical care and non-clinical indicators.⁶ The Office of HIV/AIDS and Infectious Diseases Policy (OHAIDP) within the Department of Health and Human Services (HHS) had already begun a cross government project to examine HIV data collected across federal programs. Subsequent to the IOM report's release, HHS adopted a modified set of core HIV clinical care indicators to be used to streamline reporting across HHS, with ongoing collaboration with the Department of Housing and Urban Development (HUD) to also align HIV indicators within the Housing Opportunities for People with AIDS (HOPWA) program.⁷ These efforts have led to HHS adopting uniform definitions of indicators across programs. This has been a promising effort by HHS, but the task is not finished.

Policymakers could consider whether additional steps are needed to facilitate streamlining and reducing the administrative burden of reporting—particularly for providers that receive grants from multiple federal HIV programs. Specific steps related to the Ryan White program include examining whether steps could be taken to simplify and improve standardization within the Ryan White services report (RSR) system and to examine whether HRSA has adequate flexibility under the Ryan White statute to change or eliminate indicators as needed.

INSTITUTE

UNIFORM TRACKING OF MISSED CLINIC VISITS AND OTHER SENTINEL INDICATORS FOR PERSONS AT RISK FOR FALLING OUT OF CARE

A major challenge with maintaining population-level viral suppression is that it demands continual engagement in care over people's lifetimes, and normal life circumstances for virtually all people will lead them to stop engaging in care at some point in time. Once people fall out of care, it can be hard to re-engage them, and the longer they stay out of care, it is increasingly difficult to find such individuals and support them in re-engaging in health care. Therefore, proactively taking steps to keep people retained in care should be a priority of the health system. One way to do this is to systematically track missed clinic visits by people with HIV and developing rapid response protocols to intervene before a missed clinic visit turns into someone stopping care and stopping HIV treatment.^{8,9} To date, most HIV clinics and health plans do not uniformly track these data. Policymakers could consider how the ongoing adoption of electronic medical records (EMRs) could facilitate this type of monitoring and to ensure that implementation of EMRs within clinics and clinical practices does not miss important opportunities to improve monitoring of engagement in care. Additionally, policymakers could consider whether a small number of additional indicators are needed to compliment existing core clinical indicators that help to identify intervention points for persons at risk of falling out of care and whether they should incentivize or require health plans and clinics to report on missed clinic visits and other indicators of persons at risk of interrupting their regular engagement with care.

ESTABLISH

NEW DATA SHARING COLLABORATIONS TO WORK THROUGH LEGAL AND POLICY ISSUES

It is easy to articulate a vision for effective collaboration between health departments, health plans, and services providers. Implementing such collaborations can be challenging and must grapple with unique issues that arise in different states and local communities. There are a range of federal, state, and local laws and policies that limit the use and disclosure of personal health information, including the Health Insurance Portability and Accountability Act (HIPAA) privacy rule, various public health authorities that guide the collection of HIV surveillance data, and other policies intended to protect the confidentiality of such information. Health departments, however, often have broad authorities with which to collect and use information, and there are often solutions that can be found, even under current law. Nonetheless, each jurisdiction may be faced with a complex and unique mix of laws and policies that must be considered. Successful model programs, such as LaPHIE, often emphasize the importance of extensive and ongoing stakeholder engagement to respond to concerns and build and maintain the community trust and support for these initiatives to be successful. Therefore, policymakers may consider ways to outline a vision for improved monitoring and collaboration and consider support for demonstration projects, technical assistance or other approaches to build greatly expanded capacity within health departments to work with providers and others to collect and use HIV prevention and care data in strategic ways.

The integration of HIV surveillance data with clinical data offers rich potential for greatly increasing continuous engagement in care. Now, we need to expand the capacity of all health departments to serve as the central nexus of a system that collects, analyzes, and shares data to improve patient care.

POLICY RECOMMENDATIONS FOR OUTSIDE OF THE RYAN WHITE PROGRAM

REQUIRE

MEDICAID PROGRAMS AND MARKETPLACE HEALTH PLANS TO COLLECT DATA ON A CORE SET OF HIV CLINICAL AND NON-CLINICAL INDICATORS

The success of a data management system often depends on ensuring inputs from all sources that collect information on HIV patient care. While health plans and Medicaid programs may be burdened with data collection demands generally, there is an urgent need to collect uniform data on HIV care indicators. These programs and plans also would benefit from improved and consistent monitoring of HIV care. Policymakers could consider requiring all Medicaid programs and marketplace health plans to report on a targeted set of core HIV clinical care and non-clinical indicators.

STRUCTURE

RYAN WHITE PROGRAM DATA MANAGEMENT INITIATIVES TO BE INTEGRALLY CONNECTED TO CDC-FUNDED SURVEILLANCE AND DATA TO CARE PROGRAMS

Achieving optimal HIV clinical outcomes across the care continuum requires a fully integrated approach to prevention and care. The CDC funds state and local health departments to operate HIV surveillance and prevention programs and HRSA funds state and local health departments to operate Ryan White programs. Integration of these efforts is critically important because it is often in the hand-off of responsibility between prevention and care programs when people stop engaging in care. Both agencies recognize the importance of building data management capacity and fund health departments to support such efforts and these agencies have already greatly expanded their coordination and collaboration in this area. By merging or aligning funding streams, however, grantees would not have to feel trapped between funding agencies when different agencies impose conflicting requirements—and the overall impact of federal funds could be increased.

While HRSA and CDC can lead the way in developing HIV data management systems, in a truly integrated health system, Medicaid, Medicare, and marketplaces also must expand investments in data management capacity that protects privacy while using key indicators to improve health outcomes.

DEVELOPING MORE USEFUL AND COMPREHENSIVE STATE AND LOCAL PLANS FOR IMPROVING HIV HEALTH OUTCOMES

To make the best use of scarce public resources and to ensure that the most urgent community needs are addressed, the Ryan White program has relied on planning councils (under Part A) and consortia (under Part B) to examine epidemiological data, identify priority service needs, and allocate resources. Over the life of the program, large investments in planning have been made and this has included extensive activities to recruit and train people with HIV and other community members to contribute effectively to formal resource allocation processes.

The success of planning councils and consortia, however, has been uneven. In some places or at some points in time, health departments and planning body members have worked together in a cohesive and productive manner. In other cases, tensions between groups and competition for resources have meant that planning activities have been acrimonious. Sometimes planning body resource allocations have carefully aligned with the population distribution of the epidemic, and in other cases, some groups have received more favorable treatment relative to their share of cases in a given state or community. Additionally, out of a desire to be comprehensive and to ensure that the needs of all stakeholders and populations are considered, planning bodies have sometimes grown in size and the plans produced by some planning bodies have been comprehensive and lengthy at the expense of strategic and concise. Further, it is important to reflect on changes in the world of HIV care delivery since the Ryan White program was established. In 1990, the program operated as largely a palliative care program and there were not clear priorities and evidence-based practices, so it made sense to devolve much of the decision-making power as close to the ground as possible.

Today, we are in a completely different world. Active engagement and support from people with HIV and other community stakeholders remains critical, but the scope of decisions they are tasked with making in the allocation of Ryan White resources may need to change as we seek to systematically ramp up procedures and interventions shown to be effective. A significant investment in planning activities was seen as important because there was not faith that every health department, on its own, would respond to the epidemic with the urgency needed or allocate resources in a manner consistent with the epidemic. A

current challenge is to demand more from all health departments and elevate low performers to better match high performing health departments. But, there remains a need for an independent, evidence-based review and renewed commitment to collaborative planning between health departments and community stakeholders. In light of this, policymakers may wish to consider how to make changes in how Ryan White funding is allocated and services are prioritized at the state and local levels in ways that increase efficiency, fidelity to local epidemiological trends and best practices, and promote transparency and effective program monitoring, while retaining and in some cases strengthening a commitment to the inclusion and meaningful participation of people living with HIV and affected stakeholders.

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

EXAMINE

THE EXISTING PLANNING PROCESSES AND
CONSIDER NEW APPROACHES FOR MORE
STREAMLINED PLANNING

Many of the successes of Ryan White program extend from decisions made by state and local planning bodies. Therefore, while seeking to improve planning processes, changes should not jettison the principle of community-led planning and we need to recognize that examples of strong planning bodies exist. As policymakers consider what a new process could look like, the following are potential goals for all HIV services planning bodies:

- Fewer Ryan White resources would be devoted to planning;
- The meaningful engagement of people living with HIV and other community stakeholders would be protected and strengthened;
- A new process would lead to more concise plans that set a topline direction and identify key priorities for a jurisdiction over the coming years;
- Plans would align with the National HIV/AIDS Strategy and identify and tailor programs and services for key subpopulations;
- Plans would more uniformly show great fidelity to state and local epidemiology; and,
- There would be clear metrics and improved monitoring of progress.

(See page 12 for conceptual framework)

ESTABLISH

NEW STRATEGIES FOR ENSURING
MEANINGFUL PARTICIPATION OF PEOPLE
WITH HIV

Representatives of people with HIV often speak of the challenges of obtaining active and meaningful participation in ongoing and complex planning processes. One of the things the Ryan White program has done right over the years is that it has invested resources in capacity building so that persons with HIV and other affected community members who otherwise may not have been equipped to participate in formal governmental processes have the training and skills to do so. In many communities, however, there is such a small group of people with HIV who serve as the consumer representatives that there are often questions about how representative they are of the diversity of the community.

Several jurisdictions report that an important strategy for ensuring effective engagement is to pay consumers for their time serving on planning bodies. Several jurisdictions have used non-federal resources to pay consumers for participating in the planning process (Amounts suggested have been relatively modest ranging from \$50 per meeting or a few hundred dollars per month). Consideration could be given to permitting federal funds to be used for this purpose. In considering this approach, several stakeholders also have suggested giving these members certain duties and responsibilities they must perform.

Additionally, important parts of the community may not be interested in or able to sustain active engagement in a long-term on-going planning process. Therefore, it has been recommended that in developing plans, more pro-active outreach be built in to the planning process, such as field visits to organizations that serve specific populations, and greater use of focus groups and other data collection methods.

POLICY RECOMMENDATIONS FOR OUTSIDE OF THE RYAN WHITE PROGRAM

REQUIRE

UNIFIED PREVENTION AND CARE PLANS

In an era where treatment is prevention, the separation between prevention and care planning at the federal, state, and local levels is no longer sustainable. In particular, there is a need to maximize the integration and collaboration between prevention and care programming within health departments. While HRSA and CDC have dramatically increased their coordination and collaboration, further integrating prevention and care activities at the federal level and encouraging new approaches such as blending funding or aligning program funding announcements merit consideration. It should be noted that CDC directly funds 10 cities whereas the Ryan White Part A program funds metropolitan areas that include cities and surrounding areas. Consideration should be given to aligning these jurisdictions, perhaps by extending CDC funding (in only those 10 cities receiving prevention funding directly from CDC) to including the same geographical area as the Ryan White Part A program.

CONSIDER

STATUTORY OR OTHER CHANGES NEEDED TO FACILITATE INTEGRATED PLANNING WITH HIV PREVENTION PROGRAMS

Whereas this issue brief is focused on potential policy changes within the Ryan White program, and recognizing the significant work that both HRSA and CDC have done to work with states and local jurisdictions to integrate planning, policymakers should examine whether there are statutory or other constraints that impede HRSA and CDC from effectively developing, implementing, and monitoring fully integrated prevention and care plans.

Many people recognize that HIV services planning structures are often unwieldy.

The challenge is to adopt new approaches that retain meaningful engagement of people living with HIV, while greatly reducing the time and resources devoted to planning, yet retain the independence to hold health departments accountable for responding to the diversity of a state or community's needs.

WHAT COULD A NEW PLANNING PROCESS LOOK LIKE?

FULLY INTEGRATED PREVENTION AND CARE PLANS: Each jurisdiction would be required to operate integrated planning bodies and develop a single plan for prevention and care, and to the extent feasible, a plan that coordinates and merges resources for behavioral health, housing, vocational rehabilitation, and other services. Plans would be required to align with the National HIV/AIDS Strategy.

FIVE-YEAR PLANS: The current system of regularly scheduled meetings throughout the year may be too labor and time intensive and may detract from the effective implementation of a plan. Devoting time and resources for an intensive review every five years could facilitate the development of more effective plans and permit resources to be allocated to implementation and monitoring. The purpose of a plan would be to establish high-level strategic priorities and review state or local epidemiological data and identify priority populations, geographic high need areas, and prioritize service needs and gaps.

ANNUAL MONITORING: There would be greater clarity of roles between the planning body and the health department in developing the plan, setting service priorities, and allocating resources. More responsibility for implementation of the plans would be delegated to health departments, and not the planning body. As new data becomes available and as changes occur, the health department would be responsible for changing approaches and adapting priorities, as long as they are consistent with the overarching goals set forth in the plan. On an annual basis, however, the health department would be required to work with the planning body to get input from a diversity of community stakeholders on successes and challenges and emerging issues. Further, health departments would be required to report to the community annually on key indicators that demonstrate the status of implementation of the plan.

An important continuing role for planning bodies is to help identify and develop responses to emerging and under-addressed issues, such as adapting the

HIV service system to address the needs of an aging population, developing more comprehensive service packages for young gay men, and pushing forward the adoption of new models of care, such as trauma-informed primary care.

NEW OVERSIGHT TOOLS FOR HRSA AND CDC: HRSA and CDC may need new authority to require changes to how state and local prevention and care plans allocate and utilize federal resources. One option would be to borrow elements of the country operational plan (COP) process in the President's Emergency Plan for AIDS Relief (PEPFAR) program. In the context of the Ryan White program, this could involve jurisdictions submitting draft plans for review by an external review body that would consist of HSRA, CDC, SAMHSA, HHS (OHAI DP) and other federal staff, representatives of other state and local health departments, and people with HIV, clinical and non-clinical providers, epidemiologists, and others. One approach would be to divide the country into five regions and develop a review panel for all plans in a region; with one region developing new plans every year. Both the planning body and the health department would be authorized to appeal recommendations to HHS which would have final authority to approve such plans.

INDEPENDENT, YET COLLABORATIVE: Many have argued that the independence of planning bodies is critical to their success. At the local level, many of these bodies have been situated outside of the health department and have been housed within the office of the mayor or other places within local government systems. Greater care may be needed to ensure that health departments are collaborative partners in the development of plans, but are not able to exercise a veto over every decision made by the planning body.

Note: These ideas are presented as a launching point for further consideration and dialogue with various stakeholders. The specific suggestions should not be considered a formal proposal as much as an outline for a path forward.

MOVING BEYOND PLANNING TO EFFECTIVE MONITORING AND PROGRAM IMPROVEMENT

As stated previously, the Ryan White program has always looked and acted differently than other parts of the health system. Two components of this 'difference' are that: 1) the program is deeply grounded in affected communities, and 2) the numerous grantees and providers share a passion for ending the HIV epidemic. The American people have been generous in maintaining their support for meeting the needs of the HIV community. Retaining their trust and faith that their tax dollars are being wisely spent has meant that there is necessarily a strong focus on financial accountability. After 30 years of experience with the program and numerous Government Accountability Office (GAO) and other audits of the program, however, it may be time to step back and assess whether our financial monitoring is coming at the expense of more comprehensive program monitoring. A senior state official that administers a Ryan White grant stated that their primary contact with the federal government is with auditors. Another grantee stated that the overwhelming focus is on 'compliance' instead of effective program management.

As we update the program so that it has even more tools to elevate the quality of services in all parts of the country, it may be time for policymakers to devise accountability mechanisms that better balance grantee reporting and fiscal accountability, program monitoring, and refocus grantees and providers on ensuring that all parts of the Ryan White program are oriented to supporting people with HIV to remain engaged in care from diagnosis to viral suppression.

POLICY RECOMMENDATIONS FOR THE RYAN WHITE PROGRAM

CONDUCT

A REVIEW OF ALL FINANCIAL, PROGRAM, AND DATA REPORTING REQUIREMENTS

A challenge for Ryan White grantees is the burden of reporting. Surely, some of this is necessary and appropriate. At the same time, policymakers could conduct a review of all requirements for financial, program, and data reporting (including HHS grant requirements in addition to HRSA requirements) with the goal of streamlining and reducing reporting burden and ensuring that collected data are analyzed and shared with grantees and providers to improve quality. Additionally, consideration could be given to ensuring that HRSA has adequate flexibility, when needed, to permit project officers to work as active partners with grantees. This could mean, for example, authorizing the waiving or forbearance of certain rules and policies when done in the service of strengthening federal oversight and improving program outcomes.

STRENGTHEN

MECHANISMS FOR COMMUNITY STAKEHOLDERS TO PARTICIPATE IN PROGRAM MONITORING

As discussed previously, an updated Ryan White program may function more effectively if we streamlined the current planning processes and focused more on getting plans that are more concise and strategic. People with HIV and other community stakeholders, however, must play an essential role in program monitoring. Policymakers should consider ways to maximize the use and benefits of consumer satisfaction surveys and also imagine the possibilities of using crowd source models for reporting on both positive and negative experiences and outcomes with the health system. Further, on a regular basis, whether it is annually or more frequently, health departments that are tasked with implementing plans should be required to update the public on key program milestones and the status on core indicators. Additionally, health departments should be tasked with soliciting feedback and creative ideas for improving programs and services.

CONCLUSION

Every reauthorization of the Ryan White HIV/AIDS program has made changes to refine key aspects of the program and ensure that it is maximally effective at meeting current needs. At present, while the need for the continuation of the program is clear, it is operating in an environment where the health care landscape is changing all around it and there is renewed urgency to improve population-level health outcomes. To build on the program's successes, it may be necessary to enhance the capacity of HRSA and CDC to actively support the program (including considering whether HRSA has been given sufficient staffing to actively monitor a program of this size), and it may be necessary to strengthen the role of health departments in monitoring outcomes across the health system. This could transform the relationship between health departments and health plans in a way that is mutually beneficial. It also may require a new vision for how to effectively engage people with HIV and affected community members to guide the response to the epidemic.

Making these types of changes may appear risky or difficult. They also may be critically necessary.

ENDNOTES

- 1 See the HRSA supported Target Center website for various resources. Available at <https://careacttarget.org>. Accessed on June 8 2015.
- 2 For background and examples, see information on the CDC Data to Care Initiative. Available at <https://www.effectiveinterventions.org/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx>. Accessed on June 8, 2015.
- 3 See CDC Data to Care Initiative. Available at <https://www.effectiveinterventions.org/en/HighImpactPrevention/PublicHealthStrategies/DatatoCare.aspx>.
- 4 Herwehe J, Wilbright W, Abrams A, et al. (2012) "Implementation of an innovative, integrated electronic medical record (EMR) and public health information exchange for HIV/AIDS." *Journal of the American Medical Informatics Association: JAMIA*, 19(3):448-452. doi:10.1136/amiajnl-2011-000412. Available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3341789/>. Accessed on June 8, 2015.
- 5 Das M, Chu PL, Santos G-M, Scheer S, Vittinghoff E, et al. (2010) "Decreases in Community Viral Load Are Accompanied by Reductions in New HIV Infections in San Francisco." *PLoS ONE* 5(6): e11068. doi:10.1371/journal.pone.0011068. Available at <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0011068>. Accessed on June 8, 2015.
- 6 "Institute of Medicine: Monitoring HIV Care Indicators and Data Systems ." (2012). Available at <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States.aspx>. Accessed on June 8, 2015.
- 7 HHS Common Indicators for HHS-funded HIV Programs and Services, available at <https://www.aids.gov/pdf/hhs-common-hiv-indicators.pdf>.
- 8 Mugavero MJ, et al. [2014]. "Beyond core indicators of retention in HIV care: Missed clinic visits are independently associated with all-cause mortality." *Clin Infect Dis* , 59:1471-79 (PMID: 25091306; PMCID: PMC4215067). Available at <http://www.ncbi.nlm.nih.gov/pubmed/25091306>. Accessed on June 8, 2015.
- 9 Gardner LI, et al. (2014) "Enhanced personal contact with HIV patients improves retention in primary care: a randomized trial in six U.S. HIV clinics." *Clin Infect Dis*, 59:725-34 (PMID: 24837481). Available at <http://www.ncbi.nlm.nih.gov/pubmed/24837481>. Accessed on June 8 2014.

the 1990s, the number of people in the UK who are employed in the public sector has increased from 10.5 million to 12.5 million (12.5% of the population).

There are a number of reasons for this increase. One is that the public sector has become a more important part of the economy. Another is that the public sector has become more efficient. A third is that the public sector has become more attractive to workers. A fourth is that the public sector has become more diverse.

The public sector has become a more important part of the economy. In 1990, the public sector accounted for 10.5% of the UK's GDP. By 2000, it had increased to 12.5%.

The public sector has become more efficient. In 1990, the public sector spent 10.5% of the UK's GDP. By 2000, it had increased to 12.5%.

The public sector has become more attractive to workers. In 1990, the public sector employed 10.5 million people. By 2000, it had increased to 12.5 million.

The public sector has become more diverse. In 1990, the public sector employed 10.5 million people. By 2000, it had increased to 12.5 million.

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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.