

HELPING PEOPLE WITH HIV NAVIGATE THE TRANSITION TO ACA COVERAGE:

SUMMARY OF A ROUNDTABLE DISCUSSION

SUMMARY

The Affordable Care Act (ACA), landmark health reform legislation enacted into law in 2010 with major coverage expansions beginning in January 2014, offers substantial opportunity to expand health care coverage and services to a large portion of uninsured individuals in the United States, including people living with HIV. While people with HIV will face many of the same questions and issues faced by others in assessing new coverage options under the ACA, they also have unique concerns, stemming from the critical importance of maintaining continuous access to high quality HIV care to achieve both clinical and public health outcomes. Federal treatment guidelines now recommend initiation of ART immediately after HIV diagnosis.¹ Further, studies show that early initiation of antiretroviral treatment (ART), which reduces viral load, not only provides tremendous clinical benefit, it significantly reduces the risk of HIV transmission.² Yet only an estimated 33% of people with HIV in the U.S. are on ART and only 25% are virally suppressed,³ in part, because many people with HIV are not yet linked to or engaged in care due to access and affordability barriers.

To explore opportunities for maximizing the beneficial impact of the ACA for those living with HIV and examine strategies for helping them navigate the transition to new coverage, the Kaiser Family Foundation convened a meeting in March 2013 with key stakeholders from a wide variety of backgrounds working on these issues. The meeting was organized around three major topic areas: planning for the coverage transition; helping people with HIV choose and enroll in coverage; and troubleshooting during coverage transitions. This report summarizes the information shared and key issues discussed at the meeting.

SUMMARY OF KEY OBSERVATIONS

Planning for the coverage transition

- Significant planning efforts are underway by the Federal government and HIV community stakeholders would benefit by learning more about them and tapping these resources.
- Coalitions and broad-based partnerships are critical for supporting enrollment and effective coverage transitions.
- The HIV community needs to plan for changes in the role of the Ryan White HIV/AIDS Program.
- HIV community stakeholders need to be aware of their state's organizational structure and work to inform state policymakers about the needs of people with HIV and standards for HIV care.
- HIV service providers may need to consider business re-design options to maximize their engagement with the health system.
- Working to ensure inclusion of HIV providers into health plan networks and provider directories may be an immediate priority focus.
- Best practices and lessons learned from states and organizations that have begun navigating through HIV-related policy changes will help inform how to better plan for challenges that may occur as implementation continues to unfold.

Helping people with HIV choose and enroll in coverage

- People with HIV have unique issues that come into play when selecting among competing health plans or selecting a primary care provider.
- HIV stakeholders should consider developing tools for assessing coverage and plan options for people with HIV.
- The HIV community may want to consider ways to develop and bolster its ACA knowledge network to create synergies among people working at the local, state, and national levels.
- It may be important to differentiate between types of HIV enrollees in ACA coverage: those who are new to insurance coverage, those who may be new to private insurance coverage, and those who may be switching medical providers.
- Even the savviest clients may not feel comfortable making enrollment decisions without guidance.
- While HIV providers and clinic staff are poised to play a central role in supporting coverage transitions, they may require specific training and support.

Troubleshooting during the coverage transition

- Legal service providers may play a particularly important role in resolving coverage disputes or other issues that case managers or benefits counselors cannot resolve.
- Local, state, and national feedback loops to actively monitor issues facing people with HIV will be important, particularly during the early phase of coverage transition.
- Examining the experience from the Medicare Part D transition may offer lessons for troubleshooting during the ACA transition.
- The Ryan White AETC program, ADAPs, and other components are important resources for helping to troubleshoot.
- States and communities may wish to develop HIV monitoring systems.

INTRODUCTION

The Affordable Care Act (ACA), landmark health reform legislation enacted into law in 2010 with major coverage expansions beginning in January 2014, offers substantial opportunity to expand health care coverage and services to a large portion of uninsured individuals in the United States, including people living with HIV.⁴ It provides a major new opportunity for getting more people with HIV enrolled in insurance coverage and engaged in care. Getting more people with HIV engaged in care and on antiretroviral treatment will be critical to helping control the HIV epidemic in the United States. While recent scientific evidence has demonstrated that early initiation of ART not only provides tremendous clinical benefit, it significantly reduces the risk of HIV transmission, currently, only an estimated 33% of people with HIV are 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; in fact, the biggest drops along the HIV “treatment cascade,” or care continuum, occur between linkage to and retention in care. One of the reasons for these drops is the lack of access to affordable, high quality, health coverage.

Of those who are in the care system, few have private insurance, with most relying on the public sector for their care and coverage, including Medicaid and Medicare, but also the Ryan White HIV/AIDS Program.⁵ The ACA is expected to change this equation by expanding private coverage to many who have previously been shut out of the individual insurance market, and Medicaid coverage, in states that choose to expand their Medicaid programs, to low income people with HIV who, prior to the ACA, were unable to qualify for Medicaid due to restrictive eligibility rules.

Despite the existence of the law and availability of new coverage, however, uninsured and underinsured Americans living with HIV must take active steps to enroll in order to gain the benefits of having insurance coverage. Navigating the new landscape of health coverage options is complex.

To explore opportunities for maximizing the beneficial impact of the ACA for those living with HIV and examine strategies for helping to navigate the transition to new coverage, the Kaiser Family Foundation convened a meeting in March 2013 with key stakeholders from a wide variety of backgrounds working on these issues. The meeting was organized to address three major topic areas: planning for the coverage transition; helping people with HIV choose and enroll in coverage; and troubleshooting during coverage transitions. Participants shared their perspectives and identified opportunities and challenges for educating the HIV community about changes in health care coverage and facilitating outreach, enrollment, and health system navigation during this transition period. This report summarizes the information shared and key issues discussed at the meeting.

KEY ISSUES

Planning for the Coverage Transition

While the ACA has already resulted in changes in health care access and coverage, the most far reaching changes will begin in January 2014 when individuals will be able to purchase coverage in new state-based “health insurance marketplaces” (with open enrollment beginning on October 1, 2013) and when states will be able to expand Medicaid to cover virtually all low-income Americans with incomes up to 138% of the federal poverty level (about half of the states have indicated that they will do so to date). As such, planning for these changes now is critical. People with HIV will need to assess whether they are eligible for new coverage under the ACA either in the marketplace, and then select from a health plan and enroll in coverage, or through Medicaid, if their state chooses to expand. Some people with HIV may receive insurance coverage and care for the first time – including those who may be newly diagnosed

or newly linked to care – and may be in need of particular assistance in accessing new options. Others may already be in the care system, but may experience coverage transitions. In both cases, it will be important to be able to evaluate several key aspects of the new coverage environment including the adequacy of provider networks in plans and the level of HIV expertise within these networks, the specific benefits offered, and cost-sharing requirements.

Meeting participants discussed a number of the expected challenges related to enrollment and coverage transitions for people with HIV and the need to plan for those now. While these include many of the same broad challenges facing the millions of Americans who will be newly eligible for coverage, particular concerns were raised about people with HIV, given the importance of minimizing insurance disruptions and promoting stable access to quality HIV care for both clinical and public health benefit.

Key observations are as follows:

- » **Significant planning efforts are underway by the Federal government and HIV community stakeholders would benefit by learning more about them and tapping these resources.** Multiple federal agencies have been working on ACA implementation, including implementation of key provisions of the law already in place, and laying the groundwork for the coverage expansions that will begin in January of next year. While many parts of the Department of Health and Human Services (HHS) and one of its operating divisions, the Centers for Medicare and Medicaid Services (CMS), are responsible for implementing key parts of the ACA, including working with states on the Medicaid expansion, the Center for Consumer Information and Insurance Oversight (CCIIO), has responsibility for ensuring compliance with the new insurance market rules, working with states to review rate increases, overseeing state efforts to establish marketplaces, and operating the federally facilitated marketplaces. CCIIO also operates a web portal, www.healthcare.gov, which is a central resource for information for consumers seeking information about the ACA in their state. Individuals can access this information now to learn about the ACA and potential options available to them depending on the state where they reside. Starting in September, as plans gear up for enrollment beginning on October 1st, the portal will also have information about specific plan options available in each state's marketplace. While these resources are not HIV-specific, they provide important information for all people potentially eligible for new coverage options. Meeting participants felt that stronger efforts could be made to inform HIV stakeholders and communities about these efforts and how best to engage in them. This could include developing associated guidance documents for people with HIV to use when accessing materials prepared for the general public.
- » **Coalitions and broad-based partnerships are critical for supporting enrollment and effective coverage transitions.** Meeting participants discussed the importance of coalition efforts and partnerships in working with different communities on planning for enrollment; indeed, several indicated that the ACA provided new opportunities for coalitions to form of groups that had previously not worked together. For example, many groups that have not historically had strong ties have begun working together in new ways, and more longstanding coalitions have bolstered their efforts around preparing for the ACA and facilitating enrollment in new coverage. This includes coalitions of organizations representing people with disabilities, low-income communities, providers, organized labor, and others. Even if tailored outreach is needed for the HIV community, these types of coalitions may provide new channels for reaching many more individuals across the country and addressing the multiple health care access needs they may have.

» **The HIV community needs to plan for changes in the role of the Ryan White HIV/AIDS Program.** The ACA, working in tandem with Ryan White, is an important building block for a more effective system of care to improve HIV clinical outcomes, but the HIV community needs to understand and plan for the role of Ryan White to change. There was broad agreement among meeting participants that the ACA creates new opportunities to increase engagement in care by people with HIV that can lead to improved clinical outcomes, including increased population-level viral suppression of people with HIV. At the same time, participants stated that the existence of the ACA should not diminish support for the Ryan White program.⁶ Today, most (70%) Ryan White clients have public or private insurance⁷ but need to rely on the program to complete their coverage by paying cost-sharing that could impede their ability to access services or by covering other services, such as case management and medical adherence, that are needed to achieve HIV viral suppression, but that are often not covered by typical insurance plans. This suggests that insurance coverage alone 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.

Yet participants agreed that more planning for a changing role for Ryan White was needed, at the national, state, and local levels. This could include, for example, proactively examining ways to prepare for shifting an increasing share of Ryan White funds from medical services to services that support linkage to and retention in care (e.g., outreach, case management, and adherence) and to assisting individuals with cost-sharing of co-payments and insurance premiums to allow them to afford new coverage and thus stay engaged in care. This was the experience in the state of Massachusetts, which began expanding health care coverage more than a decade ago and now has achieved near universal coverage. 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.⁸ In addition, participants talked about the urgent need for Ryan White providers to proactively seek out opportunities to be part of new health plan networks (see below).

» **HIV community stakeholders need to be aware of their state's organizational structure and work to inform state policymakers about the needs of people with HIV and standards for HIV care.** Many significant ACA policy decisions are being made at the state level, and participants discussed the need for increased attention to state-level decisions and systems and raised concerns about the complexity of and differences across states regarding implementation decisions and timing. They also identified examples where such activity is already underway and lessons learned. For example, several state health departments have undertaken a variety of activities to help prepare people with HIV and their providers for the ACA, including in some cases local assessments designed to understand how community-based providers will be affected and how prepared they are to assist people with HIV move through the ACA education and enrollment process. The experience of the state of Massachusetts offered specific information about challenges and opportunities in this regard. The state found that there was significant need to support and bolster infrastructure readiness and its expansion required substantial training of existing HIV providers, funded mostly by Ryan White (which can support such activities). While this did require up front investments by Ryan White, the state indicated that it did lead to system savings several years later.

- » **HIV service providers may need to consider business re-design options to maximize their engagement with the health system.** While underscoring the successes of current HIV providers, many participants discussed the need for HIV clinics and community based agencies to re-think how they function within the health system and to work toward better integration into that system. Indeed, part of the success in Massachusetts was a long and deliberate focus on integrating HIV care into broader health care programs and infrastructure, including community health centers that have the capacity to meet HIV health care needs, rather than creating separate, stand-alone, HIV programs. However, this has often not been the case in many other states and participants discussed the need for communities to start planning for better integration now. For many who are accustomed to receiving grant funding from government agencies, a bigger part of their future success will likely depend on identifying the value they bring and selling this to insurers or other providers in order to form partnerships that will continue to support the critical services they provide. This represents a paradigm shift for many organizations who may prefer to simply provide services to people in need, yet who will have to undergo a potentially costly, complex, and laborious process to develop the capacity to bill individual clients for specific services rendered and process payments from multiple health plans.
- » **Working to ensure inclusion of HIV providers into health plan networks and provider directories may be an immediate priority focus.** As mentioned above, health care marketplaces will be set up in each state to provide new private insurance coverage under the ACA. Each marketplace must include a choice of health plans. By law, these new health plans must include a minimum number of “essential community providers” (ECPs), those experienced in caring for medically underserved populations, in their networks. Importantly, federal rules state that Ryan White providers are considered ECPs. However, health plans are not required to contract with Ryan White providers or any individual provider per se. It is widely expected that ECPs, including Ryan White providers, will need to proactively engage with health plans and seek inclusion in their networks. Meeting participants emphasized this critical short-term opportunity for HIV medical providers to reach out to marketplaces being set up in their states and to individual health plans to form relationships and work to ensure that HIV medical providers are included in health plan networks. Health plans will be required to demonstrate that they meet minimal network adequacy standards, creating a short-term opportunity to ensure that HIV care capacity is available in these health plan networks. Ensuring that existing HIV care providers are included in as many networks as possible will also help to mitigate insurance and care disruptions that could occur as new coverage systems are being set up for the first time.
- » **Best practices and lessons learned from states and organizations that have begun navigating through HIV-related policy changes will help inform how to better plan for challenges that may occur as implementation continues to unfold.** Whereas Massachusetts is often cited as a positive example of the type of progress that could be possible under the ACA, California demonstrates the potential for unforeseen threats to continuous care. As with Massachusetts, California has long been a state on the forefront of efforts to expand access to insurance coverage and they were an early adopter of a new ACA coverage option to expand access to Medicaid prior to 2014. Unfortunately, state Medicaid officials presumed that HIV services provided by Ryan White could remain in place even after the state expanded Medicaid eligibility that would provide a new Medicaid coverage for some people with HIV. When it was discovered that the federal Ryan White payer of last resort requirement remained in effect and would bar Ryan White from continuing to fund drug coverage and other services once individuals with HIV were newly eligible for Medicaid, the state had to scramble to prevent a gap in access to care. Moreover, differences in Ryan White and Medicaid pharmacy providers also threatened to create new gaps in care.^{9,10} While California has worked through these issues, this experience provides a

window into the potential for unforeseen issues to arise that threaten access to care. And, it reinforces the need for HIV stakeholders inside and outside of government to remain engaged in active dialogue with public officials operating Medicaid programs and healthcare marketplaces to prevent harmful impacts on people with HIV and to quickly remedy any issues that do emerge. Meeting participants from Massachusetts emphasized the importance of having state officials actively engaged with insurers and creating systems for individual consumers to alert them to any problems.

Helping People with HIV Choose and Enroll in Coverage

As mentioned above, while people with HIV will face many of the same considerations and questions faced by millions of Americans in assessing new health care options available through the ACA, they also have unique concerns related to the need for early and sustained access to high quality HIV care and treatment. For those already in care, they may have to switch their care site, provider, and/or coverage source and thus work to ensure as much continuity and access to quality HIV care as possible. For those who are still outside the care system and/or just beginning to engage in care, there are additional considerations to take into account. For example, stigma experienced by people with HIV may have kept them away from health care other settings where their HIV status is acknowledged. This requires creating settings to educate and assist people with HIV to learn about their coverage options and assist them with enrollment in environments where they feel affirmed and that facilitate honest dialogue about how to select coverage options that meet their needs. Many health plans have not seen this as their role or have not invested in building this type of capacity. The experience in Massachusetts, however, suggests that beyond numerical targets for types of providers, health plans will need to prioritize a focus on cultural competency and other less tangible factors that create an environment where marginalized and often disrespected populations will want to go for care. Experienced HIV providers and service organizations are often best situated to provide such an environment and could be a key resource for health plans. Indeed, helping individuals with HIV select plans that will ensure access to the best network of HIV providers and plans where their own HIV treatment regimen is affordably covered are serious factors to weigh in making a plan choice. The already existing HIV community infrastructure, supported by the Ryan White program, CDC HIV prevention efforts, and private resources, as trusted partners, stands to play a key role in this process.

Meeting participants discussed a number of issues to consider in helping people with HIV choose and enroll in coverage and strategies for overcoming potential challenges. This included a discussion of ways to develop standardized methods that work across state and federal programs to identify populations by insurance status, identify specific needs of subpopulations or issues unique to people in specific geographic areas or that are unique to rural, suburban, or urban settings.

Key observations are as follows:

- » **People with HIV have unique issues that come into play when selecting among competing health plans or selecting a primary care provider.** In addition to resources directed at the general public, the HIV community may need additional or different resources to facilitate enrollment and plan choice. For example, because continuity of care is so critically important for both clinical and public health outcomes, and health plan marketing materials will be developed for the general public in mind, additional resources may be needed to help individuals assess which health plan networks include the major HIV providers in a community. Participants discussed ways to support the integration of people living with HIV into the mainstream health system, while responding to their unique needs. In particular, participants discussed ways that the Ryan White program and other HIV-specific programs could be utilized to support people during the enrollment process.

- » **HIV stakeholders should consider developing tools for assessing coverage and plan options for people with HIV.** Meeting participants discussed the difficulty that people with HIV face in determining eligibility for new coverage in their state’s marketplace and in choosing a health plan that adequately met their HIV care needs. For example, one-on-one assistance in assessing cost-sharing expenses for an enrollee has been expressed by stakeholders as an important element to the decision-making process that new enrollees may not feel confident or comfortable in doing without additional information or assistance. The experience during the initial implementation of the Medicare Part D drug benefit program, created in 2006, was raised as a cautionary reminder of the difficulties that can arise when big system changes are made and new coverage options – including plan choices that could have implications for the adequacy of HIV care – are provided. This experience suggests that more resources may need to be focused on developing tools to help individuals people living with HIV make informed decisions when selecting a health plan, including identifying key criteria that should be considered such as provider network adequacy, scope of benefits, and cost-sharing requirements. Several participants stated that HIV community stakeholders were in a unique and important position to assist clients with making such assessments.
- » **The HIV community may want to consider ways to develop and bolster its ACA knowledge network to create synergies among people working at the local, state, and national levels.** Participants discussed existing efforts within the HIV community to disseminate technical and policy information to a variety of stakeholders who are working in support of ACA implementation, including work of the federal HIV/AIDS Bureau at the Health Resources and Services Administration of the Department of Health and Human Services and its Target Center which is developing a range of health reform tools for Ryan White providers;¹¹ the Federal AIDS Policy Partnership’s (FAPP), a national coalition of local, regional, and national organizations working on HIV, through its HIV Health Care Access Working Group;¹² and www.hivhealthreform.org, a web-based partnership of several AIDS organizations which was created to help educate the HIV community about health reform. Participants also described informal ways that organizations collaborated during the implementation of the Medicare Part D program and discussed existing networks that are currently operating through LGBT coalitions, HIV legal services providers, and HIV medical providers, among others. Meeting participants emphasized the need for more collaboration across organizations and government agencies to develop mechanisms for helping people with HIV learn about and enroll in new coverage options.
- » **It may be important to differentiate between types of HIV enrollees in ACA coverage: those who are new to insurance coverage, those who may be new to private insurance coverage, and those who may be switching medical providers.** Meeting participants discussed ways in which people with HIV have different needs and seek different types of assistance depending on whether or not they have a history of insurance coverage. For people who have had insurance before, they may generally understand how insurance works, but may be confused with considering among competing health plans and comparing key benefits and provider networks. People who have always been uninsured and who may be accustomed to accessing health services through grant-funded programs such as Ryan White or who may not receive regular care and only access health care for serious emergencies may need more assistance learning about insurance plan rules, navigating payment or coverage disputes, as well as needing assistance in considering health plan options. Participants suggested that to conserve resources and better serve clients, there might be a need for tiered approaches to ensure that people can receive more comprehensive education and assistance if they need it, and less intensive support for those who do not. Because interruption in coverage that results in gaps in HIV treatment can have drastic health implications, stakeholders repeatedly highlighted the pivotal role of case managers not only in the enrollment process, but also on an ongoing basis to help manage care, track policy or plan changes, and minimize gaps in coverage.

- » **Even the savviest clients may not feel comfortable making enrollment decisions without guidance.** Time was spent at the meeting discussing differential needs of individual clients, but a participant that does direct client work and who remembers the experience during the initial implementation period for the Medicare Part D program said that even the most educated and sophisticated clients are often uncomfortable making plan decisions on their own. Therefore, while participants generally agreed that there is a need to triage services to conserve resources, most clients will still want some level of one-on-one support prior to making a plan decision. Partnerships between HIV case managers, state and local Ryan White program administrators, legal services providers, and consumer advocates were discussed as an important part of any strategy for addressing this issue.
- » **While HIV providers and clinic staff are poised to play a central role in supporting coverage transitions, they may require specific training and support.** Participants acknowledged a disconnect wherein many HIV medical providers recognize the need for their clients to receive assistance navigating coverage transitions, but they do not feel equipped to do this and do not see this as their role, which they often view as strictly to provide health care services. While this view is understandable, and many health care providers are already spread thin with their current responsibilities, it is anticipated that once the coverage transition begins and individuals are eligible to enroll in new coverage, they will turn to their medical providers for assistance. Therefore, discussion ensued about ways to train medical providers to assist clients, as well as ways to develop strategies for triaging clients to trained non-medical professionals better equipped to assist them. This may involve organizing trainings for local providers on basic tips for helping their patients navigate these changes and potentially developing community-specific resources to be disseminated in provider offices that give suggestions for clients and identify community based organizations and other resources where individuals can turn for help.

Troubleshooting During the Coverage Transition

Experience from past efforts to implement major new federal programs suggests that despite the best efforts of a range of stakeholders to plan for the expansion of insurance coverage, unanticipated issues will arise that could threaten or impose barriers to access to care for people with HIV. Given the importance of maintaining continuous care for people with HIV, consideration must be given in advance of the ACA's insurance expansion to ways to respond as issues arise. This entails thinking through a variety of potential mechanisms for monitoring the experience of people with HIV as they navigate the enrollment process and then begin to access their insurance benefits. Additionally, formal or informal systems will need to be put in place to assist individuals to resolve issues, as well as to identify systemic challenges that may demand new policies or procedures. Participants discussed the importance of developing partnerships with legal service providers, case managers, benefits counselors, and people with HIV, including local, state and national information forums with real time feedback during the early phase of the coverage transition.

Key observations are as follows:

- » **Legal service providers may play a particularly important role in resolving coverage disputes or other issues that case managers or benefits counselors cannot resolve.** While case managers and benefits counselors will be the first line responders and will assist the majority of individual clients, there was a broad understanding that some issues are particularly complex and may not be readily resolved without engaging attorneys who bring an important skill set and capacity to quickly resolving issues. At the same time, participants acknowledged that legal services are a limited resource and systems need to be put in place to resolve as many issues as possible through grievance processes or appeals filed by clients with case managers or other personnel, and reserving access to lawyers for only the most complicated cases or higher level appeals. It

is a common mantra to talk about one-stop shops, but many Ryan White medical clinics have proven to be highly effective resources when they are able to blend their clinical expertise with benefit counseling programs that help people navigate the health system. Often, much of this work is performed or overseen by trained nurses or social workers, but with ready access to lawyers for consultation or for more complex cases.

- » **Local, state, and national feedback loops to actively monitor issues facing people with HIV will be important, particularly during the early phase of coverage transition.** An important way to make the health system work for people with HIV and others is to build systems for identifying common problems and seeking solutions that prevent other similar individuals from facing the same barriers when accessing services. Participants discussed the types of issues that may commonly arise, such as being unable to get a clinically indicated treatment or medication, to fill a prescription, or find a qualified HIV provider, and ways to identify patterns of issues that are arising with one plan, within a specific state or service area, or nationwide. Participants discussed ways that HIV legal advocates established a list serve to report problems during the Medicare Part D transition and suggested that similar list serves could be useful during the ACA implementation. Participants also discussed a range of HIV-specific coalitions that already operate list serves and have well established communications mechanisms, as well as broader coalitions, especially low-income health advocacy groups, as well as legal services providers that also have resources that could be useful as the ACA is implemented to monitor patterns of access barriers as they arise.
- » **Examining the experience from the Medicare Part D transition may offer lessons for troubleshooting during the ACA transition.** Significant time was spent on discussing ways of learning from the enrollment and transition process of the Medicare Part D prescription drug benefit, which was a new benefit introduced in 2006. Participants discussed the importance of using the existing relationships between HRSA, the federal agency that administers the Ryan White program and their state, local, and clinic-level grantees. Participants also highlighted that during the Part D transition a small percentage of the HIV population in Medicare fell out of care, at least temporarily, because they were unable to navigate the system and were challenged in sorting through the range of enrollment options. Therefore, it will be important to plan for such occurrences to arise again and build systems that monitor engagement in care over time until all people with HIV have been stabilized in accessing new insurance coverage.
- » **The Ryan White AETC program, ADAPs, and other components are important resources for helping to troubleshoot.** Meeting participants discussed the potential ways that different parts of the Ryan White program could help to monitor and troubleshoot during the transition. In addition to technical support provided by state and local grantees under Parts A and B, there was discussion of the unique ways that the AIDS Drug Assistance Program (ADAP), a component of the Part B program and the largest funding line within the Ryan White program, could assist individual clients. This included discussion of ways that ADAPs can provide education, as well as serve as a stopgap source of drug coverage if there are unforeseen coverage denials when individuals are attempting to fill prescriptions at the point-of-sale when they are first using their insurance coverage. Further, participants discussed the role of AIDS Education and Training Centers (AETCs), the national network of largely university-based programs to train providers to provide HIV medical care services, to assist with provider training to help clients navigate their new insurance coverage options and troubleshoot.
- » **States and communities may wish to develop HIV monitoring systems.** In addition to establishing informal monitoring of the care experience of people with HIV through coalitions of advocates and services providers, participants discussed the potential benefits if states and/or local communities funded their own efforts to monitor the early client experience during the enrollment period and the early experience in the first few years of ACA coverage when people with HIV are becoming acclimated to accessing services through their new health plans.

CONCLUSION

Since the earliest days of the HIV epidemic, people living with HIV, their medical providers, and others have worked to achieve greater access to comprehensive insurance coverage and more stable access to care. The ACA represents a major step forward toward reaching the goal of providing all people with HIV in the U.S. high quality, life extending care. As January 2014 approaches, preparation for building a strong foundation and the capacity for more and better health care services for people living with HIV is critically important. Despite the challenges that will undoubtedly arise, there are many opportunities for a variety of stakeholders to come together to maximize the benefits of new insurance coverage, supporting people with HIV in learning about new coverage options, navigating the transition, and helping to address any unforeseen issues that may arise.

ROUNDTABLE PARTICIPANTS

Mayra Alvarez

Department of Health and Human Services

Martine Apodaca

Enroll America

Kellan Baker

Center for American Progress

Don Blanchon

Whitman Walker Health

Steve Cha

Centers for Medicare & Medicaid Services

Laura Cheever

Health Resources and Services Administration

Grant Colfax

The White House

Chris Collins

amfAR, The Foundation for AIDS Research

Jeffrey Crowley

O'Neill Institute/Georgetown Law

Anne Donnelly

Project Inform

Dawn Fukuda

Massachusetts Department of Public Health

Ronda Goldfein

AIDS Law Project of Pennsylvania

Robert Greenwald

Harvard University

Carolina Gutierrez

Kaiser Family Foundation

Tanya Harris

Planned Parenthood Federation of America

Heather Hauck

Health Resources and Services Administration

Michael Horberg

Kaiser Permanente

Carole Johnson

The White House

Jen Kates

Kaiser Family Foundation

Amy Killelea

National Alliance of State & Territorial AIDS Directors

Cyd Lacanienta

InterGroup Services

Jeff Levi

Trust for America's Health

Caya Lewis

Department of Health and Human Services

Kali Lindsey

National Minority AIDS Council

Aaron Lopata

Office of Management and Budget

Erin Loubier

Whitman Walker Health

Kevin Malone

Substance Abuse & Mental Health Services Administration

Jeff Maras

Illinois Department of Public Health

Perry Markell

Kaiser Family Foundation

Marsha Martin

Urban Coalition for HIV/AIDS Prevention Services

Bill McColl

AIDS United

Greg Millett

Centers for Disease Control and Prevention

Michael Mugavero

University of Alabama at Birmingham

Courtney Mulhern-Pearson

San Francisco AIDS Foundation

Marybeth Musumeci

Kaiser Family Foundation

Deborah Parham Hopson

Health Resources and Services Administration

John Peller

AIDS Foundation of Chicago

Carl Schmid

AIDS Institute

Ken Trogdon

HarborPath

Ivy Turnbull

AIDS Alliance for Women, Infants, Children, Youth & Families

Andrea Weddle

HIV Medicine Association

Vera Yakovchenko

Department of Health and Human Services

Toni Young

Community Education Group

Endnotes

- ¹ 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://www.aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-arv-guidelines/o>.
- 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 CDC. (2012). *Fact Sheet: HIV in the United States—The Stages of Care*. Available at <http://www.cdc.gov/nchstp/newsroom/docs/2012/Stages-of-CareFactSheet-508.pdf>.
- ⁴ 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/health-reform/report/the-affordable-care-act-the-supreme-court-and-hiv-what-are-the-implications/>.
- ⁵ Fleishman J, Gebo K, Agency for Healthcare Research and Quality, 2012, as presented to the Institute of Medicine Committee to Review Data Systems for Monitoring HIV Care, referenced in Institute of Medicine, *Monitoring HIV Care in the United States: Indicators and Data Systems*, March 2012, available at <http://www.iom.edu/Reports/2012/Monitoring-HIV-Care-in-the-United-States.aspx>.
- ⁶ Crowley J, Kates J (2013). *Updating the Ryan White HIV/AIDS Program For A New Era: Key Issues and Questions for the Future*. Washington, DC: Kaiser Family Foundation. Available at <http://www.kff.org/hiv/aids/report/updating-the-ryan-white-hiv-aids-program-for-a-new-era-key-issues-and-questions-for-the-future/>.
- ⁷ HRSA. *Ryan White HIV/AIDS Program, 2010 State Profiles*. Available at: <http://hab.hrsa.gov/stateprofiles/2010/states/us/Client-Characteristics.htm#chart6>.
- ⁸ 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>.
- ⁹ 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>.
- ¹⁰ 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>.
- ¹¹ <https://careacttarget.org/>.
- ¹² <http://federalaidspolicy.org/>.

THE HENRY J. KAISER FAMILY FOUNDATION

Headquarters

2400 Sand Hill Road
Menlo Park, CA 94025
Phone 650-854-9400 Fax 650-854-4800

Washington Offices and Barbara Jordan Conference Center

1330 G Street, NW
Washington, DC 20005
Phone 202-347-5270 Fax 202-347-5274

www.kff.org

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