



# The Transition of People Living with HIV/AIDS from Ryan White-Funded Care to California's Early Medicaid Expansion Program: Lessons Learned and Looking Ahead\*

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## Introduction

In 2010, the Federal Centers for Medicare & Medicaid Services (CMS) approved a California Medicaid waiver (pursuant to § 1115 of the Social Security Act) that authorized counties to receive federal Medicaid funds for health services they provide to certain low-income individuals. In July, 2011 California took the first steps toward statewide Medicaid expansion by implementing a partial expansion under this waiver. The waiver expanded coverage through new programs called Low Income Health Programs (LIHPs) to over 500,000 low-income Californians. Counties began to provide those services in 2011, through the LIHPs. The county LIHPs can set income eligibility for the program at up to 200 percent of the Federal Poverty Level (FPL). The counties also may cap the program and create waiting lists. In 2012, several thousand Californians with HIV/AIDS who had previously received services through the Ryan White HIV/AIDS Program began to receive services through LIHPs instead. As California moves towards full health reform implementation in 2014, the experience with early expansion reveals several important lessons regarding care for people living with HIV/AIDS.

## The Ryan White HIV/AIDS Program

The Ryan White HIV/AIDS Program was created by Congress in 1990 to provide HIV care and services to low-income people who are uninsured and underinsured. The program has become a major source of the nation's HIV care and support services and is currently funded at \$2.4 billion annually.<sup>1</sup> The Ryan White Program provides funding for services for low-income HIV positive individuals, including to states for the AIDS Drug Assistance Program (ADAP), which helps low-income uninsured and underinsured HIV positive individuals access prescription medications.<sup>2</sup> Ryan White funding has been credited for building some of the first effective medical homes for people with a chronic

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disease, necessitated by the complexity of HIV care and the frequent presence of complicating factors including substance abuse, poverty, comorbidities, and social stigma.<sup>3</sup> Ryan White-funded clinics around the country offer a range of services in addition to primary and specialty medical care, which include case management, psychological counseling, social services, pharmacy consultation, substance use treatment, palliative care, spiritual counseling, and adherence counseling.<sup>4</sup> In addition, many Ryan White-funded clinics have established “care teams” that work with each patient.<sup>5</sup> Many of these services and the coordination necessary to ensure that they are delivered in a patient-centered model are not covered by Medi-Cal or the LIHPs. In California, many low-income people living with HIV/AIDS depend on Ryan White services. In 2010, 97,626 clients received Ryan White services and 39,783 clients used ADAP.<sup>6</sup>

### **The Low Income Health Program (LIHP) and People living with HIV/AIDS**

The State Office of AIDS, which administers California’s Ryan White-funded ADAP, and the Department of Health Care Services (DHCS), which oversees the LIHPs, did not effectively coordinate services for uninsured people living with HIV/AIDS. Nor did CMS communicate with the Health Resources and Services Agency (HRSA), the federal agency which oversees the Ryan White Program, about responsibility for services under the waiver. As a result, the State and counties did not plan to provide services for people living with HIV/AIDS in LIHPs. Instead, counties mistakenly believed they could rely on Ryan White funding, including ADAP, to provide primary care and medications to people living with HIV/AIDS rather than transfer responsibility for their care to the LIHPs.

### **Ryan White Funds as “Payer of Last Resort” and the LIHPs**

Neither the state nor the counties clearly understood that Ryan White would not pay for services where coverage was available from another source, including Medicaid funds through the LIHP. The Ryan White HIV/AIDS Treatment Extension Act of 2009 “payer of last resort” provision prohibits grantees from expending Ryan White funds:

- to make payments for any item or service to the extent that payment has been made, or can reasonably be expected to be made, with respect to that item or service;
- under any State compensation program, under an insurance policy, or under any Federal or State health benefits program (except for a program administered by or providing the services of the Indian Health Service); or
- by an entity that provides health services on a prepaid basis.<sup>7</sup>

This is intended to ensure that Ryan White funds will only be expended for services when no other source of payment is available. Because California’s LIHPs are Medicaid programs, they fit the definition of “Federal or State health benefits program,” and

therefore Ryan White funds may not be used to pay for any services that LIHPs will cover.

In July, 2011, CMS clarified that LIHPs must ensure that their provider networks are adequate to meet the needs of enrollees with HIV, including those who had previously received Ryan White-funded care.<sup>8</sup> People living with HIV often need a wide variety of services, including medical case management, peer advocacy, and employment supports, not all of which are part of the LIHP benefits package. Since LIHPs must cover many services that were previously funded through Ryan White, including physician services, prescription and non-prescription medications, medical equipment and supplies, and outpatient hospital services,<sup>9</sup> LIHPs must ensure that their provider networks include enough providers, and those with HIV expertise, to meet the needs of enrollees with HIV. Ryan White funds can, however, continue to pay for services that a LIHP does not cover. Ryan White funding will continue to be needed to fill the gaps when the Medi-Cal Expansion is implemented in 2014, to pay for specialty services needed by people living with HIV when these services are not fully covered by Medi-Cal.<sup>10</sup>

### **Transitioning People living with HIV/AIDS from Ryan White to LIHP**

Because the California Administration did not understand the Ryan White Program's "payer of last resort" provision, the state and counties did not plan for the costs, provider networks, or transition of people living with HIV/AIDS from Ryan White services to LIHPs. When the oversight was discovered, people living with HIV/AIDS and their providers experienced an abrupt and unplanned transition as the LIHPs scrambled to make changes to address their obligations. Because there was no formal coordination between the State Office of AIDS, which administers Ryan White funds and services, and DHCS, which administers the LIHPs, there was no state oversight to plan for the transition. Since the LIHPs had not anticipated the cost of these services, some counties chose to dramatically lower program eligibility levels to limit their financial obligations. For example, San Francisco, which originally planned to cover individuals with incomes up to 133% FPL in its LIHP, reduced income eligibility to only 25% FPL.<sup>11</sup> Other LIHPs attempted to recruit Ryan White providers into their provider networks in order to ensure continuity of care for LIHP enrollees with HIV who had previously received coverage through Ryan White.<sup>12</sup> One of the biggest struggles for the LIHPs was funding an adequate drug formulary for people with HIV, since the antiretroviral (ARV) prescription medications used by most people with HIV are expensive. Most LIHPs began looking for options to purchase ARVs at discounted rates.<sup>13</sup>

Once the LIHP was operating in a county, Ryan White grantees were asked to submit plans to the State Office of AIDS outlining how they planned to transition their LIHP eligible Ryan White clients to the LIHPs. In some jurisdictions the transition went

forward reasonably quickly, and fairly smoothly, while in others there was a need for significant planning prior to beginning the transition. Beginning in March 2012, ADAP administrators in the counties that were ready were instructed to begin screening people for potential LIHP eligibility at their next Ryan White or ADAP redetermination, referring them to the LIHPs if they were likely eligible.<sup>14</sup> Despite these efforts, for some people the transition from Ryan White to LIHP required switching to a new provider and pharmacy with little to no notice. In Los Angeles and Alameda County, two counties with some of the largest number of LIHP eligible Ryan White clients, the transition did not begin until July and August of 2012 respectively.<sup>15</sup> Not all Ryan White providers, including pharmacy providers, were included in LIHP networks.

Advocates raised concerns about the potential for disruption and loss to continuity of care during the transition from Ryan White services to LIHPs and questioned whether the LIHPs have the capacity to provide comprehensive coordinated care like that provided under Ryan White. Today, there are thousands of former Ryan White clients enrolled in LIHPs; in Los Angeles county, the largest LIHP in the state, approximately 5,000 people with HIV/AIDS are enrolled.<sup>16</sup> While the LIHPs have managed to provide services for all the Ryan White clients so far, similar concerns about capacity exist as California prepares to transition this population into the Medi-Cal program in 2014.

### **Changes to the LIHPs to accommodate the Transition of People living with HIV/AIDS**

While people living with HIV/AIDS transitioned from Ryan White to LIHPs, advocates continued to seek solutions to ensure they received appropriate services with as little disruption to care as possible. In 2012 the state successfully obtained an amendment to the 1115 Waiver that allowed the state to roll over certain authorized but unexpended funds to the state's Safety Net Care Uncompensated Care Pool.<sup>17</sup> As a result, the state was able to establish an HIV Incentive Transition Program for infrastructure development by designated public hospitals to support services for people with HIV in LIHPs.<sup>18</sup> These new funds are intended to help counties that have both large numbers of low-income people living with HIV/AIDS and a public hospital. Counties that do not have a designated public hospital, however, are not able to benefit from the new funds that are available.

### **Lessons Learned and Looking Ahead**

California's experience of transitioning people living with HIV/AIDS from Ryan White-funded care into new coverage highlights the importance of careful planning and collaboration for transitions of this kind. As California prepares to transition many more people into Medi-Cal and Covered California in 2014, we offer the lessons below to help ensure that future transitions are as smooth as possible.

- **Leadership and Collaboration**—No single agency at the federal level is formally charged with assisting the transition for people living with HIV/AIDS and planning for coordinated care after 2014. A new level of leadership from HIV-focused agencies, such as the Health Resources and Services Agency (HRSA), will be essential to ensure a successful transition of these individuals into Medi-Cal in 2014, as well as to fill gaps in services after 2014. In addition, new coordination between CMS and HRSA is critical to ensure that HIV services are integrated into the Medi-Cal expansion or Exchange coverage after 2014 and that Ryan White programs continue to provide coverage where gaps exist. HRSA should develop adequate and timely guidance, with stakeholder input, to assist Ryan White providers to integrate their care within Medi-Cal or Exchange coverage and provide wraparound coverage. CMS should direct state Medi-Cal agencies to reach out to Ryan White grantees and other providers to plan for the Medi-Cal Expansion.

Similarly, because there is not a single California agency with ultimate responsibility, the State Office of AIDS, DHCS and Covered California should work together to coordinate the transition of coverage for people living with HIV/AIDS in 2014. The agencies will need to communicate frequently and collaborate closely to ensure a smooth transition. All three agencies must also engage with stakeholders to identify and address transition issues, including continuity of care for individuals with AIDS/HIV with Ryan White providers.

- **Planning and Engagement**—Many critical decisions regarding health care reform implementation are being made at the federal and state level, including the development and implementation of insurance marketplaces, Medicaid expansion, the essential health benefits and alternative benefits plans, and new insurance protections. Advocates for people living with HIV/AIDS and Ryan White providers should be engaged in these conversations to ensure that the needs of those with HIV/AIDS are addressed.

In California, planning for the integration of HIV care services into the Medi-Cal Expansion and Covered California is critical to ensure that there is no disruption in care and to ensure comprehensive HIV care is available in 2014 and beyond. Many uninsured HIV positive Ryan White clients will likely be eligible for Medi-Cal in 2014. Therefore, HIV advocates need to directly engage at the state level on Medi-Cal policies to ensure that the program will meet the needs of people living with HIV/AIDS. In addition, the State Office of AIDS must continue its health care reform stakeholder advisory committee meetings and secure appropriate representation from DHCS and Covered California. As part of the planning process, DHCS and Covered California should continue to regularly convene

their LIHP Transition Stakeholder meetings, and include stakeholders with HIV care expertise, to ensure a smooth transition from LIHP to Medi-Cal Expansion (and Covered California) for enrollees living with HIV.

- **Transition and Access**— Most uninsured people living with HIV/AIDS will be moving from Ryan White to new insurance coverage through Medi-Cal or Covered California. It is unlikely that the health care systems will be fully ready to support a safe transition for all eligible HIV-positive people by January 2014 without disruptions or loss to care. In order to fulfill the promise of health care reform for people living with HIV/AIDS, ongoing transition strategies that will minimize disruption in care must be developed before people living with HIV/AIDS are moved into the new coverage options.

Nationally, HRSA should ensure that all new Medicaid Expansion and Marketplace networks are capable of serving clients transitioning from Ryan White services to new coverage, including having adequate provider, clinical and pharmacy networks as well as a complete drug formulary. HRSA should also establish updated payer of last resort guidance to address the Ryan White services coverage and access issues during the transition. While Ryan White cannot pay for services covered under other programs, this requirement should not impede Ryan White from providing access to services that are not provided by another payer, or effectively coordinating services among payer sources. In addition, in each state, HRSA should work with state agencies and community stakeholders to articulate and plan for services that will need to continue to be provided through Ryan White to ensure the continuity of the cost effective and quality HIV care. HIV care providers are experts in care delivery and are central to maintaining the patient centered care that has improved HIV health outcomes. HRSA should also continue to work with clinical health services to ensure that clients can continue to receive Ryan White services up until they are fully engaged in new coverage and able to access all services, including prescription medications.

In California, the State Office of AIDS and local Ryan White planning bodies should work with DHCS and Covered California to plan Ryan White resource allocation. The allocation must ensure that the needs of LIHP enrollees with HIV and AIDS are addressed in the Medi-Cal expansion and Covered California. Continuity of care with existing specialty providers should be a high priority. Finally, Ryan White programs will continue to be needed to provide services that improve health outcomes for all people with HIV but may not be covered under Medi-Cal or Covered California. Increases in medical case management, health benefit counseling and navigation resources should be made available to people living with HIV/AIDS who will be eligible for new insurance coverage in 2014.



- **Education and Communication**—Because Ryan White funding and services have developed a continuum of HIV-specific expert care, people living with HIV/AIDS and their providers have come to depend on Ryan White agencies for necessary information about their health care benefits and rights. Therefore, many people living with HIV/AIDS and their providers are not well connected to Medi-Cal or private insurance. It will be essential to develop improved education and communication materials in this rapidly changing environment. To ensure successful integration and continuity of all aspects of quality HIV care, Ryan White grantees and providers will require timely and reliable information, updates, technical assistance and guidance. HRSA, the National Association of State and Territorial AIDS Directors and the AIDS Education and Training Centers should provide capacity building and technical assistance aimed at helping AIDS/HIV providers navigate moving from grant-driven systems to negotiating, contracting, and interacting with multiple coverage products.

In California, HIV entities, including the State Office of AIDS, HIV-specific agencies and the AIDS Education and Training Centers, need to take a stronger role in creating communication networks and ensuring that accessible and usable information regarding changes in all systems of care gets distributed regularly. Ryan White allocation planners will also need to increase resources for individual health benefits counseling and navigation assistance. In particular, premiums and co-pays in the Exchange may be far greater than what LIHP enrollees have been paying, and Ryan White providers should be prepared to counsel those individuals who transition into Covered California about their options for assistance with costs. Moreover, provider rates, both medical and pharmacy, are likely to be lower in Medi-Cal and Covered California than in Ryan White-funded programs. Thus, all stakeholders will have to collaborate to develop strategies to address sustainability of service delivery and continuity of patient centered medical care.

Additionally, the transitions to managed care in California thus far have illustrated that individual assistance will be needed by many people living with HIV/AIDS who will be newly eligible for the Medi-Cal expansion or Covered California to navigate healthcare access and patient protections. DHCS and Covered California should work with the State Office of AIDS to ensure that information is distributed through trusted networks. DHCS and Covered California should also convene outreach events that involve community-based organizations. For LIHP enrollees, DHCS and Covered California must collaborate with the counties and the State Office of AIDS to send appropriate notices about the transition, to ensure that enrollees have all the information they need. Counties without LIHPs, or with very low LIHP income caps, should also find ways to outreach to county

health program beneficiaries and users of Ryan White-funded services who will likely become newly eligible for the Medi-Cal Expansion and Covered California in 2014. To help ensure that notices are comprehensive as well as understandable to consumers, advocates familiar with HIV care should have the opportunity to review and comment on any draft notices or other outreach materials with enough advance notice before they are finalized.

## **Conclusion**

Thousands of people who currently access health care services through the Ryan White program will become eligible for new coverage in 2014. California's experience moving people from Ryan White-funded care into LIHPs highlights the importance of careful planning for this transition. Government agencies, care providers and advocates will need to work closely together to ensure that people living with HIV/AIDS maintain their access to critical services while they move into these new coverage options.



## Endnotes

<sup>1</sup> Health Resources and Servs. Admin., About the Ryan White HIV/AIDS Program, <http://hab.hrsa.gov/abouthab/aboutprogram.html> (last visited May 20, 2013).

<sup>2</sup> ADAP is funded by Part B of the program. See 42 U.S.C. § 300ff-21. In addition, Part A funds eligible cities and counties to provide outpatient HIV care and supportive services in the geographic areas that have been hardest hit by HIV. *Id.* § 300ff-11. Part C funds certain health care clinics and non-profit organizations to provide comprehensive HIV outpatient care and in medically underserved areas. *Id.* § 300ff-51. Part D provides family-centered care for women, infants, children and youth. *Id.* § 300ff-71. Ryan White also funds training for first responders, special projects for innovative models of care and support services, training for health care providers, dental programs, and funding to evaluate and address the disproportionate impact of HIV on African Americans and other minorities. See, e.g., *id.* §§ 300ff-80, 300ff-101, 300ff-111.

<sup>3</sup> See, e.g., Mike S. Saag, *Editorial: Ryan White: An Unintentional Homebuilder*, 19 AIDS READER 166, 166 (2009).

<sup>4</sup> *Id.*

<sup>5</sup> *Id.*

<sup>6</sup> U.S. Dep't of Health & Human Servs., Health Servs. Resources Admin., 2010 State Profiles: Ryan White HIV/AIDS Program – California – AIDS Drug Assistance Program, <http://hab.hrsa.gov/stateprofiles/2010/states/ca/AIDS-Drug-Assistance-Program.htm> (last accessed Apr. 15, 2013) (figure for Ryan White services may include duplicated clients).

<sup>7</sup> 42 USC § 300ff-15(a)(6) (Part A Grants); see also *id.* §§ 300ff-27(b)(7)(F) (Part B grants), 300ff-64(f)(1) (part C grants); see also HRSA, CLARIFICATIONS REGARDING MEDICAID-ELIGIBLE CLIENTS AND COVERAGE OF SERVICES BY RYAN WHITE HIV/AIDS PROGRAM: POLICY CLARIFICATION NOTICE (PCN) #13-01 (2013), available at <http://hab.hrsa.gov/manageyourgrant/pinspals/1301pcnmedicaideligible.pdf> (explaining these provisions in the context of expanded Medicaid coverage).

<sup>8</sup> Letter from Victoria Wachino, Centers for Medicare and Medicaid Servs., to Toby Douglas, Cal. Dept. of Health Care Servs. Jul. 22, 2011 (on file with author); see also Email from Bob Baxter, Cal. Dept. of Health Care Servs., to LIHPs, Aug. 16, 2011 (on file with author) (“The local LIHPs are not required to include Ryan White providers as part of their network, but they must ensure an adequate provider network for all of their enrollees including those that formerly received services through a Ryan White- funded program. This requirement means that local LIHPs may need to increase the number of health care providers/clinics that provide HIV-related primary and specialty care in their provider networks to meet the time/distance and 30 days appointment requirements. The local LIHPs should determine the cost and quality implication of expanding their provider networks to include current Ryan White-funded clinical programs because the local LIHPs are responsible for any medically necessary covered service required by its enrollees even if that service cannot be performed by a provider within its provider network.”)

<sup>9</sup> CENTER FOR MEDICARE & MEDICAID SERVICES, SPECIAL TERMS AND CONDITIONS, AMENDED APRIL 1, 2012, CALIFORNIA BRIDGE TO REFORM DEMONSTRATION ¶ 63 available at [http://www.dhcs.ca.gov/provgovpart/Documents/LIHP/Publications/California%20STCs%20\(3-30-12\).pdf](http://www.dhcs.ca.gov/provgovpart/Documents/LIHP/Publications/California%20STCs%20(3-30-12).pdf).

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<sup>10</sup> See CINDY MANN, DIRECTOR, CENTER FOR MEDICAID AND CHIP SERVICES & MARY WAKEFIELD, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, COORDINATION BETWEEN MEDICAID AND RYAN WHITE HIV/AIDS PROGRAMS (2013), *available at* [http://content.govdelivery.com/attachments/USCMS/2013/05/01/file\\_attachments/208160/CIB-05-01-2013.pdf](http://content.govdelivery.com/attachments/USCMS/2013/05/01/file_attachments/208160/CIB-05-01-2013.pdf).

<sup>11</sup> BILL BLUM & TANGERINE BRIGHAM, SAN FRANCISCO DEP'T OF PUBLIC HEALTH, LOW INCOME HEALTH PROGRAM AND RYAN WHITE CARE PROGRAM 7 (2011), *available at* <http://www.dhcs.ca.gov/provgovpart/Documents/LIHP/Meetings/MIHT/T.Brigham.ppt>.

<sup>12</sup> JULIE CROSS, DIVISION OF HIV AND STD PROGRAMS, TRANSITIONING RYAN WHITE CLIENTS TO HEALTHY WAY LA 13 (2011), *available at* <http://ph.lacounty.gov/aids/HealthcareReform/TransitioningRWClients11-11.pdf>.

<sup>13</sup> Many LIHPs explored limiting their pharmacy contracts to “covered entities” eligible under Section 340B of the Public Health Service Act (PHSA) to purchase certain pharmaceuticals at deep discounts. See 42 U.S.C. § 256b.

<sup>14</sup> Letter from Deborah Parham Hopson, Health Research Services Agency, to California LIHPs, Aug. 9, 2011, *available at*

<http://www.cdph.ca.gov/programs/aids/Documents/LIHPHSALtr080911.pdf>; CAL. DEP'T OF PUBLIC HEALTH, RYAN WHITE REQUIREMENTS AND THE LIHP - FREQUENTLY ASKED QUESTIONS (FAQs) #3 at 1 (2011), *available at* <http://www.cdph.ca.gov/programs/aids/Documents/LIHPFAQ3.pdf>.

<sup>15</sup> Memo from Office of AIDS, AIDS Drug Assis. Prog. to ADAP Coordinators, ADAP Enrollment Workers in Los Angeles, Riverside, San Bernardino and Santa Cruz Counties, Jun. 20, 2012 (memo #12-04), *available at*

<http://www.cdph.ca.gov/programs/aids/Documents/ADAPMM201204ADAPLIHPScreeningImplementation.pdf>; Memo from Office of AIDS, AIDS Drug Assist. Prog. to ADAP Coordinators, ADAP Enrollment Workers in Alameda, Placer, and County Medical Services Program, Jul. 23, 2012 (memo #12-05), *available at* <http://www.cdph.ca.gov/programs/aids/Documents/ADAPMM201205LIHPScreeningImplementation.pdf>.

<sup>16</sup> Email from Kyle Baker, Government Relations, Office of AIDS Programs and Policy, to Courtney Mulhern-Pearson Director of State and Local Affairs, San Francisco AIDS Foundation, Apr. 17, 2013 (on file with author).

<sup>17</sup> Letter from Angela D. Garner, Deputy Director, Division of State Demonstrations and Waivers, Center for Medicaid and Medicare Services, to Toby Douglas, Director, Cal. Dep't of Health Care Servs., Nov. 19, 2012, *available at* <http://www.dhcs.ca.gov/provgovpart/Documents/LIHP/Publications/HIV%20Protocol%20Approval%20Letter%20Nov%2019%202012.pdf>.

<sup>18</sup> *Id.*