Annals of Health Law

Volume 23
Issue 1 *Winter 2014*

Article 4

2014

THE AFFORDABLE CARE ACT AND PEOPLE LIVING WITH HIV/AIDS: A ROADMAP TO BETTER HEALTH OUTCOMES

Mark Bolin

THE AFFORDABLE CARE ACT AND PEOPLE LIVING WITH HIV/AIDS: A ROADMAP TO BETTER HEALTH OUTCOMES

Mark Bolin*

I. INTRODUCTION

Since the discovery of HIV/AIDS in June of 1981, more than 1.8 million people have been diagnosed with the disease.[1] Since that time, medical advances have significantly improved the life expectancy of people living with HIV/AIDS (PLWHA).[2] However, many PLWHA have been unable to access the benefits of these advances because they do not receive regular medical treatment.[3] Without regular medical treatment, PLWHA cannot reap the benefits of these advances or achieve the improved health outcomes that have otherwise become the norm.[4]

There is more than one reason why PLWHA do not receive regular medical care. Commonplace social stigma and pervasive discrimination in

---

* J.D. Candidate, May 2014, Loyola Law School Los Angeles; B.A., University of California Santa Barbara, 2008. I would like to thank everyone who has helped me in the drafting and editing of this Article. This Article would not have been possible without my faculty advisor, Professor Brietta Clark, who provided me with invaluable suggestions and critiques throughout its drafting. Finally, I would like to thank the Annals of Health Law for publishing this Article and working so hard to improve and update it wherever possible.

1. Kaiser Family Found., HIV/AIDS Policy Fact Sheet: The HIV/AIDS Epidemic in the United States 1 (2013) [hereinafter HIV/AIDS Epidemic], http://kaiserfamilyfoundation.files.wordpress.com/2013/03/3029-14.pdf. Currently, more than 1.1 million people worldwide live with HIV/AIDS. Id.

2. See, e.g., Bernard M. Branson et al., Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings, MORBIDITY & MORTALITY WKLY. REP., Sept. 22, 2006, at 2, available at http://www.cdc.gov/mmwr/pdf/rr/rr5514.pdf (describing how treatment has improved the survival rates of PLWHA dramatically, especially since the introduction of highly active antiretroviral therapy).

3. See Michael Carter, Majority of HIV-Positive Patients in the US Not Receiving Regular Medical Care, NAM AIDSMAP (Jan. 30, 2012), http://www.aidsmap.com/Majority-of-HIV-positive-patients-in-US-not-receiving-regular-medical-care/page/2228542/ (reporting that an article in the Journal of Acquired Immune Deficiency Syndromes has suggested that only forty-five percent of HIV-positive patients in the U.S. are receiving regular medical care).

4. See Jeffrey S. Crowley & Jen Kates, The Affordable Care Act, the Supreme Court, and HIV: What Are the Implications? 1 (2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/03/8363.pdf.

the workplace, at the doctor's office, and elsewhere play a part.[5] Perhaps the biggest reason, however, has been their inability to access comprehensive and affordable health care coverage.[6] In the private health insurance market, providers have systematically excluded PLWHA in an effort to contain costs by categorizing the disease as a "pre-existing condition."[7] In doing so, providers have been able to categorically deny PLWHA health insurance, or in the alternative, simply price it out of reach.[8] Public health plans have also suffered from access issues relating to the cost of care and comprehensiveness of coverage.[9] These problems have only been exacerbated in recent years as healthcare costs have grown and budgets have shrunk, resulting in the institution of stricter managed care plans by states across the country.[10]

In passing the Patient Protection and Affordable Care Act (PPACA), Congress intended to address these barriers to treatment by including most Americans in a health insurance market that offers affordable, comprehensive care.[11] However, the implementation of PPACA comes with its own significant hurdles.[12] As a result of the Supreme Court's decision in National Federation of Independent Business v. Sebelius,[13] PPACA's Medicaid expansion will likely reach fewer low-income childless adults than intended.[14] This result will have a disproportionate impact on PLWHA, who rely on the program for their health needs at higher rates

5. See Jennifer N. Sayles et al., The Association of Stigma with Self-Reported Access to Medical Care and Antiretroviral Therapy Adherence in Persons Living with HIV/AIDS, SOC'Y OF GEN. INTERNAL MED. 1101, 1105 (2009) (finding that low rates of self-reported access to medical care was strongly associated with experiences of HIV stigma among underserved communities); Lambda Legal, HIV Stigma and Discrimination in the U.S.: An Evidence-Based Report 1 (Nov. 2010), http://www.lambdalegal.org/sites/default/files/publications/downloads/fs_hiv-stigma-and-discrimination-in-the-us_1.pdf; Press Release, Am. Civil Liberties Union, ACLU Survey Reveals Massive Civil Rights Violations Against People with HIV/AIDS: 19-Year-Old HIV-Positive Nebraska Woman Brings Lawsuit Against Former Employer for Discrimination (Nov. 13, 2003), https://www.aclu.org/lgbt-rights_hiv-aids/aclu-survey-reveals-massive-civil-rights-violations-against-people-hivaids (detailing incidents of HIV discrimination across the country).

6. See Crowley & Kates, supra note 4, at 2 (citing studies that suggest access to healthcare is strongly associated with the availability of insurance).

7. See infra Part III.B.

8. See id.

9. See infra Part IV.B.

10. See id.

11. See infra Part II.

12. See infra Part IV.

13. 132 S. Ct. 2566 (2012).

14. See id. at 2607 (holding that the Spending Clause forbids the federal government from withdrawing existing Medicaid funds from States that do not implement PPACA's Medicaid expansion).

than the rest of the population.[15] Moreover, the Department of Health and Human Services (HHS) has indicated that it plans to cede much of its regulatory authority in defining what benefits must be included in new plans to the States,[16] some of whom have already refused to fully enforce PPACA.[17] PPACA also does not address certain longstanding health care access problems in the Medicaid program that have resulted from years of cuts in physician reimbursement rates.[18] In order for PPACA to achieve its goal of affordable, comprehensive health insurance for not only PLWHA, but all Americans, it must be implemented in a way that addresses these issues.

Part II of this Note explores the goals of PPACA through the lens of Congressional statements and the public debate that surrounded its passage. Part III explains the means by which PPACA expands access to insurance and health care for PLWHA. Part IV raises the question of what problems and potential pitfalls lay ahead in the implementation of PPACA. Part V recommends that (1) HHS mandate that its Seven Core Indicators of Effectiveness be used by HHS funding grantees; (2) advocates and medical experts both influence political actors to expand Medicaid coverage in their states and ensure that benchmark plans include coverage for medically necessary treatment for PLWHA; (3) HHS require insurance providers to cover a broader range of HIV care; and (4) Congress continue to fully fund the Ryan White Program in order to meet the health care needs of PLWHA in need of supplemental coverage. Part VI concludes with a summarization of the potential and problems moving forward in the implementation of PPACA.

II. THE PROMISE OF THE PATIENT PROTECTION AND AFFORDABLE CARE ACT

President Barack Obama signed PPACA into law on March 23, 2010.[19] PPACA created an entirely new national health insurance framework and was the most comprehensive piece of healthcare reform legislation in decades.[20] Congress enacted PPACA with two primary goals: (1) to expand

15. See Crowley & Kates, supra note 4, at 6 (noting that Medicaid is the largest payer of HIV care in the U.S.).

16. See infra text accompanying notes 108-09.

17. See infra text accompanying notes 193-94.

18. See infra Part IV.B.2.

19. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified in scattered sections of the U.S.C.).

20. See Abigail R. Moncrieff & Eric Lee, The Positive Case for Centralization in Health Care Regulation: The Federalism Failures of the ACA, 20 KAN. J.L. & PUB. POL'Y 266, 266

access to health care and (2) to make the nation's health care system more efficient and less costly.[21] PPACA was Congress's answer to the longstanding twin problems of access and cost that have plagued the American health care system.[22] Recognizing that PLWHA have suffered disproportionately from lack of health care access, Congress included a number of consumer protections prohibiting health insurance providers from denying PLWHA coverage.[23] For example, in the debate over PPACA's passage, the commonplace insurance industry practice of denying people with pre-existing conditions desperately needed care was widely criticized.[24] In order to build upon the framework laid by PPACA, the Obama Administration also issued the National HIV/AIDS Strategy, which calls upon both state and non-state actors to address the HIV epidemic.[25]

(2011) (introducing PPACA as the U.S.'s "most sweeping reform of healthcare law and our greatest expansion of healthcare access since the 1965 enactment of Medicare and Medicaid," and, in the words of Vice President Joe Biden, "a 'big f—-ing deal.'"); Health Law Advocates, National Health Care Reform Initiative, http://www.healthlawadvocates.org/priority-areas?id=0018 (last visited Nov. 21, 2013) (noting that the passage of PPACA brought "decades of efforts to enact national health care reform . . . to a successful conclusion"); see also Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2609 (2012) (Ginsburg, J., concurring in part and dissenting in part) (noting that in passing the PPACA, Congress "comprehensively reformed the national market for health-care products and services" and that "[b]y any measure, that market is immense"); CONG. BUDGET OFF., ESTIMATES FOR THE INSURANCE COVERAGE PROVISIONS OF THE AFFORDABLE CARE ACT UPDATED FOR THE RECENT SUPREME COURT DECISION 13 (2012), available at http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf (estimating by taking into account the effects of National Federation that PPACA will result in an additional twenty-nine to thirty million people gaining health insurance by 2019).

21. See Nat'l Fed'n of Indep. Bus., 132 S. Ct. at 2571 (describing PPACA as an effort by Congress to "increase the number of Americans covered by health insurance and decrease the cost of health care").

22. See Kaiser Family Found., Health Care Costs A Primer: Key Information on Health Care Costs and Their Impact 1 (May 2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7670-03.pdf (noting that "[h]ealth care accounts for a remarkably large slice of the U.S. economic pie"); Kaiser Family Found., Kaiser Commission on Medicaid and the Uninsured Key Facts: The Uninsured and the Difference Health Insurance Makes 1 (2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/1420-14.pdf (asserting that in 2011, the number of uninsured, non-elderly Americans totaled 47.9 million, approximately seventeen percent of the population).

23. Dep't Health & Human Serv., The Affordable Care Act Helps People Living with HIV/AIDS, http://aids.gov/federal-resources/policies/health-care-reform/ (last visited Sept. 26, 2013).

24. See infra Part II.B.

25. WHITE HOUSE, NATIONAL HIV/AIDS STRATEGY FOR THE UNITED STATES (2010), available at http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf.

A. Pre-existing Conditions

Addressing the issues of the country's large number of uninsured PLWHA would be difficult without tackling the problem of pre-existing conditions. Pre-existing conditions are physical or mental health conditions, disabilities, or illnesses that a person has before enrolling in a health plan.[26] They run a wide gamut from relatively minor conditions like asthma to chronic and debilitating illnesses like diabetes, cancer, and HIV/AIDS.[27] Insurance providers have commonly avoided insuring such people in an effort to avoid the costs of medical treatment that they inevitably require.[28] The industry's exclusionary practices have included either categorically denying their applications or pricing their plans out of reach.[29] While information on how many people with pre-existing conditions have been denied health insurance is not realistically obtainable, about 33.2 million people between the ages of nineteen and sixty-four had a pre-existing condition in 2009.[30] Before the passage of PPACA, the private insurance market excluded these people merely by virtue of their illness.[31]

---

26. Jay Angoff, What is a Preexisting Condition?, HEPATITIS C RES. & NEWS (Aug. 18, 2010), http://hepatitiscresearchandnewsupdates.blogspot.it/2010/08/what-is-pre-existing-condition.html.

27. Id.; Ctrs. for Medicare & Medicaid Servs., State by State Enrollment in the Pre-Existing Condition Insurance Plan [hereinafter State by State Enrollment], http://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/pcip-enrollment.html (last visited Sept. 26, 2013). There are also a number of well-documented incidences in which insurance providers have denied people coverage for pre-existing conditions that seem completely unlike the traditional definition. Id.; see also Doroshow v. Hartford Life & Acc. Ins. Co., 574 F.3d 230, 236 (3d Cir. 2009) (upholding the trial court's finding that seeking medical advice regarding a suspected, but not yet diagnosed, ailment may constitute a pre-existing condition); Nancy Lofholm, Heavy Infant in Grand Junction Denied Health Insurance, DENVER POST (last updated Oct. 12, 2009), http://www.denverpost.com/ci_13530098 (describing the experience of a mother whose child was denied health insurance because he was deemed to be "obese").

28. Robert Pearl, 4 Ways New Exchanges Will Radically Alter Health Insurance, FORBES (Oct. 1, 2013), http://www.forbes.com/sites/robertpearl/2013/10/01/4-ways-new-exchanges-will-radically-alter-health-insurance/ ("By denying coverage [patients with chronic diseases], insurance companies limit their risk, reduce their claims costs and increase their profits.").

29. See State by State Enrollment, supra note 27 (promoting the Pre-existing Condition Insurance Plan as a viable option for people who have been denied coverage by insurance companies or had plans priced out of reach due to a pre-existing condition).

30. Id.; U.S. GOV'T ACCOUNTABILITY OFF., GAO-12-439, PRIVATE HEALTH INSURANCE: ESTIMATES OF INDIVIDUALS WITH PRE-EXISTING CONDITIONS RANGE FROM 36 MILLION TO 122 MILLION 1 (2012), available at http://www.gao.gov/assets/590/589618.pdf. People with preexisting conditions also spend thousands of dollars more annually on healthcare. Id.

31. See Kathleen Sebelius, Barring Insurance Discrimination Based on Pre-Existing Health Conditions (Nov. 20, 2012) [hereinafter Sebelius, Discrimination], http://www.hhs.gov/healthcare/facts/blog/2012/11/marketrules112012.html (describing the

In the long and heated debate that took place up to the passage of PPACA, members of Congress cited the exclusion of people with pre-existing conditions as one of the most egregious problems in our health care system. For example, during her extended remarks upon voting for PPACA, Representative Anna G. Eshoo remarked that "[p]erhaps most tragically, our current system turns its back on those most in need—those with a pre-existing condition. Health insurance is meaningless if it's only available to the healthy."[32] Numerous other members of Congress echoed these remarks when it passed PPACA.[33]

The public debate also reflected the importance of prohibiting bans on people with pre-existing conditions. In order to address the critical issue of health reform, the White House held a Bipartisan Meeting on Health Reform on February 25, 2010.[34] At that meeting, Representative Louise Slaughter, a Democrat from New York, spoke about the need for health care reform stemming from a moral imperative that Congress had to stop "cruel" and "capricious" denials by health insurance providers of people with pre-existing conditions.[35] In many states, she pointed out, being the victim of domestic violence could even cause the denial of your application.[36] The Secretary of HHS also condemned this widespread insurance industry practice subsequent to PPACA's passage.[37]

---

importance of PPACA's prohibition on denials based on pre-existing conditions).

32. CONG. REC. E2762 (daily ed. Nov. 7, 2009) (statement of Rep. Anna G. Eshoo).

33. See, e.g., CONG. REC. S12153 (daily ed. Dec. 2, 2009) (statement of Sen. Cardin) ("The Patient Protection and Affordable Care Act will address this need and will help achieve the goals outlined by the theme of this year's World AIDS Day campaign of 'universal access and human rights.' First and foremost, the bill eliminates discrimination based on pre-existing conditions. Individuals with HIV will no longer be rejected from insurance coverage because of their disease."); CONG. REC. E2176 (daily ed. July 31, 2009) (statement of Rep. Linda T. Sánchez) ("What stands out to me the most from my work are the stories I hear from my district in California. Neighbors like Blasa Ochoa, who lost her insurance when her employer went bankrupt, and who has been unable to get another policy because she has a pre-existing condition.").

34. See Representative Louise Slaughter, quoted in Rep. Louise Slaughter makes remarks on preexisting conditions at White House health summit, WASH. POST (Feb. 25, 2010), http://www.washingtonpost.com/wp-dyn/content/article/2010/02/25/AR2010022503133.html (describing the bipartisan meeting as an effort by the Obama Administration to find common ground between the different health care proposals in Congress).

35. Id.

36. Id.

37. See Kathleen Sebelius, U.S. Sec'y of Health & Human Serv., Speech at 2012 Democratic National Convention, in Kathleen Sebelius DNC speech, POLITICO (Sept. 4, 2012), http://www.politico.com/news/stories/0912/80711.html (condemning the previously lawful insurance industry practice of categorizing C-sections, breast cancer, and even domestic violence as pre-existing conditions); Sebelius, Discrimination, supra note 31 (noting the unfortunately commonplace nature of denials based on pre-existing conditions

B. The National HIV/AIDS Strategy

The Obama Administration released the National HIV/AIDS Strategy (Strategy) on July 13, 2010, just four months after the passage of PPACA. The Administration designed the Strategy to be a comprehensive roadmap to greater health outcomes for PLWHA.[38] It encourages governmental agencies and medical service providers to focus on preventive measures, target high-risk populations, and ensure access to effective medical procedures as means to achieve better HIV care nationwide.[39] Although the Strategy contains no new regulations and has no binding legal effect, it is significant because it signals the Administration's acknowledgement that problems in HIV care persist, and can only be addressed by concerted efforts by both state and non-state actors.[40]

III. PROVISIONS THAT IMPROVE MEDICAL CARE ACCESS

Congress included a number of provisions in PPACA that are intended to address these health care access issues for PLWHA.[41] It addresses these issues primarily by expanding popular federal programs[42] and issuing stricter consumer protections.[43] In the public plan arena, the most drastic change is the expansion of Medicaid.[44] In the private plan arena, the biggest changes are: (1) the prohibition on exclusions based on pre-existing conditions[45] and (2) the prohibition on annual and lifetime spending limits.[46] Although these provisions have the potential to dramatically improve health care access, their ultimate impact upon PLWHA is still uncertain because of the effects of National Federation as well as cost and access problems in the nation's health care system that PPACA does not address.

---

before the passage of PPACA).

38. See WHITE HOUSE, supra note 25, at vii.

39. See id. at viii.

40. See id. at i (stating that supporting a successful implementation of this law is essential to improving health outcomes for people living with HIV); see also Press Release, White House Off. of the Press Sec'y, Presidential Memorandum: Implementation of the National HIV/AIDS Strategy (July 13, 2010), http://www.whitehouse.gov/the-press-office/presidential-memorandum-implementation-national-hivaids-strategy.

41. See infra Part III.A-B.

42. See infra Part III.A.

43. See infra Part III.B.

44. 42 U.S.C.A. § 1396a(a)(10)(A)(i)(VIII) (West, WestlawNext through 2012 P.L. 112-209); see also Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2572 (2012) ("Another key provision of the Act is the Medicaid expansion.").

45. 42 U.S.C.A § 300gg-3.

46. 42 U.S.C.A § 300gg-11.

A. Public Health Plans

In passing PPACA, Congress sought to improve access to medical care by expanding the nation's public health care system. PPACA has a substantial effect on two of the nation's most vital public programs for PLWHA in the United States, Medicaid and the Ryan White Program. PPACA eliminates all non-income-based requirements for participation in Medicaid, giving low income childless adults living with HIV/AIDS the opportunity to enroll in the program for the first time.[47] The law has a more indirect effect on the Ryan White Program, as the changes it has in store for the nation's system of HIV care will ultimately create an entirely new role for the program.[48] These changes will have a substantial impact on PLWHA, who disproportionately rely on public assistance for their medical needs.[49]

1. Medicaid

Medicaid is a public health insurance option administered jointly by the States and the federal government.[50] Although Congress does not require states to participate in the program, those that do must meet a number of eligibility and coverage requirements if they want to receive federal funding.[51] For example, Congress requires that states receiving federal funding cover certain people, while giving them the option of covering others.[52] Congress calls groups that states are required to cover "mandatory eligibility groups," and groups that states may or may not cover "optional eligibility groups."[53] If a state chooses not to cover an optional eligibility group, it does not receive funding for that particular group only.[54] Despite

47. See infra Part III.A.2.

48. See infra Part III.A.2.

49. See Crowley & Kates, supra note 4, at 6.

50. Kaiser Family Found., Medicaid: An Overview of Spending on Mandatory vs. Optional Populations and Services, 1 (2005) [hereinafter Medicaid: An Overview], http://www.kaiserfamilyfoundation.files.wordpress.com/2013/01/medicaid-an-overview-of-spending-on.pdf.

51. Id.

52. See id. at 2 (listing examples of mandatory versus optional eligibility groups). Evolving significantly over its more than forty-year-long history, Medicaid has come to include far more people than it did originally. Id. At its inception, the Medicaid program was a type of welfare, available only to those who met those strict guidelines. Id. While those eligible for cash assistance from programs like Welfare have, for the most part, remained mandatory eligibility groups, many of the groups included in the Medicaid reforms comprise optional eligibility groups. Id.

53. Id.

54. Id.

these requirements, states retain significant power in crafting coverage and eligibility provisions, which vary significantly from state to state.[55] Most states determine eligibility criteria for Medicaid based in part on the applicant's income in relation to the federal poverty level (FPL)[56] and on other factors such as disability or age.[57] Until the passage of PPACA, many of the United States's poorest citizens were not eligible for Medicaid because they did not meet the additional requirements that they be disabled, elderly, a parent, or a child.[58]

PPACA addresses the problems surrounding access to Medicaid and its cost by eliminating all non-income based eligibility requirements.[59] Beginning in 2014, states will receive federal funding for Medicaid benefits paid to individuals earning less than 138% of the FPL.[60] Before National Federation, PPACA authorized HHS to rescind Medicaid funds entirely from states that refused to expand Medicaid eligibility to this group of people.[61] In other words, HHS could force states to pay for their Medicaid program without the benefit of any federal funding if they maintained any non-income based eligibility requirements or refused to raise the income

55. See SOC. SEC. ADMIN., ANNUAL STATISTICAL SUPPLEMENT TO THE SOCIAL SECURITY BULLETIN, 2011 56 (2012), available at http://www.socialsecurity.gov/policy/docs/statcomps/supplement/2011/supplement11.pdf; Timothy Jost, Implementing Health Reform: State Innovation and Medicaid Waivers, HEALTH AFFAIRS BLOG (Feb. 23, 2012), http://healthaffairs.org/blog/2012/02/23/implementing-health-reform-state-innovation-and-medicaid-waivers/ (commenting that even though federal requirements do exist, states have often received waivers to depart from those minimum standards which result in either an expansion or contraction of eligibility criteria, often quite dramatically).

56. The Department of Health and Human Services annually sets the FPL by issuing "poverty guidelines," which administrative agencies use to determine who is eligible for public assistance. Dep't Health & Human Servs., 2013 Poverty Guidelines, http://aspe.hhs.gov/poverty/13poverty.cfm (last visited Nov. 20, 2013). The District of Columbia and every state but Alaska and Hawaii share the same FPL. Id.

57. Ctrs. for Medicare & Medicaid Servs., Eligibility, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Eligibility.html (last visited Nov. 20, 2013); see also Ctrs. for Medicare & Medicaid Servs., 2013 Poverty Guidelines, http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Eligibility/Downloads/2013-Federal-Poverty-level-charts.pdf (last visited Nov. 20, 2013). The 2013 FPL for a family of four was $23,550. Id.

58. See SOC. SEC. ADMIN., supra note 55, at 56-57.

59. 42 U.S.C.A. § 1396a(a)(10)(A)(i)(VIII) (West, WestlawNext through P.L. 112-283).

60. See id.; State Health Access Data Assistance Ctr., ACA Note: When 133 Equals 138 – FPL Calculations in the Affordable Care Act (Jan. 13, 2011), http://www.shadac.org/blog/aca-note-when-133-equals-138-fpl-calculations-in-affordable-care-act (noting that the language of PPACA states that childless adults with a "Modified Adjusted Gross Income" below 133% are eligible for Medicaid and that the eligibility threshold for Medicaid is effectively 138% because of how PPACA and the Internal Revenue Service calculate adjusted gross income).

61. Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2607 (2012).

requirement to at least 138% of the FPL.[62] However, in National Federation, the Court held that this provision is not within Congress' constitutional authority under the spending clause.[63] Therefore, HHS is limited to withholding funds associated with the expansion, effectively making individuals earning less than 138% of the FPL an optional eligibility group.[64] As of November 2013, eighteen states had decided not to expand eligibility to include such optional groups,[65] three states were leaning towards not participating,[66] and five states were pursuing alternative expansion plans.[67]

The Medicaid expansion will have a tremendous impact on PLWHA's access to medical care. According to a recent study, Medicaid covers forty-two percent of PLWHA receiving regular medical care.[68] By expanding Medicaid eligibility, PPACA ensures that more PLWHA will gain access to this vital public program.[69] Currently, PLWHA are not eligible for Medicaid in many states until they qualify as disabled pursuant to the program's non-income based requirements.[70] This presents a cruel catch-22, in which PLWHA must often wait until they are too disabled to work to qualify for the program they need to pay for medication that will prevent HIV-related disability.[71] Even in states with more inclusive standards, strict income guidelines forced many PLWHA to turn down opportunities for income in response to the fear that they will become ineligible for Medicaid

62. Id.

63. Id. at 2604.

64. Id. at 2607.

65. Nat'l Assn. of States United for Aging & Disabilities, State Medicaid Expansion Tracker (Nov. 1, 2013), http://www.nasuad.org/sites/default/files/State%20Medicaid%20Expansion%20Tracker%20November%201.pdf. Alabama, Florida, Georgia, Idaho, Kansas, Louisiana, Maine, Mississippi, Missouri, Montana, Nebraska, North Carolina, Oklahoma, South Carolina, South Dakota, Texas, Utah, and Wisconsin have all indicated that they will not implement the expansion. Id.

66. Id. Alaska, Virginia and Wyoming have indicated that they are unlikely to expand. Id.

67. Id. Arkansas, Indiana, Iowa, Pennsylvania, and Tennessee are all seeking some alternative to the expansion. Id. Arkansas is the only state that has an approved alternative plan. Id. at 3. Arkansas's plan creates a "private option" whereby Arkansas will use the federal funds Congress intended to be used for Medicaid to purchase private plans for low income residents instead. Id.

68. See Crowley & Kates, supra note 4, at 2.

69. See id. at 6.

70. Kaiser Family Found., How the ACA Changes Pathways to Insurance Coverage for People with HIV 3 (July 2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/07/8462-helping-people-with-hiv-navigate-the-transition.pdf (noting that "[p]rior to the ACA, federal law categorically excluded non-disabled adults without dependent children from Medicaid, unless a state obtained a waiver or used state-only dollars to cover them").

71. Id.

coverage.[72] In states that refuse to expand Medicaid eligibility this painful dynamic will likely continue.

Despite its substantial benefits for PLWHA and others who rely disproportionately on Medicaid, many states have pointed to the expansion's alleged financial costs as a justification for refusing to implement it.[73] Politicians from these states argue that expanding the program, which they often describe as broken and inefficient, is simply too expensive.[74] However, states do not have to pay for the expansion at all until 2016, at which point the federal government will continue to pay for ninety percent of the program's costs.[75] Moreover, even if that ten percent was too financially burdensome, a state could easily participate in the program until 2016 and then withdraw.[76] These states are having a devastating impact on the poor and uninsured by refusing to implement the expansion.[77] Their decisions will result in approximately eight million more uninsured people, all of whom the expansion would have covered.[78] In Mississippi, where the Medicaid ceiling will be only $5,669 a year beginning in January 2014,[79] thirteen percent of the population is poor and uninsured.[80] These people will not be eligible for Medicaid because the State refuses to implement the expansion.[81]

---

72. See Jessica Camille Aguirre, Cost of Treatment Still a Challenge For HIV Patients in the U.S., NPR (July 27, 2012), http://www.npr.org/blogs/health/2012/07/27/157499134/cost-of-treatment-still-a-challenge-for-hiv-patients-in-u-s (telling the story of Ruben Bermudez, who has been forced to watch his income closely in order to ensure that it does not climb above Medicaid eligibility levels).

73. Sabrina Tavernise & Robert Gebeloff, Millions of Poor are Left Uncovered by Health Law, N.Y. TIMES, Oct. 3 2013, at A1 (quoting State Senator Chris McDaniel, a Republican who opposes the expansion, as stating "[a]ny additional cost in Medicaid is going to be too much").

74. Id.

75. 42 U.S.C.A. § 1396d (West, WestlawNext through P.L. 112-283).

76. See Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 S. Ct. 2566, 2608 (2012) (concluding that the federal government does not have the authority to threaten states with the rescission of all Medicaid funding if they do not implement PPACA's Medicaid expansion).

77. See, e.g., Tavernise & Gebeloff, supra note 73 (describing both the vast number of the uninsured who will not qualify for Medicaid because of many states' refusal to expand eligibility and telling the stories of specific people adversely effected).

78. Id.

79. Kaiser Family Found., Medicaid Eligibility for Adults as of January 1, 2014 3 (Oct. 1, 2013), http://kff.org/medicaid/fact-sheet/medicaid-eligibility-for-adults-as-of-january-1-2014/

80. Tavernise & Gebeloff, supra note 73. In the words of Willie Charles Carter, an unemployed, fifty-three-year-old resident of Mississippi, "[y]ou got to be almost dead before you can get Medicaid in Mississippi." Id.

81. Id.

2. The Ryan White Program

Congress created the Ryan White Program in 1990 with the goal of supporting health care programs for people with HIV/AIDS.[82] Congress designed the program as a "payer of last resort," meaning that it only provides coverage for those who have no other source of coverage or face coverage limits.[83] Nevertheless, the Ryan White Program is the single largest HIV-specific, grant program in the U.S., and the third largest source of public funding for HIV care after Medicaid and Medicare.[84] Congress reauthorized the program four times with a sunset provision, automatically ending the program unless Congress reauthorized it by a certain date.[85] The most recent renewal deadline passed on September 30, 2013, without any action from Congress.[86] Nevertheless, as long as Congress has appropriated funds to the Ryan White Program it will continue to function, for now.[87]

Congress has probably not reauthorized Ryan White because once PPACA is fully implemented, many people who once received funding for care through Ryan White will begin to get it from other sources, including Medicaid, the Pre-Existing Condition Insurance Plan (PCIP), and the state insurance exchanges.[88] Consequently, some commentators have questioned whether the program should be funded at previous levels, or is even necessary at all.[89] The fact that PPACA will result in more insured PLWHA, however, does not obviate the need for this vital supplemental

82. Am. Acad. HIV Med., Ryan White, http://www.aahivm.org/ryanwhite (last visited Nov. 21, 2013).

83. Id.

84. See Jeffrey S. Crowley & Jen Kates, Kaiser Family Found., Updating the Ryan White HIV/Aids Program for a New Era: Key Issues and Questions for the Future 1, 4 (Apr. 2013), http://kaiserfamilyfoundation.files.wordpress.com/2013/04/8431.pdf.

85. Id. at 1.

86. Jennifer Kates, Implications of the Affordable Care Act for People with HIV Infection and the Ryan White HIV/AIDS Program: What Does the Future Hold?, 21 TOPICS IN ANTIVIRAL MED. 141 (2013), available at https://www.iasusa.org/sites/default/files/tam/21-4-138.pdf. Advocates for the HIV/AIDS community have been divided over whether to seek reauthorization before PPACA is fully implemented on January 1, 2013. Nat'l Alliance of State & Territorial AIDS Dirs., Update: Ryan White Program Current Status (Sept. 23, 2013), http://blog.nastad.org/2013/09/update-ryan-white-program-current-status/ (noting that while their organization has advocated for delaying reauthorization, other members of the HIV/AIDS community supported reauthorization in 2013). Some advocates have supported seeking reauthorization after January 1st because of the uncertainties surrounding how PPACA will affect the Ryan White Program. Crowley & Kates, supra note 4.

87. Crowley & Kates, supra note 4.

88. Id. at 6.

89. Id.

program.[90] According to a recent report published by the Kaiser Family Foundation, seventy percent of people who use Ryan White already have some form of insurance.[91] These people rely on Ryan White to supplement costs associated with limits on their coverage or help with co-pays.[92] Such people still require supplemental funding for care because the substantial cost sharing imposed by many plans can make HIV treatment unaffordable.[93]

B. Private Health Plans

In the private arena, PPACA creates a number of consumer protections that will prevent insurance providers in the individual and small group markets from excluding PLWHA. Since January 1, 2014, PPACA has prohibited insurance providers from (1) denying anyone coverage based on pre-existing conditions[94] and (2) imposing lifetime and annual limits.[95] For individual and group plans issued after March 23, 2010, or renewed on or after September 23, 2010, the law also prohibits providers from denying children under the age of 19 coverage because of a pre-existing condition.[96] Plans that started between September 23, 2010 and September 22, 2011, could not have annual limits of less than $750,000.[97] The restricted limit then increased to $1.25 million for plans that started on or after September 23, 2011, and then to $2 million for plans that started between September 23, 2012 and January 1, 2014.[98] These provisions prohibit insurance providers from using two of their most common tools to deny PLWHA comprehensive health insurance coverage.[99]

1. Pre-existing Conditions

Perhaps the most common way in which the health insurance industry has denied insurance to PLWHA is through its practice of denying health

90. Id.
91. Id.
92. Id.
93. Id.
94. 42 U.S.C.A. § 300gg-3 (West, WestlawNext through P.L. 112-283).
95. 42 U.S.C.A. § 300gg-11.
96. Dep't Health & Human Servs., Children's Pre-Existing Conditions, http://www.hhs.gov/healthcare/rights/pre-existing/childrens-pre-existing-conditions.html (last visited Jan. 13, 2014).
97. Ctrs. for Medicare & Medicaid Servs., Annual Limits, http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Market-Reforms/Annual-Limits.html (last visited Nov. 21, 2013).
98. Id.
99. See infra Parts III.A.1-2.

coverage based on pre-existing conditions.[100] PPACA stops this practice by prohibiting insurers from rejecting people based on pre-existing conditions.[101] Previously, insurance providers could deny people coverage based solely on a preexisting condition from the moment they were born.[102] In order to ensure that these plans are affordable, PPACA also prohibits insurance companies from charging higher premiums based on preexisting conditions.[103]

To ensure that people with pre-existing conditions were not left without insurance until 2014, Congress also created the Pre-Existing Conditions Insurance Plan (PCIP).[104] The PCIP program provides health insurance to U.S. citizens and legal permanent residents as long as insurance providers have denied their application for health insurance because of a pre-existing condition and they have been uninsured for at least six months.[105] This program coveres basic health benefits for people with preexisting conditions, including primary and specialty care, hospital care, and prescription drugs.[106] As of June 30, 2013, 104,966 people had enrolled in it.[107] While information on how many PLWHA are enrolled in the PCIP program is not available, the AIDS Drug Assistance Program (ADAP)—a jointly administered federal-state program that provides HIV-related prescription drugs to low-income people with HIV/AIDS—had enrolled 4,693 clients as of December 2012.[108] Although Congress planned to end

100. See Ctrs. for Medicare & Medicaid Servs., The Affordable Care Act and HIV/AIDS, http://aids.gov/federal-resources/policies/health-care-reform/ (last visited Nov. 21, 2013).

101. Id.

102. 42 U.S.C.A. § 18001 (West, WestlawNext through P.L. 113-36); Lauren Cox & Lara Salahi, Newborn Denied Health Insurance Coverage Days After Life-Saving Heart Surgery, ABC NEWS (Mar. 27, 2010), http://abcnews.go.com/Health/HeartFailureNews/newborns-family-learns-pre-existing-conditions-apply-birth/story?id=10218514.

103. See § 18001. PPACA also contains provisions more generally aimed at affordability, such as the rule that all small group, large group, and individual health insurance providers must meet the Medical Loss Ratio. Dep't Health & Human Servs., How Does the Health Care Law Protect Me?, https://www.healthcare.gov/how-does-the-health-care-law-protect-me/#part=10 (last visited Oct. 14, 2013). This rule mandates that all insurance providers spend at least eighty percent of their premiums on direct medical care or quality improvement. Id.

104. See § 18001.

105. Id. § 18001(d).

106. Dep't Health & Human Servs., Pre-Existing Condition Insurance Plan: Costs and Benefits, https://www.pcip.gov/Costs_Benefits.html (last visited Nov. 4, 2013).

107. Ctrs. for Medicare & Medicaid Servs., State by State Enrollment in the Pre-Existing Condition Insurance Plan, https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/pcip-enrollment.html (last visited Oct. 14, 2013) (stating that the program had 107,139 enrollees by January 31, 2013).

108. Kaiser Family Found., AIDS Drug Assistance Program (ADAP) Coordination with Pre-Existing Condition Insurance Plans (PCIP), December 2012, http://www.statehealth

the program in 2014 HHS has allowed enrollees to participate in the program through the end of January to facilitate their transition into the private market.[109]

2. Annual and Lifetime Limits

Another method insurance providers commonly used before Congress passed PPACA to deny claims from PLWHA was the instituting of annual and lifetime spending limits.[110] These policies limited the amount that insurance providers would spend on an insured's covered benefits by a specific amount over a predetermined period.[111] If a person exceeded his or her spending limit, he or she had to pay all healthcare costs in excess of that amount.[112] For PLWHA, annual limits often made vital medication unaffordable because the cost of their medical treatment typically far exceeded their plan's limit.[113] PLWHA would then face the prospect of paying for medical treatment they could not possibly afford.[114] Since January 1, 2014, PPACA has prohibited these practices entirely.[115] By prohibiting this practice, PPACA eliminates one of the industry's most common means of limiting benefits of the insured.

C. Essential Health Benefits

Both public and private plans also have to offer the insured Essential

---

facts.org/comparereport.jsp?rep=94&cat=17 (last visited Oct.12, 2013).

109. Dep't Health & Human Servs., About PCIP, https://www.pcip.gov/About_PCIP.html (last visited Jan. 13, 2014).

110. Crowley & Kates, supra note 4, at 6.

111. Annual Limits, supra note 97.

112. See Dep't Health & Human Servs., Centers for Medicare and Medicaid Services, http://aids.gov/federal-resources/federal-agencies/hhs/centers-for-medicare-and-medicaid-services/ (last visited Nov. 16, 2013).

113. See Christy Feig, Study Explores High Cost of HIV Care in U.S., CNN HEALTH (July 10, 2002), available at https://bslenvironmental.wikispaces.com/file/view/Study%20explores%20high%20cost%20of...pdf/217601312/Study%20explores%20high%20cost%20of...pdf.

114. See Centers for Medicare and Medicaid Services, supra note 112.

115. 42 U.S.C. § 300gg-11 (West, WestlawNext through P.L. 112-283); note that despite this prohibition on annual limits, HHS has issued 1300 waivers to this rule that is estimated to allow more than three million people to be subject to annual limits on healthcare spending. Matthew Sturdevant, Health Insurance Waivers Allow Spending Limits on Care for 3 Million People, HARTFORD COURANT (June 16, 2011), http://articles.courant.com/2011-06-16/business/hc-waiver-annual-limits-20110616_1_spending-limits-health-plans-insurance-oversight. This is notable for a number of reasons, including the fact that it highlights the possibility that even clear mandates and prohibitions can be avoided through waivers. See id.

Health Benefits (EHBs) as defined by PPACA.[116] This provision mandates that insurance providers offer "comprehensive coverage" to avoid harmful, and common, gaps in care.[117] PPACA defines EHBs as the following: (1) ambulatory patient services; (2) emergency services; (3) hospitalization; (4) maternity and newborn care; (5) mental health and substance abuse disorders, including behavioral health treatment; (6) prescription drugs; (7) rehabilitative and habilitative services and devices; (8) laboratory services; (9) preventative and wellness services and chronic disease management; and (10) pediatric services, including oral and vision care.[118] All ten EHBs must be included in the benefits that health plans offer.[119] The scope of these benefits is supposed to equal the scope of benefits provided by the typical employer health plan.[120] Although PPACA allocates the responsibility of defining the typical employer health plan to the Secretary of HHS, HHS has since decided that it will give states a choice of four "benchmark plans."[121] These benchmark plans will act as minimum coverage mandates, effectively defining EHBs for the state.[122]

IV. PROBLEMS AHEAD IN IMPLEMENTATION

While PPACA contains substantial potential to expand access to insurance for PLWHA, it also fails to address certain longstanding access issues, while simultaneously creating new ones.[123] PPACA must be implemented with an eye to the challenges PLWHA face if it is going to achieve a reduction in the incidence of HIV, an increase in access to care and an optimization of health outcomes for PLWHA, and a reduction in HIV-related health disparities.[124] PPACA implements numerous incentives

116. § 18022(b)(1).

117. Kathleen Sebelius, Sebelius: In Defense of Health Care Law's 'Essentials', USA TODAY (Jan. 3, 2012), http://usatoday30.usatoday.com/news/opinion/forum/story/2012-01-03/sebelius-hhs-health-care-benefits/52358618/1.

118. 42 U.S.C.A. § 18022(b)(1) (West, WestlawNext through P.L. 111-48).

119. See § 18021(a)(1)(B).

120. § 18022(b)(2)(A).

121. See CTR. FOR CONSUMER INFO. & INS. OVERSIGHT, ESSENTIAL HEALTH BENEFITS BULLETIN 8–10 (2011), available at http://www.cms.gov/CCIIO/Resources/Files/Downloads/essential_health_benefits_bulletin.pdf.

122. See id. at 9-10.

123. See infra Part IV.

124. See Crowley & Kates, supra note 4, at 10 (noting that the ACA contains a number of ambiguities that have special implications for the specialized treatment that PLWHA require); Christine Vestal, How the ACA Will Affect People with HIV and AIDS, USA TODAY (Oct. 29, 2013), http://www.usatoday.com/story/news/nation/2013/10/28/how-the-aca-will-affect-people-with-hiv-and-aids/3285897/ (noting that it is unclear whether states will interpret the ACA's essential health benefits requirements to cover currently existing gaps in

and restrictions for insurance providers when it comes to insuring groups that providers consider "high cost."[125] However, PPACA fails to address a variety of longstanding medical care access problems in both the private[126] and public market.[127] In the private market, PPACA creates substantial ambiguity regarding what benefits insurers must cover.[128] PPACA also does nothing to address the damaging effects of commonplace drug formularies.[129] In the public market, PPACA does nothing to rectify the dispute over Medicaid reimbursement rates, and the resulting Medicaid access crisis that has affected the neediest in our society.[130] National Federation has also called the Medicaid Expansion into question, while creating coverage gaps in non-participating states.[131] Finally, PPACA contains little in the way of accountability measures, which the country's experience in the Medicaid context has shown are indispensable.[132]

A. Essential Health Benefits and Benchmark Plans

Assuming that someone has health insurance, PPACA leaves the question of what this coverage will ultimately look like largely unanswered.[133] Because Congress has ceded substantial authority in defining EHBs to the states,[134] the states now have the opportunity to decide what medical procedures insurance providers are required to cover.[135] Unfortunately, the chances that states will uniformly institute strict regulation of private plans, without substantial pressure by HIV advocates, are slim.[136] Federal regulation has also failed to consider the health care

---

transportation, case management, and dentistry for PLWHA).

125. See supra Part III.

126. See infra Part IV.A.

127. See infra Part IV.B.

128. See infra Part IV.A.

129. See infra Part IV.A.2.

130. See infra Part IV.A.

131. See infra Part IV.A.

132. See infra Part IV.C.

133. Stacey A. Tovino, A Proposal for Comprehensive and Specific Mental Health and Substance Use Disorder Benefits, 38 AM. J.L. & MED. 471, 515 (2012) (noting that a staff member of the Senate Health, Education, Labor, and Pensions Committee described the categories as "buckets of care" and explained that they were intentionally left vague); see also supra Part III.C.

134. See supra Part III.C.

135. Abigail R. Moncrieff & Eric Lee, The Positive Case for Centralization in Health Care Regulation: The Federalism Failures of the ACA, 20 KAN. J. L. PUB. POL'Y 266, 267 (2011); Tovino, supra note 133, at 515.

136. See U.S. GEN. ACCOUNTABILITY OFF., HEALTH INSURANCE REGULATION: VARIATION IN RECENT STATE SMALL EMPLOYER HEALTH INSURANCE REFORMS 4 (1995),

needs of PLWHA at some stages of the implementation. Recently, HHS requested that the Institute of Medicine issue a report on the question of what should qualify as essential in a health insurance plan.[137] This report nowhere addresses the health care needs of PLWHA.[138] Such omissions are especially troubling in light of the fact that the administration itself has recognized the country's need for a strong, concerted effort to improve HIV care.[139] Without explicit requirements on private insurers, they will continue to offer inadequate coverage through (1) wrongful denials of claims,[140] (2) costly specialty drug tiers,[141] and (3) the categorization of treatment as experimental or medically unnecessary.[142]

1. History of Wrongful Denials

Employers and the private insurance industry have a long history of cost avoidance through wrongful denials of claims.[143] For PLWHA, denials often take the form of complete recessions from a provider's plan once the insured is diagnosed.[144] For example, in Mitchell, Jr. v. Fortis Ins. Co., the Supreme Court of South Carolina confronted the case of an insurance provider that sought out and removed an HIV positive insured from its

available at http://www.gao.gov/assets/90/89926.pdf (noting substantial variation in the regulation of small group plans, including provisions affecting pre-existing conditions, guaranteed issue, and premium rate restrictions).

137. See INST. OF MED., ESSENTIAL HEALTH BENEFITS: BALANCING COVERAGE AND COST ix (2012).

138. See id. HHS's new proposed rule defining EHBs for newly eligible Medicaid beneficiaries raises serious concerns as well. See Amy Killelea et al., Nat'l Alliance of State & Territorial AIDS Dirs, Update: New Medicaid Essential Health Benefits Proposed Rule and What it Means for People Living with HIV and Hepatitis (Feb. 11, 2013), http://blog.nastad.org/2013/02/update-new-medicaid-essential-health-benefits-proposed-rule-and-what-it-means-for-people-living-with-hiv-and-hepatitis/. The proposed rule both increases the amount that states may charge for "non-emergency use" of emergency rooms to $8, and increases the amount of cost sharing states may charge to people with income below 150% of the federal poverty level. Id.

139. See supra Part II.B.

140. See infra Part IV.A.1.

141. See infra Part IV.A.2.

142. See infra Part IV.A.3.

143. See, e.g., Mitchell, Jr. v. Fortis Ins. Co., 686 S.E.2d 176, 190 (S.C. 2009); Mayeaux v. La. Health Serv. & Indem. Co., 376 F.3d 420, 423 (5th Cir. 2004); Sylvia A. Law, Do We Still Need a Federal Patients' Bill of Rights?, 3 YALE J. HEALTH POL'Y, L. & ETHICS 1, 2–3 (2003). Incidences in which people suffer as a result of delay caused by a medical service provider's need to check in with managed care organizations are also common. Id. at 10.

144. See Murray Waas, Insurer Targeted HIV Patients to Drop Coverage (Mar. 17, 2010), http://www.reuters.com/article/2010/03/17/us-insurers-idUSTRE62G2DO20100317 (discussing the insurance provider practice of rescission and how it can be utilized to wrongfully deny coverage).

plan.[145] The court held that in doing so, the provider rescinded his insurance in bad faith, and awarded the insured $10,150,000 in punitive and compensatory damages.[146]

Even if a provider does not completely rescind an insured's coverage once they are diagnosed, it may deny needed medical treatment.[147] For example, denials of important medical procedures for the HIV/AIDS community were so pronounced that in 2005 California enacted a statute that required health insurance providers to stop claiming that transplants for those with HIV/AIDS were not medically necessary.[148] Assembly member Paul Koretz, the bill's author, noted that insurance providers regularly deemed liver transplants for hepatitis C infected patients as medically necessary, but regularly denied claims by people who were HIV/AIDS positive.[149] These claims were denied despite the fact that they often resulted in successful outcomes and increased life expectancy.[150]

2. Specialty Drug Tiers

Another way in which insurance providers shift the burden of high cost medication onto insured is through drug formularies.[151] In essence, formularies create a tiered system in which providers agree to cover first tier drugs at the lowest level of cost sharing, second tier drugs at a higher level of cost sharing, and so on.[152] Recently, providers have begun to use formularies to limit the benefits payable to the insured for specialty medications by placing them on higher tiers—such as four or five.[153]

145. Mitchell, Jr., 686 S.E.2d at 176.

146. Id. at 190.

147. See, e.g., Governor Signs Bill Barring Denial of Transplant Coverage to Patients with HIV, 17 CAL. INS. L. & REG. REP., no. 8, 2005, at 268 (reporting that the Governor of California had signed into law a measure prohibiting health insurers from denying coverage for the costs of organ or tissue transplantation services on the basis that the insured is infected with the human immunodeficiency virus (HIV)).

148. CAL. HEALTH & SAFETY CODE § 1374.17 (West, WestlawNext through Ch. 800 of 2013 Reg.Sess., all 2013-2014 1st Ex.Sess. laws, and Res. Ch. 123).

149. CAL. STATE ASSEMBLY, CONCURRENCE IN SENATE AMENDMENTS A.B. 228, at 2 (2005), available at http://www.leginfo.ca.gov/pub/05-06/bill/asm/ab_0201-0250/ab_228_cfa_20050824_165808_asm_floor.html.

150. Id.

151. See Joseph J. Hylak-Reinholtz & Jay R. Naftzger, Is It Time to Shed A "Tier" for Four-Tier Prescription Drug Formularies? Specialty Drug Tiers May Violate HIPAA's Anti-Discrimination Provisions and Statutory Goals, 32 N. ILL. U. L. REV. 33, 34–35 (2011) (noting that drug formularies enable insurance providers to shift substantial costs onto the insured by limiting the benefits that they will pay for high cost medications).

152. See Gina Kolata, Co-Payments Go Way Up for Drugs With High Prices, N.Y. TIMES, Apr. 14, 2008, at A1 (explaining how insurance providers utilize specialty drug tiers).

153. Id.

Insurance providers may require the insured to pay between twenty-five percent and one-third of the cost of a medication on tier four or five.[154] Medications that insurance providers label as tier four or five are commonly used by people with chronic health conditions.[155] In 2011 for example, Anthem Blue Cross created a fourth drug tier that charged higher co-pays than any of the three lower tiers that included complex conditions like HIV/AIDS and cancer.[156] This has resulted in an explosion in the cost of such life-saving medication for people with chronic conditions, who are forced to pay.[157] And while PPACA imposes some limits on cost sharing, providers will still be allowed to charge co-pays of up to $6000 for an individual and $12,000 for a family.[158]

Recognizing the financial burden imposed upon the insured by these formularies, state actors have begun acting to protect both the HIV community and others with chronic conditions.[159] For example, Congressional Representatives Bob McKinley and Lois Capps recently introduced a bill entitled the Patients Access to Treatment Act 2013.[160] This bill limits cost sharing by requiring medications covered under specialty drug tiers to be covered at the equivalent dollar amount of medications in non-specialty drug tiers.[161]

---

154. See id. (telling the stories of insured whose medical service providers required them to pay twenty-five percent and one-third of the cost of their medications).

155. See id. (reporting how the advent of specialty drug tiers have made many medications prohibitively costly for people with complex medical conditions like cancer, multiple sclerosis, and others).

156. ANTHEM BLUE CROSS, COMING SOON: A NEW TIERED DRUG LIST FOR YOUR GROUPS (Nov. 2011), available at https://www.anthem.com/ca/health-insurance/nsecurepdf/pharmacy_ABC_Tier_4%20_DL_Local.

157. See Kolata, supra note 152 (explaining that some patients with chronic conditions could possibly end up paying more than their monthly income).

158. See Randi Hernandez, Specialty Drug Tier Restrictions Proposed in New Legislation, SPECIALTY PHARMACY TIMES (Feb. 12, 2013), http://www.specialtypharmacytimes.com/news/Specialty-Drug-Tier-Restrictions-Proposed-in-New-Legislation (quoting Congressional Representative David McKinley on the Patients Access to Treatment Act 2013).

159. See Memorandum from Sen. Bob Mensch on A Study of Specialty Drug Prescription Drugs to all Senate members (Mar. 1, 2013), available at http://www.pasen.gov/cfdocs/Legis/CSM/showMemoPublic.cfm?chamber=S&SPick=20130&cosponId=11953 (introducing legislation to direct a senate committee to conduct a study of specialty tier prescription drugs to determine the impact on health care access and patient care); Seth Hemmelgarn, Ma Takes Aim at HIV Drug, Other Co-Pays, BAY AREA REP. (Feb. 16, 2011), available at http://ebar.com/blogs/ma-bill-takes-aim-at-hiv-drug-co-pays/ (introducing legislation aimed at stopping health insurers from dramatically increasing the cost of medications to California citizens living with HIV).

160. Hernandez, supra note 158.

161. See id.

3. Preventative and Experimental Treatments

Health insurance providers have also commonly excluded treatment they classify as experimental or not medically necessary.[162] Providers accomplish this by including clauses in their contracts with the insured excluding such treatments.[163] Treatments that providers consider to be experimental or unnecessary, however, are wide-ranging and often life-saving.[164] To make matters worse, courts have not been consistent in interpreting what services are experimental.[165] This is because whether a treatment is experimental largely depends upon the consensus of the medical community, a concept that courts have not defined with precision.[166]

Recently, clinical tests for a new HIV prevention method called Pre-Exposure Prophylaxis (PrEP) have been promising.[167] In a study of gay men, PrEP was found to decrease a person's chance of acquiring HIV by forty-four percent, if taken in conjunction with other preventative measures.[168] The results caused some researchers to observe that PrEP is an especially important preventative measure in communities with a high risk of contracting HIV, such as among gay and bisexual men.[169] However, Truvada, the PrEP drug, costs about $14,400 a year, making it unaffordable

162. See, e.g., Sarchett v. Blue Shield of Cal., 729 P.2d 267, 272 (1987) (describing the dispute between Sarchett and Blue Shield of California, which arose after Blue Shield denied Sarchett's claim for his hospital stay based on lack of medical necessity); J. Gregory Lahr, What is the Method to Their "Madness?" Experimental Treatment Exclusions in Health Insurance Policies, 13 J. CONTEMP. HEALTH L. & POL'Y 613, 619 (1997); see also Catherine A. Voigt & Kevin J. Conlon, Insurance Coverage for Experimental Treatment: New Hope for Patients, 83 ILL. B. J. 396, 396 (1995) (describing the case of Tishna Rollo, whose Wilms' tumor treatment was denied despite the fact that it was her only chance for survival).

163. See Sarchett, 729 P.2d at 272; Lahr, supra note 162, at 624 (describing the judiciary's role in contract disputes between providers and the insured over what procedures qualify as "experimental").

164. See Voigt & Conlon, supra note 162, at 396.

165. See Lahr, supra note 162, at 623-24.

166. See, e.g., Wilson v. Office of Civilian Health & Med. Programs of the Uniformed Servs., 65 F.3d 361, 364, 366 (4th Cir. 1995) (noting that clinical trials are relevant but not dispositive and relying instead on the testimony of an expert witness and a paper published in a medical journal).

167. See Robert M. Grant et al., Preexposure Chemoprophylaxis for HIV Prevention in Men Who Have Sex with Men, 363 N. ENGL. J. MED. 2587, 2588 (2010).

168. Ctrs. for Disease Control & Prevention, PrEP: A New Tool for HIV Prevention 1 (2012), http://www.cdc.gov/hiv/prep/pdf/PREPfactsheet.pdf.

169. Id. at 2, 5, 7; see also Emily A. Arnold et al., A Qualitative Study on Provider Thoughts on Implementing Pre-Exposure Prophylaxis (PrEP) in Clinical Settings to Prevent HIV Infection, PLoS ONE (July 11, 2012), available at http://www.plosone.org/article/info:doi/10.1371/journal.pone.0040603#pone.0040603-Grant1.

without health insurance.[170] Unfortunately, the recent nature and high cost of this treatment create incentives for providers to deny coverage for PrEP.[171]

However, depending on how states interpret PPACA, it could mandate that such treatment be covered by providers with no cost sharing. Previously, insurance providers, both public and private, required the insured to pay deductibles and co-pays in order to access these services.[172] These costs discourage people from utilizing these preventative services that can catch illnesses at their early stages.[173] PPACA prioritizes preventive services by requiring that plans cover a wide range at no cost to the insured.[174] The services that plans must cover fit into four categories: (1) evidence-based screening and counseling; (2) routine immunizations; (3) childhood preventative services; and (4) preventative services for women.[175] PPACA includes screenings and counseling for high-risk populations and women with HIV/AIDS in its definition of preventive services.[176] Neither HHS nor the courts have clarified whether PrEP fits within any of PPACA's four categories of preventative care. However, as the treatment becomes more widespread and practitioners develop the infrastructure to effectively prescribe PrEP, state actors will likely be faced with the question of whether PrEP fits within PPACA's mandate on preventative care.

B. Challenges with Medicaid Expansion

PPACA and National Federation have also created new problems for Medicaid, while failing to address other longstanding ones. After the

170. See Sunny Bjerk, The Hidden Costs of PrEP, AIDS ISSUES UPDATE BLOG (Aug. 21, 2012), http://www.housingworks.org/advocate/detail/the-hidden-costs-of-prep/.

171. See Lahr, supra note 162, at 613 (noting that many have criticized the experimental/medically necessary paradigm as an excuse by providers to deny coverage for expensive treatments).

172. See Dep't Health & Human Servs., Affordable Care Act Rules on Expanding Access to Preventive Services for Women (Aug. 1, 2011), http://www.hhs.gov/healthcare/facts/factsheets/2011/08/womensprevention08012011a.html (noting that before Congress passed PPACA, Americans utilized preventive services at about half the recommended rate partially because of cost).

173. Jill Bernstein et al., Mathematica Pol'y Res. Inc., Encouraging Appropriate Use of Preventive Health Services 1, 2 (2010), http://www.mathematica-mpr.com/publications/PDFs/Health/reformhealthcare_IB2.pdf.

174. Kaiser Family Found., Preventative Services Covered by Private Health Plans under the Affordable Care Act (Sept. 2011), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8219.pdf.

175. Id.

176. Id. Table 1.

Supreme Court held in National Federation that Congress did not have the authority to completely rescind federal Medicaid funding for states that do not expand eligibility standards, the Medicaid expansion provision of PPACA became voluntary.[177] This will create substantial medical care access issues in states that choose not to expand eligibility standards.[178] Aside from the obvious fact that the stricter eligibility requirements will result in less people being covered under Medicaid in states that do not expand,[179] there is an additional problem with the newly optional expansion. Childless adults whose income falls below the FPL will fall into a gap in which they qualify for neither Medicaid nor federal subsidies to purchase private insurance.[180] PPACA also does not address longstanding disputes over Medicaid reimbursement rates between medical service providers and states, which has resulted in a debilitating shortage of participating physicians.[181] For PLWHA, who receive health care through Medicaid and other government programs at disproportionate rates, these access issues are especially important.[182]

1. The Medicaid Coverage Gap

The initial and most obvious effect of states opting out of the expansion will be that less people will qualify for health coverage. A second, unintended consequence is that childless adults with incomes below the FPL will be denied both Medicaid and federal subsidies to purchase private insurance.[183] Beginning in 2014, PPACA authorizes federal subsidies to purchase private insurance for those who earn between 100% and 400% of the FPL.[184] These subsidies will take the form of tax credits, which vary based on the applicant's income.[185] If every state expanded Medicaid eligibility as Congress intended, every American would fall within the

177. Nat'l Fed'n of Indep. Bus. v. Sebelius, 132 U.S. 2566, 2607 (2012).

178. See infra Part IV.B.1.

179. Kaiser Family Found., Faces of the Medicaid Expansion: How Obtaining Medicaid Coverage Impacts Low-Income Adults 1 (2013), http://kaiserfamilyfoundation.files.wordpress.com/2013/02/8404.pdf.

180. See infra Part IV.B.1.

181. See infra Part IV.B.2.

182. See Crowley & Kates, supra note 4, at 2.

183. See Cal. Healthline, Millions Could Enter Coverage Gap Without Medicaid Expansion (July 18, 2012), http://www.californiahealthline.org/articles/2012/7/18/millions-could-enter-coverage-gap-without-medicaid-expansion.aspx.

184. Kaiser Family Found., Explaining Healthcare Reform: Questions About Insurance Subsidies 1, 3 (July 2012), http://www.kff.org/healthreform/upload/7962-02.pdf.

185. Id. at 1.

income requirement for either (1) Medicaid or (2) federal subsidies.[186]

However, because states are free to opt out of the Medicaid expansion, childless adults who earn less than the FPL will not be eligible for either Medicaid or federal subsidies.[187] Some low-income parents and other adults who typically meet Medicaid's non-income-based requirements in states that limit Medicaid eligibility to people earning less than the FPL will fall into the same gap.[188] In these states, if a low-income parent earns less than the FPL but too much for Medicaid, that parent will also be ineligible for both Medicaid and subsidies.[189] Currently, thirty-three states have such Medicaid eligibility requirements, and seven limit Medicaid eligibility to people earning less than half of the FPL.[190] As of 2010, sixteen million people would have fallen into this gap.[191] This is a harmful side effect of the Court's ruling in National Federation that has thus far gone unaddressed.

2. The Medicaid Access Crisis

The Medicaid program itself contains significant access issues that PPACA does not address. Health care access for Medicaid enrollees is dependent on the availability of doctors willing to treat them.[192] And although the Social Security Act explicitly requires that states ensure that services are available to program participants,[193] more and more medical service providers are eliminating their Medicaid practice or lowering the number of participants they treat.[194] Physicians' lack of involvement in the program is a result of shrinking reimbursement rates from the states, many of which have turned to cutting the amount physicians have to be paid for treating Medicaid beneficiaries in the face of serious budgetary shortages.[195]

---

186. See Editorial, A Gap in Health Coverage, N.Y. TIMES, July 5, 2012, at A18.

187. Kaiser Family Found., How will the Medicaid Expansion for Adults Impact Eligibility and Coverage? 1 (2012), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8338.pdf.

188. Id.

189. Id.

190. Id.

191. Id.

192. See Brietta R. Clark, Medicaid Access, Rate Setting and Payment Suits: How the Obama Administration is Undermining its Own Health Reform Goals, 55 HOW. L.J. 771, 773 (2012); see also ANDREW B. BINDMAN ET AL., PHYSICIAN PARTICIPATION IN MEDI-CAL, 2008 2 (2010), available at http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/P/PDF%20PhysicianParticipationMediCal2008.pdf.

193. 42 U.S.C. §1396(a)(8) (West, WestlawNext through P.L. 111-48); see also Clark, supra note 192, at 794.

194. See BINDMAN ET AL., supra note 192, at 2.

195. See Clark, supra note 192, at 789.

These Medicaid reimbursement rate cuts resulted in a rash of lawsuits across the country, both by the insured lacking necessary medical services and medical service providers seeking reasonable reimbursement rates.[196] These lawsuits challenged such rates as a violation of the rights of program participants under the Social Security Act.[197] Eventually, courts foreclosed this legal theory, however, by concluding that the Social Security Act does not create a private cause of action.[198] In response, plaintiffs began suing under a different theory, alleging that the reimbursement rates themselves conflicted with and were pre-empted by the Social Security Act.[199]

This approach was taken by the plaintiffs in Douglas v. Independent Living Center of Southern California, Inc., where they argued that California's low reimbursement rates conflicted with the Social Security Act's requirement that "Medicaid 'care and services' [be] sufficiently available."[200] The plaintiffs argued that the state's low reimbursement rates conflicted with the Social Security Act's availability requirement because before adopting the rate cuts the state failed to study whether they would draw enough medical service providers into the program.[201] Even without a private right of action, the plaintiffs argued, the Social Security Act pre-empts California's rate cuts in the face of this conflict.[202] Although the Supreme Court granted certiorari to resolve the validity of this argument, the Court ultimately remanded the question to the Ninth Circuit, finding the case in a different procedural posture.[203] Similar lawsuits challenging Medicaid reimbursement rate cuts and cuts to services have been filed by medical service providers after Douglas as well.[204] The controversy is

196. See, e.g., Pashby v. Delia, 709 F.3d 307 (4th Cir. 2013); Indep. Living Ctr. of S. Cal., Inc. v. Maxwell-Jolly, 572 F.3d 644 (9th Cir. 2009), vacated and remanded sub nom., Douglas v. Indep. Living Ctr. of S. Cal., Inc., 132 S. Ct. 1204 (2012); United Hosp. Med. Ctr. v. State, 793 A.2d 1 (N.J. Sup. Ct. App. Div. 2002); see also Sara Rosenbaum, Medicaid Payment Rate Lawsuits: Evolving Court Views Mean Uncertain Future for Medi-Cal 1, 6, 13–14 (Oct. 2009), http://www.chcf.org/~/media/MEDIA%20LIBRARY%20Files/PDF/M/PDF%20MediCalProviderRateLitigation.pdf.

197. See, e.g., Clark v. Kizer, 758 F. Supp. 572 (E.D. Cal. 1990); aff'd in part, rev'd in part, Clark v. Coye, 967 F.2d 585 (9th Cir. 1992); see also Clark, supra note 191, at 800–01, 823–25.

198. Sanchez v. Johnson, 416 F.3d 1051 (9th Cir. 2005); see also Rosenbaum, supra note 196, at 1–2, 9.

199. See, e.g., Douglas v. Indep. Living Ctr. of S. Cal., Inc., 132 S. Ct. 1204, 1208 (2012) (explaining the plaintiffs' pre-emption claim based on the Social Security Act); see also Clark, supra note 191, at 823–25; Rosenbaum, supra note 196, at 1–2.

200. Douglas, 132 S. Ct. at 1208.

201. Id.

202. Id.

203. Id. at 1210.

204. See Cal. Ass'n of Rural Health Clinics v. Douglas, 10-17574, 2013 WL 5184355,

likely to continue, as federal budgetary shortages continue to put pressure on public services and reimbursement rates continue to be cut.[205]

C. Accountability and Enforcement

PPACA allocates substantial enforcement authority to the states, in part because the Public Health Service Act gives them primary enforcement authority over insurance issuers in the group and individual markets.[206] This enforcement authority includes such things as reviewing premium rate increases and establishing the health insurance exchanges.[207] As the Medicaid access crisis illustrates however, when the states exert substantial control over federal programs local budgetary concerns can encourage states to arbitrarily narrow the scope of these programs and limit the benefits available to applicants.[208] Moreover, while some states look ready to vigorously enforce many of PPACA's provisions,[209] other states have explicitly refused to do so.[210] The hostility of many states to PPACA along with the inevitable state budgetary issues potentially means a broader than expected enforcement role for federal agencies. In certain areas, like reviewing premium rate increases, state to state variation is already proving

---

at *2 (9th Cir. Sept. 17, 2013) (challenging California's elimination of Medicaid coverage for adult dental, podiatry, optometry and chiropractic services); Managed Pharmacy Care v. Sebelius, 716 F.3d 1235, 1240 (9th Cir. 2013) (challenging California's Medicaid reimbursement rate reductions); Pashby v. Delia, 709 F.3d 307, 313 (4th Cir. 2013) (challenging North Carolina's imposition of stricter eligibility requirements for in-home personal care services through Medicaid).

205. See Robert Pear, States Can Cut Back on Medicaid Payments, Administration Says, N.Y. TIMES Feb. 26, 2013, at A17.

206. Ctrs. for Medicare & Medicaid Servs., The Centers for Consumer Information and Consumer Oversight: Compliance, http://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Market-Reforms/compliance.html; see also Moncrieff & Lee, supra note 20, at 287 (noting that despite the fact that PPACA provides national standards implementation of those standards primarily takes place at the state level).

207. Id. at 289.

208. See, e.g., Pashby, 709 F.3d at 313 (holding that North Carolina had limited the availability of home personal care service in violation of the Social Security Act).

209. See Katie Keith et al., Implementing the Affordable Care Act: State Action on the 2014 Market Reforms 5 (Feb. 2013), http://www.commonwealthfund.org/~/media/Files/Publications/Issue%20Brief/2013/1662_Keith_implementing_ACA_state_action_2014_reform_brief_v2.pdf.

210. See, e.g., Oklahoma Insurance Commissioner Refuses to Enforce Affordable Care Act, INS. J. (Mar. 18, 2013), http://www.insurancejournal.com/news/southcentral/2013/03/18/285029.htm. House Republicans have engaged in similar efforts in order to slow the implementation of PPACA. See, e.g., Robert Pear, House Votes to Delay Two Requirements of the Health Care Overhaul, N.Y. TIMES, July 17, 2013, at A13. Their efforts seem to be succeeding. See Jackie Calmes & Robert Pear, Crucial Rule is Delayed a Year for Obama's Health Law, N.Y. TIMES, July 3, 2013, at A1.

to be a problem.[211]

State enforcement of PPACA presents a significant hurdle to successful implementation. According to the Center for Medicaid and Medicare Services (CMS) as of March 29, 2013, six states, Arizona, Alabama, Missouri, Oklahoma, Texas, and Wyoming, had either refused to enforce the law's market reforms, or did not have the authority to do so at all.[212] CMS will be tasked with enforcing PPACA in these states as well as any others that fail to "substantially enforce" the law's provisions.[213] A comprehensive study by the Commonwealth Fund, a private foundation committed to improving the U.S. health care system, found that as of February 2013, only one state (Connecticut) had passed legislation on all of PPACA's consumer protections, while ten states and the District of Columbia had passed legislation on at least one provision, and the remaining thirty-nine had passed no legislation at all.[214] The study also found that, at least twenty-two state regulatory agencies had potential limits on their authority to fully implement these protections.[215] The fact that so many states are hostile to PPACA's market reforms means that CMS will have a significant enforcement role as long as it finds that these states have failed to "substantially enforce" PPACA's provisions.[216] Although this standard is certainly met with regards to states that have explicitly told CMS that they will not enforce the law, it is not clear what CMS will have to find in order to conclude that a state has failed to substantially enforce in more ambiguous situations, for example in situations where state agencies simply do not take regulatory action despite authority to do so.[217]

Even if enforcement of PPACA is flawless, stakeholders—including medical service providers, government agencies, and the public—must know how the law affects PLWHA in order to hold state and federal

211. Moncrieff & Lee, supra note 20, at 288.

212. Am. Health Law. Ass'n, CMS Will Enforce ACA Insurance Market Reforms In Six States, HEALTH LAW. WKLY., April 5, 2013, http://www.healthlawyers.org/News/Health%20Lawyers%20Weekly/Pages/2013/April%202013/April%2005%202013/CMSWillEnforceACAInsuranceMarketReformsInSixStates.aspx.

213. Sarah Kliff, Will States Actually Enforce Obamacare?, WASH. POST WONKBLOG (Feb. 1, 2013), http://www.washingtonpost.com/blogs/wonkblog/wp/2013/02/01/will-states-actually-enforce-obamacare/.

214. Keith et al., supra note 209, at 1, 2.

215. Id. at 3.

216. See id. (noting that CMS will have to take on enforcement of PPACA in states that refuse to or do not have the statutory authority to); Katie Keith & Kevin W. Lucia, New Guidance: Federal Regulators Allow "Collaborative Arrangements" for ACA Enforcement, COMMONWEALTH FUND BLOG (Apr. 5, 2013), http://www.commonwealthfund.org/Blog/2013/Apr/Federal-Regulators-Allow-Collaborative-Arrangements.aspx.

217. Id.

agencies accountable. HHS has formulated a series of questions and common indicators meant to measure the law's effects on health outcomes for PLWHA called the Seven Core Indicators of Effectiveness.[218] These indicators determine, through a series of questions, whether patients are receiving regular medical care.[219] The indicators also ask for the number of people diagnosed with HIV who were homeless,[220] which has been shown to lead to disruptions in care and poorer health outcomes.[221]

While the approval of these Seven Core Indicators will assist agencies and medical service providers track the effectiveness of PPACA, HHS has not yet revealed whether it will require HHS funding grantees to provide information on these indicators.[222] Without such a requirement, HHS will have to rely on voluntary compliance of service providers. Unfortunately, the industry is not in the business of improving health outcomes for its insured for its own sake.[223] So to the extent that HHS does not require grantees to collect information on the common indicators of effectiveness the chances that the private market will widely utilize them are slim.

V. RECOMMENDATIONS

In order for PPACA's promise of comprehensive and affordable health care to reach PLWHA, HHS, Congress, and community health advocates should adopt the following four reforms. First, HHS should issue a regulation requiring that all funding grantees use the Seven Core Indicators

218. Andrew Forsyth & Vera Yakovchenko, Dep't Health & Human Servs., Secretary Sebelius Approves Indicators for Monitoring HHS-Funded HIV Services (Aug. 8, 2012), http://blog.aids.gov/2012/08/secretary-sebelius-approves-indicators-for-monitoring-hhs-funded-hiv-services.html?utm_source=feedburner&utm_medium=feed&utm_campaign=Feed%3A+aids%2Fgov+%28Blog.AIDS.gov%29. These indicators include the following: (1) the number of HIV positive test results in the last twelve month period; (2) the number of persons diagnosed with stage 3 HIV infection (AIDS); (3) the number of people linked to HIV care; (4) the number of people retained in HIV care; (5) the number of people prescribed ART; (6) the number of people virally suppressed; and (7) and the number of people with an HIV diagnoses who were homeless. See id.

219. Id.

220. Id.

221. Richard J. Wolitski et al., HIV, Homelessness, and Public Health: Critical Issues and a Call for Increased Action, 11 AIDS BEHAVIOR S167–68 (2007), available at http://aidschicago.org/pdf/2008/housing_plan_HIV.pdf.

222. See Dep't Health & Human Servs., Article in Public Health Reports Discusses New Standard HIV Core Indicators Being Deployed Across HHS (Aug. 30, 2013), http://blog.aids.gov/2013/08/article-in-public-health-reports-discusses-new-standard-hiv-core-indicators-being-deployed-across-hhs.html (describing the development of the Seven Core Indicators as a part of a comprehensive plan to standardize data collection without specifying whether HHS funding grantee will be required to collect such data).

223. See supra Part IV.A.

of Effectiveness to gather hard data on HIV care nationwide.[224] Second, HIV/AIDS health advocates and medical experts should encourage state legislators to adopt the Medicaid expansion as soon as possible.[225] Third, HHS must issue a more explicit mandate upon both private and public plans that requires them to cover vital medical treatment for PLWHA.[226] Finally, Congress must continue to fully fund the Ryan White Program in order to meet the health care needs of PLWHA in need of supplemental coverage.[227]

A. The D*epartment of Health and Human Services'* Seven Core Indicators of Effectiveness

HHS must gather concrete information from medical service providers on who is receiving regular medical care and how they are receiving it if it is going to determine why so many PLWHA are not receiving regular medical care.[228] The Seven Core Indicators of Effectiveness request information including the number of patients diagnosed with stage 3 AIDS, the number of PLWHA prescribed Anti-Retroviral Treatment (ART), the number of PLWHA receiving regular medical care, and the number of people diagnosed with HIV who are homeless.[229] This information will tell HHS whether PLWHA do not receive regular medical care because, for example, they stop seeking care after they receive their initial dose of medication or whether they stop seeking care before they are even prescribed ART.[230] The indicators will also give HHS an indication of to what extent other factors, such as homelessness, affect a person's ability to remain in regular medical care.[231]

To assist agencies and medical service providers trying to collect this hard data, HHS should mandate that all HHS funded agencies use its Seven Core Indicators of Effectiveness. If HHS mandates that all funding grantees use its factors, information will be pulled from as many sources as possible, including common sources of health insurance for PLWHA such as Medicaid.[232] Once grantees have gathered this information, HHS will be better able to determine what steps should be taken to improve adherence to

224. See infra Part V.A.
225. See infra Part V.B.
226. See infra Part V.C.
227. See infra Part V.D.
228. See Crowley & Kates, supra note 4, at 11.
229. Forsyth & Yakovchenko, supra note 218.
230. Id.
231. Id.
232. See Crowley & Kates, supra note 4, at 11.

regular medical care.[233]

B. Support for Medicaid Expansion

HIV service providers, insurers, medical experts, and advocates should actively advocate for the adoption of the Medicaid expansion in their state.[234] This includes engaging all members in the medical field, including the states' Medicaid directors, to ensure that the state legislature and executive branch are aware of the advantages of the expansion.[235] Organizations such as Community Catalyst, a non-profit that seeks to organize local consumer organizations, policymakers, and foundations in support of comprehensive health care access, have compiled strategies and extensive resources for state advocates supporting the expansion.[236] Additionally, advocates of expansion should also consider reaching out to non-traditional stakeholders for additional support, such as the business community.[237] Support from pro-business organizations who are trusted by legislators has proven critical in some conservative states, where business interests are traditionally paramount.[238]

C. The Case for More Explicit Requirements

Congress intended PPACA to both expand health insurance coverage and ensure access to a basic level of care.[239] However, what these two components entail remains unclear because HHS ceded the power to define what benefits are essential to the states.[240] To ensure that PLWHA receive the medical care they need, HHS should require insurance providers to

233. See id.

234. See Amy Killelea, Nat'l Alliance of State & Territorial AIDS Dirs., Making Health Reform Work for People Living with HIV/AIDS (Oct. 10, 2012), http://blog.nastad.org/2012/10/making-health-reform-work-for-people-living-with-hivaids/.

235. See Cmty. Catalyst, Medicaid Expansion Campaign Planning Guide 2 (Feb. 2013), http://www.communitycatalyst.org/doc_store/publications/medicaid-expansion-campaign-planning-guide.pdf.

236. See, e.g., id. at 1-5; Jina Dhillon & Deborah Reid, 10 Reasons Why the Medicaid Expansion Benefits Women Living with HIV (Aug. 21, 2012), http://www.healthlaw.org/images/stories/2012_08_21_Reasons_Medicaid_Benefits_Women_HIV.pdf; Nat'l Health Law Program, State Resources, http://www.healthlaw.org/index.php?view=article&catid=51%3Ahealth-reform&id=701%3Astate-advocacy-resources&format=pdf&option=com_content&Itemid=176 (last visited Oct. 11, 2013).

237. Rich Daly, Rounding Up Support: Medicaid Expansion Advocates Look to Business (Jan. 28, 2013), http://www.modernhealthcare.com/article/20130126/MAGAZINE/301269970.

238. Id.

239. See supra Part II.

240. See supra Part IV.A.

cover a broader range of HIV care. This includes the use of PrEP as a preventative tool in certain high-risk communities.[241] HHS has already issued similar requirements for preventative services for women[242] after concluding that such services required more stringent regulation in order to prevent coverage gaps.[243] PLWHA also face unique health challenges that have resulted in a systemic lack of health care access.[244] They require regular visits to doctors, costly medications, and screening for HIV-related illnesses.[245] Moreover, the need for additional federal guidelines for HIV care is even stronger, because the time that a person with HIV/AIDS spends without regular medical treatment is especially damaging.[246] If HHS issues guidelines to require health insurers to cover these services, PLWHA would be assured of comprehensive medical care instead of having to contend with the uncertainty of state-to-state variation.[247]

D. The Essential Gap-Filler: The Ryan White Program

Congress must also continue to fully fund the Ryan White Program in order to meet the health care needs of PLWHA who are in need of supplemental coverage.[248] Many expect that PLWHA will transition into new forms of health insurance (whether public or private) once PPACA is fully implemented.[249] However, this does not make the Ryan White

241. See supra Part IV.A.iii.

242. 42 U.S.C.A. § 300gg-13(a)(4) (West, WestlawNext through P.L. 113-36) ("[W]ith respect to women, such additional preventive care and screenings not described in paragraph (1) as provided for in comprehensive guidelines supported by the Health Resources and Services Administration for purposes of this paragraph."); Dep't Health & Human Servs., Women's Preventative Services Guidelines: Affordable Care Act Expands Prevention Coverage for Women's Health and Well-Being, http://www.hrsa.gov/womensguidelines/ (last visited Oct. 15, 2013). The services that plans are required to cover include: (1) annual "Well-woman visits," which includes preconception and prenatal care, (2) screening for gestational diabetes, (3) human papillomavirus testing ("HPV"), (4) counseling for sexually transmitted infections and diseases, including HIV, (5) contraceptive methods and counseling, (6) breastfeeding support and counseling, and (7) screening and counseling for domestic violence. Id.

243. See Women's Preventative Services Guidelines: Affordable Care Act Expands Prevention Coverage for Women's Health and Well-Being, supra note 242.

244. See supra text accompanying notes 5–11.

245. See Robin Bidwell, Supporting Patients in Care, in GUIDE FOR HIV/AIDS CLINICAL CARE (Susan Coffey ed. 2011), http://hab.hrsa.gov/deliverhivaidscare/clinicalguide11/.

246. See generally NAM Aids Map: HIV and Anti-HIV Drugs 7 (2002), http://www.aidsmap.com/v634738045080000000/file/1052204/AHD_2012_Web.pdf.

247. See U.S. GEN. ACCOUNTABILITY OFF., supra note 136, at 4.

248. See Crowley & Kates, supra note 4, at 2.

249. Id. at 6.

program any less important. As HIV health advocates and public officials focus on getting more PLWHA into regular medical care, PLWHA's need for benefits is likely to increase.[250] The history of the program also shows that even if all PLWHA were enrolled in comprehensive, affordable health plans, supplementary coverage would still be needed.[251] In this transitionary period, supplementary government programs like Ryan White will also serve as an indispensable gap-filler where implementation issues arise or where the cost of care exceeds an individual's health plan coverage.[252] Finally, Ryan White will continue to serve as an indispensable source of benefits for marginalized communities, especially undocumented immigrants, who are ineligible for Medicaid and state-based health exchanges.[253]

VI. CONCLUSION

While PPACA contains a number of provisions that will substantially expand access to medical care for PLWHA, there are no guarantees that its implementation will go smoothly. The substantial regulatory authority that the law gives to the states means that it faces hurdles from hostile legislators and other public officials.[254] To combat these implementation issues HIV health advocates and medical experts should pay close attention to efforts of uninsured applicants to sign up for insurance plans made available through state based exchanges, premium rate increases, and new patterns of coverage denials by insurance providers. The HHS should also carefully monitor the quality of health care PLWHA receive by requiring health care providers receiving HHS grants to provide information on the Seven Core Indicators of Effectiveness. Gathering hard facts on who is getting regular HIV care and why will help inform HHS efforts to get more PLWHA virally suppressed. Congress should also require that insurance providers and public programs cover important preventative services such as PrEP, that will both help contain the spread of the disease and improve health outcomes. Finally, Congress should continue to fully fund the Ryan White Program so that it can provide vital supplemental coverage for the people who need it most. Only once these steps are taken can PPACA

250. See id. (noting that public health official's increased attention on getting PLWHA into regular medical treatment could lead the demand for Ryan White services to exceed current levels).

251. Id.

252. Id. at 19.

253. Id. at 8, n. 33.

254. See supra text accompanying notes 212–217 (describing the reactions of many traditionally conservative states to PPACA, many of whom have refused to implement it).

reach its goal of improved health outcomes for not only PLWHA, but for all people in the United States.