NHeLP
NATIONAL HEALTH LAW PROGRAM

Addressing the Needs of Low-Income Women Living with HIV: The Role of Medicaid and the ACA

Prepared By: Jina Dhillon and Deborah Reid
April 1, 2013

Background

Generally, women living with HIV (WLWH) have the same reproductive health needs as all women. These include services for contraception, preconception care, maternity care, abortion services, STI (sexually transmitted infections) screenings, annual Pap tests, and routine breast cancer screenings. [1] In addition, the health goals for individuals with HIV are to suppress the HIV viral load (preferably to undetectable levels), improve quality of life, restore or preserve immune function, and prevent HIV transmission to partners.[2] In order to accomplish these goals, the usual recommended course of treatment for people living with HIV is Highly Active Antiretroviral Therapy (HAART) which includes at least three active anti-retroviral medications (ARVs) and other substances.[3] Strict adherence to the HAART regimen is essential for optimal health and to prevent drug resistance.[4]

As a result, WLWH require specific services and treatment in primary and gynecological care, and access to health providers with expertise in women's health and HIV.[5] Access to wrap-around services, such as transportation assistance, system navigation guidance, and psychosocial services is also important.[6]

---

[1] Dep't. of Veterans Aff., VA National HIV/AIDS Website, *Cancer Screening: Primary Care of Veterans with HIV* (Oct. 28, 2011), *available at* http://www.hiv.va.gov/provider/manual-primary-care/cancer-screening.asp#S4X (noting there is no clear evidence that HIV infection increases the risk of breast cancer or alters treatment outcomes).
[2] Am. C. Obstetrics & Gynecology, Practice Bulletin 117 - *Gynecologic Care For Women with Human Immunodeficiency Virus* (Dec. 2010).
[3] N.Y.U. Center for AIDS Research, et al., *HIV Info Source: HIV Treatment Options* (Jan. 22, 2009), *available at* http://www.hivinfosource.org/hivis/hivbasics/treatment/index.html.
[4] NAT'L ACAD. OF SCIENCES, PUBLIC FINANCING AND DELIVERY OF HIV/AIDS CARE: SECURING THE LEGACY OF RYAN WHITE (2005).
[5] 30 for 30 Campaign, Briefing Paper: *Making HIV Care and Treatment Work for Women*, *available at* http://www.aidsalabama.org/documents/Making%20HIV%20Care%20and%20Treatment%20Work%20for%20Women.pdf.
[6] *Id.*

Q. What are the particular health services that should be available to WLWH?

A. Women living with HIV should have access to an obstetrician/gynecologist (OB/GYN) who is not only knowledgeable about HIV care, but is interested in providing comprehensive care.[7] Providers should advise WLWH on the appropriate form of contraception that would not conflict with her HIV treatment. Specifically, the American College of Obstetricians and Gynecologists (ACOG) does not recommend that patients using certain aggressive HAART regimens to suppress the progression of the disease also take combined oral contraceptive pills.[8] When taken together, both of these drugs become less effective. Providers should counsel patients to use condoms as a barrier method to prevent the spread of HIV and STIs in combination with another contraceptive method to prevent unintended pregnancies.[9]

In addition to annual gynecological examinations, routine Pap smears, and contraception, other services should be included for WLWH, such as: access to HIV testing for partners, evaluation and management of abnormal Pap smears and vaginal bleeding, treatment of genital tract infections, preconception care, and abortion care as well as access to individual peer counseling and support groups for women.[10]

Pregnant WLWH should receive appropriate education and counseling about the risks of perinatal transmission, ways to reduce those risks, and potential effects of HIV infection or treatment during pregnancy.[11] Currently, HHS guidelines recommend against breastfeeding to prevent postnatal transmission of the HIV-1 virus to their infants through breast milk.[12] Other pregnancy-related complications (e.g., ectopic pregnancy, hypertension, diabetes, preterm delivery, etc.) should be identified and treated as soon as possible to avoid life-threatening complications. Lastly, women should also be advised to continue their ARV regimen post-partum to remain healthy.[13]

---

[7] The Women's Collective, *Reproductive Laws for the 21st Century Papers: HIV and Sexual and Reproductive Health in the District of Columbia* (Feb. 2012) (Center for Women Policy Studies, ed.), *available at* http://www.centerwomenpolicy.org/news/newsletter/documents/REPRO_WomensCollective.pdf.

[8] Am. C. Obstetrics & Gynecology, *supra* note 2.

[9] *Id.*

[10] *See e.g.,* JOHNS HOPKINS MEDICINE, DEP'T. OF GYNECOLOGY AND OBSTETRICS, THE JOHNS HOPKINS HIV WOMEN'S HEALTH PROGRAM, *available at* http://www.hopkinsmedicine.org/gynecology_obstetrics/specialty_areas/gynecological_services/treatments_services/hiv_womens_health_services.html.

[11] AM. C. OBSTETRICS & GYNECOLOGY, *supra* note 2.

[12] Ctrs. for Disease Control & Prevention, *Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Virus (AIDS)* (Mar. 4, 2010), *available at* http://www.cdc.gov/breastfeeding/disease/hiv.htm. *See also* Science Daily, *Breast Milk Antibody Fights HIV but Needs Boost, Study Finds* (Sept. 19, 2011), *available at* http://www.sciencedaily.com/releases/2011/09/110919113337.htm (breastfeeding WLWH and infants require additional protections to prevent HIV transmission).

[13] Deborah Cohan, M.D., *HIV and Pregnancy*, HIV SPECIALIST 10-11 (Spr. 2011), *available at* http://www.aahivm.org/hiv_specialist/upload/hivspecialistmagazinespring2011.pdf.

Accordingly, pregnant WLWH should ideally be managed by an experienced OB/GYN and an HIV specialist, and referred to a maternal-fetal medicine specialist if complications arise.[14]

Medicaid

Q. Why is Medicaid considered an essential health care program for low-income WLWH?

A. Medicaid is a jointly-funded and administered federal and state program for certain individuals with low incomes who meet one or more categorical needy eligibility requirements, such as disability, being pregnant, or having a dependent child. Childless WLWH who are not disabled are not eligible. Still, the program is critically important for people with HIV. Currently, having a disability is the most common Medicaid eligibility factor.

Almost a fourth (23 percent) of people who have been diagnosed with HIV in the U.S. are enrolled in Medicaid.[15] Medicare covers about 19 percent of people living with HIV, including some individuals with private insurance.[16] WLWH are more likely to have lower incomes than men – nearly two-thirds of all WLWH receiving medical care report annual incomes below $10,000 (64 percent), compared with 41 percent of men.[17] In spite of this, the majority of Medicaid enrollees with HIV in FY 2007 were male (57 percent) and 43 percent were female.[18] It is unclear what is driving this gender disparity, however, when the Patient Protection and Affordable Care Act (ACA) is fully implemented in 2014, many WLWH will be eligible for the mandatory expansion of Medicaid (see discussion of the ACA below).[19]

In addition, Medicaid enrollees with HIV are disproportionately people of color. More than half of Medicaid enrollees, male and female, with HIV were African American (50 percent) compared to 26% of Medicaid enrollees without HIV, a quarter were white (25

---

[14] Am. C. Obstetrics & Gynecology, *supra* note 2.
[15] KAISER FAM. FOUND., MEDICAID AND HIV: A NATIONAL ANALYSIS (Oct. 2011), *available at* http://www.kff.org/hivaids/upload/8218.pdf.
[16] RONALD ANDERSON, et al., CHANGING THE U.S. HEALTH CARE SYSTEM: KEY ISSUES IN HEALTH SERVICES POLICY AND MANAGEMENT (2011).
[17] HIV LAW PROJECT, INVESTING IN HEALTH: SUPPORTIVE SERVICES FOR WOMEN LIVING WITH HIV/AIDS (July 2012), *available at* http://www.hivlawproject.org/resources/cwha/Investing%20in%20Health%20Supportive%20Services%20for%20Women%20Living%20with%20HIV.pdf.
[18] KAISER FAM. FOUND., MEDICAID AND HIV, *supra* note 15, at 6. *But see id*. The same statistics reflect an opposite picture of Medicaid enrollees without HIV. More women without HIV are enrolled in Medicaid than their male counterparts (57% versus 43%).
[19] Patient Protection and Affordable Care Act, Pub. L. No. 111-148 (March 23, 2010) (hereinafter ACA). Amendments to the ACA were included in the Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152 (March 30, 2010); 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII).

percent) compared to 42% without HIV, and 17 percent were Latino compared to 20% without HIV.[20]

Federal Medicaid rules require states to cover a set of mandatory services for individuals who are categorically needy. These mandatory services include: inpatient and outpatient hospital services, physician visits, laboratory and x-ray services, family planning services and supplies, pregnancy-related services, and federally qualified health center services. States may also choose to cover one or more optional services, such as: dental, prescription drugs (which all states provide), hospice care, personal care services, and physical therapy and related services. For individuals living with HIV on Medicaid, many of the optional services, such as the prescription drug benefit, are critical.[21] Further research is needed to assess whether this scope of services is adequately meeting the needs of WLWH.[22]

In addition, states have the option of providing community-based, long term care services to assist individuals with disabilities through Home and Community Based Services and Supports (HCBS) demonstration (waiver) programs. These waiver programs are important for individuals with HIV as they can provide homemaker, adult day health, respite care, day treatment, and case management services. As of 2010, 16 states had HCBS waivers with specifically designed benefit packages for individuals with HIV.[23] Similarly, § 1915(c) waivers also allow states to provide a variety of standard and specialized community-based and long-term care services. Some of the standard services include: personal care, homemaker, habilitation (day and residential), and case management (support and coordination). The specialized services give states the ability to offer Medicaid enrollees coverage for services to avoid institutionalized care and to transition them into other home and community settings.[24] For individuals who are not

---

[20] *Id.*

[21] Kaiser Fam. Found., *Financing HIV/AIDS Care: A Quilt with Many Holes* (May 2004), *available at* http://www.kff.org/hivaids/upload/Financing-HIV-AIDS-Care-A-Quilt-with-Many-Holes.pdf. *But see* KAISER FAM. FOUND., MEDICAID AND HIV, *supra* note 16, at 1 (discussion relating how states can limit the number of prescriptions covered per month). For a detailed discussion of the requirements of federal Medicaid law related to administration, eligibility, and services, including citations to all pertinent Medicaid statutory and regulatory provisions and cases, see National Health Law Program, *An Advocate's Guide to the Medicaid Program* (May 2011, revised Sept. 2012) (available from the National Health Law Program, Los Angeles, CA, www.healthlaw.org).

[22] *See generally* 30 for 30 Campaign, Briefing Paper: *Making HIV Care and Treatment Work for Women*, *available at* http://www.aidsalabama.org/documents/Making%20HIV%20Care%20and%20Treatment%20Work%20for%20Women.pdf.

[23] Nat'l Acad. for Health Policy, *Implementing the Affordable Care Act – New Options for Medicaid Home and Community Based Services* (Oct. 2010), *available at* http://www.nashp.org/sites/default/files/LTSS_SCAN-FINAL-9-29-10.PDF.

[24] *See e.g.,* Colorado, *Persons Living with AIDS - 1915(c) Details*, *available at* http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915%28c%29#waivers (includes medication reminders and consumer directed home care services).

yet disabled, states can use § 1115 waivers to allow these individuals to access treatment earlier. Under 1115 waivers, states are authorized to implement "experimental, pilot or demonstration projects" which are "likely to assist in promoting the objectives" of the Medicaid Act.[25] Covering pre-disabled people living with HIV through an 1115 waiver allows states to provide early intervention that will help the individual maintain a healthier lifestyle, reducing the higher costs associated with waiting until a person becomes disabled, and allows the state to leverage federal matching funds for this care.

Medicaid enrollees under the age of 21 are entitled to services through the Early and Periodic Screening, Diagnostic and Treatment Program (EPSDT) benefit. EPSDT provides children and adolescents enrolled in Medicaid with age appropriate preventive, mental health, dental, developmental, and specialty services. EPSDT can be essential to young WLWH, who otherwise may have difficulties accessing recommended screening, counseling, and treatment services.[26]

Q. What other public programs are important for women with HIV who don't qualify for Medicaid?

A. The Department of Health and Human Services (HHS) administers another publicly funded program, the Ryan White HIV/AIDS Program, through the Health Resources and Services Administration (HRSA).[27] In FY 2009, 32% of the Ryan White HIV/AIDS Program clients were women.[28] In addition to Medicaid and Medicare, Ryan White is a significant payer of HIV care. Ryan White funding is awarded to agencies nationwide, which in turn provide services to eligible individuals living with HIV/AIDS through several funding categories (Parts):

- A - provides assistance to Eligible Metropolitan Areas and Transitional Grant Areas most impacted by HIV and AIDS;
- B - provides grants to all 50 states, U.S. Territories, Guam, U.S. Virgin Islands, and the District of Columbia (e.g., for the AIDS Drug Assistance Program ("ADAP");
- C - provides comprehensive outpatient care;
- D - provides family-centered care for youth, women, infants, and children living with HIV; and
- F - provides funding for several HIV/AIDS related programs, such as: dental, the Minority AIDS Initiative (serving communities of color), and the AIDS Education

[25] 42 U.S.C. § 1315(a) (§ 1115 of the Social Security Act).
[26] For more on Medicaid and adolescent health, *see* NHeLP Issue Brief, *Addressing Adolescent Health: The Role of Medicaid, CHIP, and the ACA* (Nov. 2012), *available at* http://healthlaw.org/index.php?option=com_content&view=article&id=116:childrens-health-publications&catid=40&Itemid=186.
[27] The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, 42 U.S.C. § 300ff (2003).
[28] Dep't. of Health & Human Servs., Health Resources Serv. Admin., *FY 2012* Online Performance Index, *available at* http://www.hrsa.gov/about/budget/performanceappendix2012.pdf.

and Training Program (a network of training programs for providers treating people living with HIV and AIDS).[29]

Demand for the ADAP component of the Ryan White programs is growing. In 2011, 14 ADAPs had waiting lists. In September 2011, 9,298 individuals in 11 states were eligible for ADAPs but they were unable to access medications.[30] In July 2012, the Obama Administration announced the availability of almost $80 million in grant funding for HIV/AIDS care.[31] About $69 million of these funds will be provided to 25 states and territories through ADAPs to eliminate waiting lists. The remaining $10 million will be given to Ryan White community-based health centers and other programs to increase access to 14,000 new patients for essential medical and support services for individuals living with HIV/AIDs, and to reduce HIV-related health disparities.[32] Although advocates are encouraged by this development, some caution that many people living with HIV are also adversely impacted by other barriers to care, such as eligibility restrictions and cost sharing.[33]

Medicare is another federal health insurance program for individuals age 65 and older and younger people with permanent disabilities. An estimated 100,000 people living with HIV depend on Medicare for their health coverage.[34]

Title X (of the Public Health Service Act) funded family planning centers and other publicly funded clinics also serve a vital role for people living with HIV. One in three women received HIV testing, treatment and counseling for other STIs at a publicly funded clinic, including half of all low-income women seeking these services.[35]

---

[29] Dep't. of Health & Human Servs., Health Resources Serv. Admin., *About the Ryan White HIV/AIDS Program-Legislation*, *available at* http://hab.hrsa.gov/abouthab/legislation.html; Dep't. of Health & Human Servs., Health Resources Serv. Admin., *About the Ryan White HIV/AIDS Program-Part B AIDS Drug Assistance Program*, *available at* http://hab.hrsa.gov/abouthab/partbdrug.html. *See also* Nat'l Acad. of Sciences, *Public Financing*, *supra* note 4. Income eligibility for the ADAP program varies by state, but can range from under 300 – 500% FPL.
[30] Kaiser Fam. Found., *Fact Sheet: AIDS Drug Assistance Programs (ADAPs)* (Sept. 2012), *available at* http://www.kff.org/hivaids/upload/1584-11.pdf.
[31] Dep't. of Health & Human Servs., News Release, *Investment by Obama Administration will Eliminate ADAP Wait Lists* (July 19, 2012), *available at* http://www.hhs.gov/news/press/2012pres/07/20120719b.html.
[32] *Id.*
[33] ADAP Advocacy Association, *ADAP Advocacy Association Welcomes $80 Million to Increase Access to HIV/AIDS Care & Treatment* (July 20, 2012), *available at* http://www.adapadvocacyassociation.org/pdf/2012_aaa_Press_Obama-ADAP-Investment_07-20-12.pdf.
[34] Kaiser Fam. Found., HIV/AIDS Policy: *Fact Sheet – Medicare and HIV/AIDS* (Feb. 2009), *available at* http://www.kff.org/hivaids/upload/7171_04.pdf.
[35] Guttmacher Inst., *Facts on Publicly Funded Contraceptive Services in the United States* (May 2012), *available at* http://www.guttmacher.org/pubs/fb_contraceptive_serv.html.

Additionally, women who might not be eligible for traditional Medicaid can obtain confidential HIV and other reproductive health services if they reside in one of the 26 states with Medicaid family planning expansions.[36]

Q. What have been the challenges of privately insured women and women enrolled in Medicaid managed care programs in accessing HIV services and treatment?

A. Some privately insured WLWH report difficulties in paying for copayments and deductibles for the services they need in their plans.[37] Other barriers include getting access to HIV specialists in plan networks, and affording the out-of-pocket cost of prescribed medications that are not covered by private insurance plans.[38] Similarly, some women in Medicaid managed care plans faced difficulties in getting referrals to HIV specialists.[39] Smaller Medicaid managed care organizations may not cover certain HIV drugs, erecting an additional cost barrier for some women enrolled in these plans.[40]

Q. What types of discrimination have WLWH experienced when seeking health care and services?

Individuals living with HIV are still exposed to many local and state policies and laws that undermine efforts to fight the HIV epidemic. Legal provisions such restrictive state Medicaid eligibility requirements, limited funding for prescription drug programs, and criminal penalties for failing to disclose HIV status create stigma and discriminate against individuals living with HIV/AIDs.[41] Moreover, many of these policies and laws fuel an atmosphere of stigma and discrimination against people living with the disease. For example, although African American women have the second highest HIV infection rate in Mississippi -- the state's "Just Wait" abstinence only campaign fails to provide evidence-based HIV prevention information to communities.[42]

In addition, other studies indicate that unlawful provider refusals to provide health care and services also disproportionately impact people living with HIV. A study by the Williams Institute at UCLA found that various providers in Los Angeles County illegally refused individual testers posing as people living with HIV access to care.[43] From 2003

---

[36] Guttmacher Policy Review, *Back to Center Stage: ACA Decision Gives New Significance to Medicaid Family Planning Expansions* (Fall 2012), *available at* http://www.guttmacher.org/pubs/gpr/15/4/gpr150413.pdf.
[37] Kaiser Fam. Found., *The Healthcare Experience of Women with HIV/AIDS – Insights from Focus Groups* (Oct. 2003), *available at* http://www.kff.org/hivaids/upload/The-Healthcare-Experiences-of-Women-with-HIV-AIDS-Insights-from-Focus-Groups-pdf.pdf.
[38] *Id.*
[39] *Id.*
[40] Nat'l Acad. of Sciences, *Public Financing*, *supra* note 4.
[41] *See e.g.,* Human Rights Watch, *State Response to HIV in Mississippi* (Mar. 9, 2011), *available at* http://www.hrw.org/reports/2011/03/09/rights-risk.
[42] *Id.*
[43] Brad Sears, The Williams Institute, Los Angeles Daily Journal, *Brad Sears on Addressing HIV Discrimination in Health Care* (Dec. 2, 2011), *available at*

to 2007, 46% of skilled nursing facilities, 55% of OB/GYNS, and 26% of plastic surgeons in this area failed to provide services to the testers.[44] Such results demonstrate the continuing need for provider outreach and education, and enforcement of existing local and federal civil rights laws prohibiting health discrimination.

The Affordable Care Act

Q. How does the ACA expand coverage options for low-income WLWH?

A. The ACA adds a new mandatory coverage group to the Medicaid program. Beginning in 2014, states must enroll low-income adults who are under 138 percent FPL, which is $30,843 for a family of four in 2011.[45] As of April 1, 2010, states could begin early expansion of Medicaid coverage to these newly eligible individuals by filing a state plan amendment with the Centers for Medicare & Medicaid Services (CMS).[46] To qualify for the Medicaid Expansion, individuals must be:

- under age 65;
- not pregnant;
- not entitled to or enrolled in Medicare Part A;
- not enrolled in Medicare Part B; or
- excluded from any of the previously existing mandatory categorically needy groups set forth in the Medicaid statute.

This coverage expansion is significant because, for the first time, Medicaid will be extended to all individuals below the income threshold without requiring a categorical link. Those most affected are very low-income childless, nondisabled adults. This expansion will eliminate the "Catch-22" for people with HIV that exists under current law, where most people are not eligible for Medicaid until they become unable to work, despite the ability of effective treatments to prevent disability and promote both health and continued employment.

The recent Supreme Court decision ruling on the constitutionality of the ACA allows states to refuse to implement the Medicaid expansion without consequences.[47] While

---

http://williamsinstitute.law.ucla.edu/headlines/brad-sears-on-addressing-hiv-discrimination-in-health-care/.

[44] *Id.*

[45] *See* ACA § 2001(a)(1) (adding 42 U.S.C. § 1396a(a)(10)(A)(i)(VIII)). *See also* Kaiser Fam. Found., *Focus on Health Reform: Determining Income for Adults Applying for Medicaid and Exchange Coverage Subsidies* (March 2011), *available at* http://www.kff.org/healthreform/upload/8168.pdf (describing how the ACA sets a new national minimum level of Medicaid coverage at 133% FPL with a standard income disregard of 5% that raises the limit to 138% FPL in 2014).

[46] CMS, DEAR STATE HEALTH OFFICIAL/MEDICAID DIRECTOR (April 9, 2010).

[47] *See Nat'l Fed'n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566 (2012) (upholding constitutionality of most of the ACA, but finding that states have flexibility to expand Medicaid, and must comply with all of the Medicaid Act if they do so, but they will not lose all federal Medicaid funding if they choose not to expand Medicaid).

this holding very narrowly limits itself to enforcement of the Medicaid expansion provision, it creates many unanswered questions as to how states are likely to proceed with this important aspect of the law. States may now decide not to cover these newly eligible individuals.

The Medicaid expansion is important for low-income WLWH, especially as a quarter of those living with HIV in the US are women, and they are disproportionately women of color and low-income women. Medicaid can be a critical entry point into the necessary and comprehensive treatment regime for HIV care that would allow more women with HIV to live healthier lives, improving not only their own health outcomes but also those of their families and their communities. It is imperative that advocates hold their states accountable to the women of their communities, emphasizing the importance of Medicaid to the health and wellness of low-income WLWH and demanding that their state continue with the Medicaid expansion as required by the ACA.

Q. How does closing the Medicare Part D donut hole help WLWH?

A. Individuals enrolled in Medicare have an optional monthly premium for outpatient prescription drug coverage, known as Medicare Part D. Before the passage of the ACA, Part D enrollees paid for monthly premiums and had to meet an annual deductible of $310.00 before their drug coverage began. After the $310.00 deductible was met, enrollees paid 25% of the cost of their prescription drugs, and the Part D plan paid the remaining amount until the total reached $2,800.[48] At this point, enrollees became responsible for 100% of their prescription drugs until they have paid $4,550 in yearly out-of-pocket spending.[49] This gap in coverage is known as the “donut hole.” Above the donut hole level, enrollees typically pay about 5% of the cost of their prescription drugs.

The donut hole posed a serious hardship for many low-income enrollees who often faced the impossible decision of paying for needed medications or other essentials of living.[50] Low income WLWH enrolled in Medicare Part D often lack the financial resources to fill the donut hole gap. As a result, they may experience treatment interruption causing anti-retroviral therapies to lose their effectiveness and encourage drug resistance. This can be especially harmful for long term HIV survivors who develop resistance to multiple drugs and essentially run out of therapy options as a result of this interruption.

Other programs, including ADAP or compassionate use programs from pharmaceutical companies, are often difficult to access, have long wait lists, or may take too long to apply for and process. Given the potentially serious health consequences of starting and stopping antiretroviral therapy, clinicians are placing much greater emphasis on treatment adherence as a key factor in maintaining wellness and avoiding drug resistance.

---

[48] Jonathan Blum, CMS, *What is the Donut Hole?* (Aug.9, 2010), *available at* http://www.healthcare.gov/blog/2010/08/donuthole.html.
[49] *Id.*
[50] *Id.*

ACA § 3301 closes the donut hole. Specifically, drug manufacturers are required to participate in the Medicare coverage gap discount program. This program gradually increases the discount benefit to consumers until the gap is eliminated in 2020. [51] As a result, this provision can go a long way in supporting and maintaining the health and well-being of low income WLWH.

Q. How will other provisions in the ACA improve access to private insurance for WLWH?

A. Section 1557 of the ACA prohibits discrimination on the basis of race, color, national origin, sex, age and disability in health programs or activities that receive federal financial assistance, are administered by an Executive agency, or were established by Title I of the ACA.

Discriminatory insurance premium rates are restricted by the ACA, with variation only allowed for factors such as geography/rating area (subject to the Secretary's review), age (limited to a ratio of 3:1), tobacco use, and family structure.[52] This means that insurance premium rates may not be higher for individuals with a serious illness or condition, including HIV.

The "guaranteed issue" provision of the ACA requires health insurance issuers to accept every employer and individual in the state who applies for coverage in the individual and group markets, subject to open or special enrollment periods.[53]

Beginning in 2014, insurance plans are not permitted to exclude adults from coverage due to an existing illness (those that are considered pre-existing conditions) or other elements of health status at the time of application.[54] Further, group health plans and insurers that offer group or individual coverage may not establish eligibility requirements based on the following factors:

- health status;
- medical condition (including both physical and mental illnesses);
- claims experience;
- receipt of health care;
- medical history;
- genetic information;
- evidence of insurability (including conditions arising out of acts of domestic violence);
- disability; or

[51] For a more detailed analysis of this provision, *see* NHeLP, *Analysis of the Health Care Reform Law: PPACA and the Reconciliation Act* (Aug. 2010), *available at* www.healthlaw.org.
[52] ACA § 1201 (adding PHSA §2701).
[53] *Id.* (adding PHSA § 2702).
[54] *Id.* (adding PHSA § 2704).

- any other health status-related factor determined appropriate by the Secretary.[55]

This non-discrimination provision is very important for women in general, and especially WLWH. Previously, women have been denied health coverage due to perceived pre-existing conditions such as being a domestic violence survivor, being pregnant, or having had a cesarean section delivery. Individuals have also been unable to obtain health coverage because of chronic illnesses, such as cancer and HIV/AIDS. It is likely that such denials of coverage to individuals with these and other health-related factors is in fact a pretext for underlying and impermissible discrimination. The ACA now prohibits such discrimination.

Lastly, insurers must also guarantee that coverage is renewable.[56] Previously, individuals who developed serious illnesses or those who used significant amounts of health resources were susceptible to cancelled or non-renewable health coverage because of their health status.

Q. Will low-income WLWH be able to afford private coverage in the Exchanges?

A. The high cost of private insurance premiums and burdensome co-payments for prescriptions and office visits can be a significant barrier for WLWH whose incomes are too high for Medicaid.

The ACA creates a mechanism by which individuals and families enrolled in private health insurance in the newly created Exchanges will be able to obtain financial assistance for payment of the monthly premium and cost-sharing.

Premium assistance comes in the form of a tax credit determined according to an eligible individual's household income for the year, up to 400 percent FPL. This tax credit pays for a significant portion of the monthly premium, and the eligible individual is responsible for contributing the remainder of the premium based on a percentage of his/her income. For example, a policy for an individual with two children and an annual household income of $26,700 (just over 139 percent FPL for a family size of three) would likely cost $11,500 per year. Her premium assistance tax credit would be $10,699, and she will be responsible for paying $801 for the year (3 percent of her income).[57]

---

[55] *See e.g.,* Lynn Rosenthal, White House Advisor on Violence Against Women, White House Blog, *For Victims of Domestic Violence – Health Care is A Lifeline* (Mar. 23, 2010), *available at* http://www.whitehouse.gov/blog/2010/03/23/victims-domestic-violence-health-care-a-lifeline (describing how prior to the ACA, insurance companies in eight states and the District of Columbia could discriminate against survivors of domestic violence by declaring domestic violence a preexisting condition and denying health insurance coverage).
[56] *Id.* (adding PHSA § 2703).
[57] Income based on 2012 Federal Poverty Guidelines. The individual contribution is calculated by $26,700 x .03 = $801 and the tax credit amount calculated by $11,500 - $801 = $10,699.

Another affordability measure of the ACA is reduced cost-sharing for deductibles and co-payments for individuals enrolled in qualified health plans (QHPs) in the Exchange.[58] The cost-sharing reductions will reduce expensive co-pays for long-term treatment regimes for WLWH, often cited as a major barrier for continuous care for women who are uninsured, underinsured, or even with private insurance. Removing this cost barrier will be an important step towards ensuring that women can access and remain in their prescribed HIV treatment programs.

Both the premium tax credits and cost-sharing reductions will apply to eligible individuals with income between 100 and 400 percent FPL and for lawfully present immigrants with household income under 100 percent FPL who are ineligible for Medicaid based on immigration status.

Another important step in removing cost barriers to HIV care is the ACA's prohibition on lifetime or annual limits. The ACA prohibits a group health plan or issuer offering group or individual health insurance from establishing lifetime or annual limits on the monetary value of benefits for any participant.[59] This restriction is limited, however, to "essential health benefits" (discussed below). Plans may still impose annual and lifetime limits on non-essential health benefits.

Q. How will the ACA improve access to preventive, wellness, and treatment services for WLWH?

A. The ACA requires coverage of certain preventive health services for individual and group health plans with no cost-sharing.[60] These services must include evidence-based items and services rated as an "A" or "B" by the U.S. Preventive Services Task Force ("USPSTF"), certain immunizations and screenings, as well as additional women's health preventive care and screenings. The women's health preventive services have been defined to include contraception coverage, STI/HIV screening and counseling for at-risk women, domestic/interpersonal violence (IPV) screening and counseling for all women, and well-woman visits. These services are very important for WLWH, especially the screening for IPV, which has been shown to strongly correlate to a woman's risk of HIV exposure. Low-income women and women of color experience higher rates of domestic violence than other women, which can directly impact their ability to negotiate contraceptive use (or otherwise protect themselves from sexual transmission of HIV and other STIs).[61] The well-woman visits present another opportunity for WLWH to receive comprehensive preventive services. The guidelines explicitly contemplate that women with high health needs can obtain more than one well-woman visit per year, and can

---

[58] ACA § 1402.
[59] ACA § 1001.
[60] ACA § 1001, codified as PHSA § 2713.
[61] 30 for 30 Campaign, White Paper, *Affordable Care Act Priorities: Opportunities for Addressing the Critical Health Care Needs of Women Living with or at Risk for HIV* (July 2012), *available at* http://www.nblca.org/wp-content/uploads/2012/03/Affordable_Care_Act_.pdf.

obtain preventive services in a variety of health settings.[62] The provision of these and other preventive health services with no cost-sharing will be an important step towards identifying and responding to the unique health needs of WLWH.

The ACA sets the minimum benefit standards for most private health plans beginning in 2014. Essential Health Benefits (EHB) must be provided in all non-grandfathered health plans operating in and out of the Exchanges, as well as for individuals newly eligible for Medicaid as a result of the expansion and for those enrolled in a Basic Health Program (BHP). The ACA requires that EHB be defined as equal in scope to “typical employer coverage” but at minimum it must include coverage of ten statutory categories of services.[63] These categories include the preventive services described above, as well as other important categories that are often inadequately, if ever, covered in the private market--for example, plans must cover mental health and substance use disorder treatment services, rehabilitative and habilitative services, maternity and newborn care, and prescription drug coverage among others in order to comply with the EHB standard.

Final rules on implementation of the EHB standard have delegated much authority and flexibility in defining and designing EHB standards to both states and insurers. This can be problematic to the extent that it promotes and encourages existing geographic disparities in coverage. States and insurers may have financial incentives for keeping the EHB benefits standard weak and promoting harmful utilization management techniques that impede access to care, all in the name of reducing their own costs. There are, however, opportunities for advocates to encourage states to expand access and coverage for vulnerable populations, including WLWH.

For example, the requirement that EHB must include prescription drug coverage will be an important opportunity for advocacy for WLWH, as this is one way to ensure that all necessary HIV medications are affordable and accessible to those covered by the EHB. Targeted inclusion of HIV primary care and specialty providers in Medicaid and QHP provider networks, including possibly by integrating Ryan White models discussed above into Medicaid and Exchange EHB systems, are some of the ways that states can make new health insurance programs more responsive to the needs of WLWH. Ensuring that WLWH are able to access adequate mental health and substance use disorder services, and maternity and newborn care that takes into account their unique needs, are additional points for targeted advocacy on behalf of WLWH.

In addition to these benefits standards, the ACA requires HHS to issue competitive community grants to state and local governments and community-based organizations to implement and evaluate community prevention programs that promote healthy living and reduce health disparities.[64] These grants are an important opportunity for local communities to work towards reducing chronic illness and disability, and assisting populations that are particularly disadvantaged, as well as addressing ongoing health

[62] Health Res. & Servs. Admin., Women’s Preventive Services: Required Health Plan Coverage Guidelines, http://www.hrsa.gov/womensguidelines/.
[63] ACA § 1302.
[64] ACA § 4201.

disparities. They offer the opportunity to identify and respond to geographic and health disparities affecting WLWH, who are disproportionately women of color living in the South.

Activities which qualify for these grants include creating healthier school environments; developing and promoting programs that advance nutritional, social and emotional wellness or a chronic disease priority area; prioritizing strategies that help reduce health disparities, including social, economic and geographic determinants of health; and assisting special populations including persons with disabilities.

There are also community-based prevention and wellness programs for Medicare beneficiaries, with special emphasis on targeting different populations equitably, and focusing on populations that have the poorest health status and are most in need of improved access to preventive services.[65]

HHS is also required by the ACA to allocate funding to states for programs that work to reduce teen pregnancy and birth rates by educating adolescents ages 10-19 on abstinence and contraception, prevention of pregnancy and STIs and HIV, and preparation for adulthood.[66] The minimum state allocation is $250,000 per year. Qualifying programs must be evidence-based, medically accurate, complete, age appropriate, culturally competent, and include skill development such as healthy relationships, healthy marriages, financial literacy, career skills, and healthy living skills.

The ACA also creates opportunities to improve coordination and integration of care and emphasizes the need for community providers who can serve low-income and underserved communities.

The newly created Center for Medicare and Medicaid Innovation ("CMI") is responsible for innovative payment and delivery models aimed at reducing costs while improving quality.[67] The Secretary is empowered to select models to be tested, including the creation of community support teams for medical homes, home health provider chronic care management, and care coordination in rural and urban areas. These innovative programs can transform health system delivery in ways that benefit WLWH, including by providing more community support and opportunities to connect with wraparound services necessary to adequately meet their needs.

The ACA also invests in community health teams to help manage chronic illnesses; supports patient-centered medical homes to provide coordinated and comprehensive care; and emphasizes the availability of community providers for low-income and underserved communities. This type of integrated care is essential to assist women in managing HIV.

[65] ACA § 4204.
[66] ACA § 2953.
[67] ACA § 3021.

Q. What are some of the shortcomings of the ACA for WLWH?

A. While it makes great strides for low-income women with HIV, the ACA does fall short in several important ways. Limited access to abortion services and little emphasis on wraparound services such as those covered in the Ryan White Program are missed opportunities to improve and expand comprehensive coverage for WLWH. For example, the focus on the medical model of care represents a shift away from important supportive services such as housing, employment, child care, transportation, etc. that are available in other programs.

The ACA restores funding for abstinence-only education.[68] Significant research and evidence have shown that abstinence-only-until-marriage education is not effective in delaying sexual activity, and may cause higher rates of STIs among adolescents.[69] This ineffectiveness to convey comprehensive and accurate information deprives young people of the knowledge they need to protect themselves from exposure to HIV.

The ACA does nothing to change existing restrictions in access to Medicaid for immigrants subject to the five year waiting period. Such policies do little to improve the health of immigrant women, but rather will perpetuate the inequities created by inadequate access to needed health services by these women.

State officials should prioritize the needs and concerns of WLWH in their policy decisions to better support the health and wellbeing of all residents. However, budget cuts are hitting state HIV programs especially hard. Officials implementing early Medicaid Expansion programs should consistently address and prioritize the needs of WLWH—for example, the type of access to pharmacies that individuals now have in ADAP programs should be similarly adopted in expansion programs; also, access to HIV specialists to ensure continuity of care may continue to be a problem if is not addressed by the state early on.

The bottom line for WLWH and ACA implementation is the need to emphasize and incorporate the concerns of these women early and consistently throughout all phases of implementation.

---

[68] ACA § 2954.

[69] John Santelli, et al., *Abstinence and abstinence-only education: A review of U.S. policies and programs*, 38 J. ADOLESCENT HEALTH 72 (2006); Hazel Beh & Milton Diamond, *The Failure of Abstinence-Only Education: Minors Have the Right to Honest Talk about Sex*, 15 COLUM. J. GENDER & L. 12 (2006).