Affordable Care Act Priorities and Opportunities for Addressing the Critical Health Care Needs of Women Living with and at Risk for HIV

A 30 for 30 Campaign white paper prepared in partnership with the Harvard Law School Center for Health Law and Policy Innovation and the Treatment Access Expansion Project.

OVERVIEW

In 2010, Congress enacted the Patient Protection and Affordable Care Act (ACA), federal health care reform legislation that is already helping millions of Americans. On June 28, 2012, the U.S. Supreme Court issued a decision upholding as constitutional most provisions of the law, paving the way to move forward with implementation of the ACA. Provisions of the ACA – including major expansion of public and private insurance coverage and investments in prevention, wellness, health infrastructure, and coordinated "whole person" models of care – have the potential to significantly increase access to comprehensive care for women living with or at risk for HIV. The ACA provides a number of opportunities to better integrate HIV care, primary care, and reproductive health care services in ways that meet the multiple and overlapping needs of women living with or at risk for HIV, needs that are too often poorly addressed by fragmented systems of health care.

For women, the HIV epidemic is compounded by the intersections of race, gender, gender identity, and poverty; these factors impact their health and social services needs. Often, women are the primary caretakers of children and other family members and are likely to put the needs of family members above their own health care needs. In addition, the majority of women living with HIV have incomes below the federal poverty level (FPL), meaning that added to their health care needs, these women are likely to have unmet housing, nutrition, and other social services needs.[1] Low-income women, particularly women of color, also experience higher rates of domestic violence, which can impact their ability to use contraception (or otherwise protect themselves from the sexual transmission of HIV and sexually transmitted infections (STIs)) as well as to remain in care if they become HIV positive.[2]

WOMEN AND HIV: THE FACTS

- The majority of women living with HIV have income below the federal poverty level.
- Women of color account for 80% of women living with HIV (64% and 17% of women living with HIV are Black and Latina, respectively).
- Women living with HIV who have private insurance are likely to face higher costs and more interruption in coverage due to gender discrimination (e.g., higher premiums).
- Women living with HIV are less likely than men to receive antiretroviral therapy and thus have higher HIV/AIDS mortality rates.
- The South and Northeast have some of the highest rates of new HIV infections among women

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The health care services needs of women living with HIV demand attention to the overlap between women's primary health care, HIV care, and reproductive health care needs. The multiple and overlapping needs of these women are often poorly addressed by fragmented systems of health care.[3] These statistics point to the need for policies and programs that are tailored to the health care and social services needs of women living with or at risk for HIV and that incorporate their voices and experiences, particularly those of women of color and transgender women. Such an approach is needed now more than ever, as laws and policies aimed at restricting access to critical reproductive and women-focused health services are increasingly prevalent nationwide. This white paper provides an overview of the major opportunities for expanding access to care within the ACA as well as a road map for federal and state implementation priorities to ensure that the ACA is implemented in ways that work for women living with or at risk for HIV.

Federal and state implementation decisions over the coming months and years will dictate whether the promises of the ACA become a reality.

To ensure that the law is implemented in ways that work for women living with or at risk for HIV, the voices and experiences of these women, particularly women of color and transgender women, must be incorporated into the process (e.g., by participating on ACA implementation advisory committees).

In addition, many women living with HIV are currently being served through the Ryan White Program, and it is essential that implementation efforts ensure that the services, provider expertise, and effective models of care that are the hallmark of this program are preserved. Focusing efforts on ensuring that the ACA meets the care and treatment needs of women living with or at risk for HIV is needed now more than ever as laws and policies aimed at stripping away access to essential reproductive and women-focused health services are increasing nationwide.

SUMMARY OF KEY ACA PROVISIONS AND RECOMMENDATIONS

Medicaid. The ACA contains a provision requiring states to expand Medicaid eligibility, beginning January 1, 2014, to include most people with income up to 133% FPL (about $14,800/year for an individual and $30,000/year for a family of four). In its decision, the Supreme Court upheld the Medicaid expansion as constitutional, but ruled that the federal government may not withdraw *all* Medicaid funding from states that refuse to comply with the expansion. States that do not expand Medicaid eligibility will not receive *additional* funding, but will still get federal funding for their *existing* Medicaid programs. The Court's decision has the practical effect of making the Medicaid expansion optional for states. Nonetheless, the Medicaid expansion remains the most significant opportunity to expand access to care to thousands of currently uninsured women living with and at risk for HIV. Policy analysts predict that this change could result in coverage for up to 10 million women who are currently uninsured, including 34% of women living with HIV who are currently on Ryan White AIDS Drug Assistance Programs (ADAPs) (nearly 10,000 women).To ensure that the Medicaid expansion is implemented in ways that work for women living with or at risk for HIV:

1. *States must implement the ACA's Medicaid expansion requirement, taking advantage of the fact that the federal government will pay the overwhelming majority of the costs of the expansion (100% for the first three years, and decreasing only to 90% thereafter). Without Medicaid expansion, states' poorest residents will not have access to health insurance, as they will not be eligible for subsidized private insurance under state health insurance exchanges.*
2. *Benefits for newly-eligible beneficiaries must be able to meet care and treatment needs of women living with or at risk for HIV, and, among other benefits, must include access to comprehensive prescription drug coverage, mental and behavioral health services, reproductive health care services, and screenings for intimate partner violence;*
3. *States must utilize new opportunities within Medicaid to provide a range of family planning services to women with incomes above 133% of the FPL;*
4. *Medicaid outreach, eligibility, and application processes should be simple and implemented in ways that reduce churning and disruptions in care;*
5. *Quality measures must evaluate how well Medicaid is working to meet the care and treatment needs of women living with or at risk for HIV; and*
6. *Coordinated care models within Medicaid must address the needs of women living with or at risk for HIV and include family-centered care models (i.e., that integrate housing, childcare and nutrition support with treatment or prevention services).*

Private Insurance. Starting in 2014, states will be required to have "exchanges," which are regulated marketplaces that will allow consumers to compare and purchase health insurance plans. Insurance exchange markets have the potential to provide greater health security for women by allowing them to maintain coverage in the absence of employer-sponsored

options or long term job security. Approximately two-thirds of women have employer-sponsored health insurance, but suffer from disruption in coverage or provider networks when transitioning between jobs.[4] Only 7% of women are able to purchase individual coverage, leaving 18% uninsured.[5] The ACA provides federal assistance in the form of premium tax credits and cost-sharing subsidies to help people with income up to 400% FPL purchase coverage through the exchanges. All plans sold through exchanges must include an "Essential Health Benefits" package. In addition to affordability and benefits requirements, the ACA also makes it easier for people living with HIV (and other chronic conditions) to purchase private insurance by prohibiting many discriminatory insurance practices. While the federal government has outlined a number of important standards and requirements for exchange design, HHS has indicated that many implementation decisions will be left to states, making state-level advocacy particularly important. To ensure that private insurance reforms are implemented in ways that work for women living with or at risk for HIV:

1. *Stakeholder engagement processes for exchanges must incorporate the voices and experiences of women living with or at risk for HIV to ensure that exchanges are designed in ways that take into account the unique needs of these women;*

2. *Essential Health Benefits packages must be defined and implemented in ways that ensure access to comprehensive care and treatment for women living with or at risk for HIV;*

3. *The patient navigator program must be designed in ways that utilize the expertise of women living with or affected by HIV and enable the program to effectively reach this population; and*

4. *Monitoring and oversight mechanisms must ensure that non-discrimination and inclusion mandates that will bar discrimination against women living with HIV and expand access to comprehensive care are enforced.*

Investments in Health Infrastructure, Prevention, Wellness, and Workforce. In addition to the public and private insurance expansion provisions discussed above, the ACA includes a number of investments and initiatives aimed at increasing prevention and wellness and shoring up the nation's health workforce and community-based health care infrastructure. To ensure that health reform investments are used in ways that expand access to high-quality care for women living with and at risk for HIV:

1. *ACA investments in health infrastructure, including significant investments in community health centers, must ensure that clinics and programs are designed to meet the needs of women living with or at risk for HIV;*

2. *Investments in the Prevention and Public Health Fund must be allocated to HIV prevention initiatives geared toward women; and*

3. *Health professionals must be able to meet the care and treatment needs of women living with or at risk for HIV through training in cultural competence as well as integrated and women-focused HIV medical care.*

FILLING THE GAPS: ENSURING THAT ONGOING CARE, TREATMENT, AND SUPPORT SERVICES ARE MET

The Ryan White Program is changing – and must change – as the health care system as a whole undergoes a major transformation over the next several years. While it is too early to know the exact impact that many of the ACA provisions will have on access to HIV care (and thus too early to discuss any major transformations of the Ryan White Program), the HIV community has already started to think about how to ensure that the health care needs of women living with and at risk for HIV will be integrated into health care reform as well as the future role of the Ryan White Program. For example, advocates are working to ensure that the comprehensive support and linkage to care services that are the hallmark of Part D of the Ryan White Program (which provides family-centered services to 90,000 women and children living with and affected by HIV each year) are integrated into reforms. However, even after full implementation of the ACA, there will still be gaps in services, affordability, and populations covered, and the Ryan White Program must be able to exist effectively in a post health care reform world to ensure continued access to the vital services needed to connect women to care and keep them healthy.

Similarly, the National HIV/AIDS Strategy (NHAS) must be updated with goals and metrics specific to women living with or at risk for HIV, and fulfilling the goals of NHAS will be dependent on successful implementation of the ACA. Finally, ACA implementation is occurring against a backdrop of economic recession, a polarized political system, and increasing attacks on women's reproductive health care rights. This challenging environment makes it more important than ever that the statutory and regulatory provisions of the ACA are used to advocate for women's *right* to health care coverage and systems that work for them.

(ENDNOTES)

1 Samuel A. Bozzette, et al., "The Care of HIV-Infected Adults in the United States," New England J. of Medicine, 1998; 339(26), 1897-1904 at: http://www.nejm.org/doi/full/10.1056/NEJM199812243392606 (finding that 64% of women in medical care had incomes below $10,000, compared to 41% of men); Lucy Bradley-Springer, "Women and HIV Infection," J. of the Association of Nurses in AIDS Care, 2007; 19(1): 1-2 (finding that women with HIV were more likely to be living in poverty than men living with HIV); Mark A. Schuster, et al., "HIV-Infected Parents and their Children in the United States," American J. of Public Health, 2000; 90(7): 1074-1081, at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1446301/pdf/10897185.pdf (finding that 60% of women (in care) had children under 18 years of age, while 76% of those women had their children living with them); National Women's Law Center (NWLC), "Turning to Fairness: Insurance Discrimination Against Women Today and the Affordable Care Act," March 2012, at http://www.nwlc.org/sites/default/files/pdfs/nwlc_2012_turningtofairness_report.pdf (finding for example, that in states that still allow gender-rating, 92% of the best-selling plans charge 40-year old women higher premiums than men; and that the practice of gender-rating costs women approximately $1 billion per year); Martin F. Shapiro et al., "Variations in the Care of HIV-Infected Adults in the United States," J. of the American Medical Association, 1999; 281 (24): 2805-2815 (finding that women were less likely than men to have accessed combination therapy and had more hospitalizations and emergency room visits); L.R. Hirschhorn et al., "Gender Differences in Quality of HIV Care in Ryan White CARE Act-Funded Clinics," Women's Health Issues, 2006; 16(3)104-112 (finding that women are less likely than men to receive HAART, PCP prophylaxis, or know their Hepatitis C status despite being seen more regularly); see also John A. Fleishman, et al., "Hospital and Outpatient Health Services Utilization Among HIV-Infected Adults in Care 2000-2002," Medical Care, 2005; 43(9)(Supp.)(finding that women had higher rates of hospitalization and outpatient visits than men); Susan Reif, Kathryn Whetten, and Elena Wilson, Duke Center for Health Policy and Inequalities Research, Southern HIV/AIDS Strategy Initiative, "HIV/AIDS Epidemic in the South Reaches Crisis Proportions in Last Decade," December 2011, at http://globalhealth.duke.edu/news/2011/ResearchReportFinal3-12.pdf (finding that the South and the Northeast had the highest proportion of HIV infections and the highest rates of new HIV infections among women; and noting that in general the South has the highest HIV-related death rates and the highest level of HIV morbidity among people living with HIV/AIDS); See generally, Kaiser Family Foundation, "Women and HIV in the United States," March 2012, at http://www.kff.org/hivaids/upload/6092-10.pdf.

2 National Organization for Women, "Violence Against Women in the United States: Statistics," at http://www.now.org/issues/violence/stats.html; Seth C. Kalichman, et al., "Sexual Coercion, Domestic Violence, and Negotiating Condom Use Among Low-Income African American Women," J. of Women's Health, 1998; 7(3): 371-378 at http://online.liebertpub.com/doi/pdf/10.1089/jwh.1998.7.371; Black AIDS Institute, "Getting Real: Black Women Taking Charge in the Fight Against AIDS," December 2005, at http://www.blackaids.org/docs/12_05_women.pdf. Domestic violence rates among HIV-positive women may also be even greater: for example, Medical AIDS Outreach of Alabama in Montgomery initiated a study that included focus groups to examine the impact of intimate partner violence on women living with HIV. However, when they attempted to put together a control group of HIV-positive women who had not been impacted by intimate partner violence, they were unable to find a single client. Phone interview with Dr. Laurie Dill, Medical Director, Medical AIDS Outreach of Alabama, May 8, 2012.

3 For instance, studies have shown that women infected with HIV are at increased risk for a range of gynecological problems, including vaginitis, genital herpes, genital condylomata, pelvic inflammatory disease (PID), and lower genital tract dysplasia and neoplasia. Monique A. Tello, et al., "HIV Women's Health: A Study of Gynecological Healthcare Service Utilization in a U.S. Urban Clinic Population," J. of Women's Health, 2008; 17: 1609-2614 (citing multiple studies).

4 Lisa Codispoti, Brigette Courtot, & Jen Swedish, "Nowhere to Turn: How the Individual Health Insurance Market Fails Women," National Women's Law Center, at 3 (2008).

5 Id.

30 FOR 30 MEMBER ORGANIZATIONS

The Afiya Center HIV Prevention & Sexual Reproductive Justice, African Services Committee, AIDS Alabama, AIDS Alliance for Children Youth & Families, AIDS Foundation of Chicago, AIDS United, Bailey House, Campaign to End AIDS (C2EA), Center for Health and Gender Equity (CHANGE), Center for HIV Law and Policy (CHLP), Community Healthcare Network, HIV Law Project, HIV Prevention Justice Alliance, Housing Works, International Community of Women Living with HIV/AIDS (ICW), IRIS Center, Memphis Center for Reproductive Health, National AIDS Housing Coalition (NAHC), National Alliance of State and Territorial AIDS Directors (NASTAD); National Black Leadership Commission on AIDS, Inc. (NBLCA), National Black Women's HIV/AIDS Network (NBWHAN), National Health Law Program (NHeLP), National Network to End Domestic Violence (NNEDV), National Women and AIDS Collective (NWAC), Sisterlove Inc., SMART University, South Carolina HIV/AIDS Council, Southern HIV/AIDS Strategy Initiative (SASI), U.S. Positive Women's Network (PWN), The Well Project, The Women's Collective, Women Organized to Respond to Life-threatening Diseases (WORLD), Women with a Vision

WHO WE ARE:

The 30 for 30 Campaign is dedicated to ensuring that the unique needs of women living with and affected by HIV, including transgender women, are addressed in the national HIV response. We are especially committed to illuminating and eliminating the gaps in prevention and care services for Black and Latina women who currently make up over 80% of the epidemic among women.

CAMPAIGN CONTACT INFO:

For more information please visit our Facebook page at www.facebook.com/30for30, or email us at 30for30Campaign@gmail.com

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