

# 30<sup>FOR</sup>30 CAMPAIGN

## BRIEFING PAPER

# Ending HIV-Related Health Care Disparities for Women

Advocacy • Equity • Action

## Introduction

With the implementation of the National HIV/AIDS Strategy (NHAS), the Affordable Care Act (ACA), and the continuation of the Ryan White CARE Act, we find ourselves in a fast-paced and dramatically changing health care delivery environment for all people. For people living with or affected by HIV these changes will provide great opportunities and challenges.

The Affordable Care Act has already provided opportunities for strides in women's health including the adoption of the Institute of Medicine (IOM) guidelines on women's preventive health such as free HIV testing, intimate partner violence prevention and counseling, and sexually transmitted infections (STI) counseling. These types of critical services for women must also be explicitly integrated into HIV prevention and care.

## The U.S. National HIV/AIDS Strategy

The National HIV/AIDS Strategy (NHAS) is recognized as a game-changing development in the federal government's approach to the domestic HIV epidemic. Yet, in the creation of the NHAS, important opportunities were missed to effectively address the unique needs of women, including transgender women, living with and affected by HIV in the United States. This is especially surprising given that virtually all of the "Actions Needed" identified below in this paper were identified, articulated, and communicated during the NHAS planning process by multiple individuals and organizations. They are discussed specifically and in depth in reports issued by the National Black Leadership Commission on AIDS, Inc.,<sup>4</sup> summarizing their 2009 meeting on the topic, in a 2009 report from the Ford Foundation's Women and HIV Working Group<sup>5</sup>, and in the Gender Monitoring Tool for the U.S. National HIV/AIDS Strategy created and analyzed by a diverse group of organizations working on HIV and women in the U.S. and globally<sup>6</sup>. All of these reports were submitted to the Office of AIDS Policy and related executive agencies.

The 30 for 30 Campaign is dedicated to ensuring 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%<sup>1</sup> of the epidemic among women but only 12% and 14% of the U.S. female population respectively.<sup>2</sup>

The Campaign is concerned with the current state of HIV prevention and care for women as studies continue to show that women, especially women of color, have consistently poorer health outcomes despite there being no significant clinical difference in treating men or women living with HIV.<sup>3</sup>

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## Disparities for Women in the U.S.

Gender inequality, along with racial and ethnic disparities, have long been recognized as a key drivers of the epidemic<sup>7</sup> and were recognized as such by all United Nations members (including the U.S.) in the 2001 Declaration of Commitment in HIV/AIDS.<sup>8</sup> Research shows little clinical variance between women and men living with HIV.<sup>9</sup> Data summarized below, however, highlights the fact that U.S. women living with HIV experience substantial HIV treatment and health outcome disparities in comparison to men and suggest that these are the result of gender-related –as well as socioeconomic and racial and ethnic – factors.

This phenomenon is fueled by multiple types of discrimination, including those experienced by women of color and poor women generally in the U.S., as well as the discrimination and neglect experienced by much of the larger HIV community in the form of underfunded health care systems, discrimination in the work place, discrimination in or lack of affordable housing, and HIV-specific criminalization.<sup>10</sup>

The synergistic effects of sexism and racism are documented, for example, by 2008 Census data showing that African American women are paid 61 cents and Hispanic/Latina women 52 cents for every dollar paid to Caucasian men in the U.S.<sup>11</sup> At every educational level, women working full-time earn less than men in comparable positions.<sup>12</sup> A recent report on the “wealth gap” found that the median wealth of Caucasian single mothers in the U.S. stood at \$6,000 while that of African-American and Latino single mothers was zero.<sup>13</sup>

The non-HIV related health disparities experienced by women of color also illustrate the context contributing to poorer health outcomes of HIV-positive women and girls in the U.S. Cervical cancer is twice as common among Latina and Vietnamese women than among white women.<sup>14</sup> African American women die more frequently from breast cancer than white women<sup>15</sup> and have a 35% higher risk of dying of heart disease.<sup>16</sup> Latina women tend to get heart disease nearly a decade earlier than their white counterparts.<sup>17</sup> African-American babies are 2.4 times more likely to die than white babies<sup>18</sup> and African American women are four times more likely (and, in New York City alone, eight times more likely) to die from pregnancy-related causes than white women. The magnitude of this last disparity has been rising steadily since the mid-1990s.<sup>19</sup>

While the causes of these health disparities are complex and inter-connected, each points to deficiencies in access to medical care, screening and information for women of color and women who are poor, as well as much higher rates of inadequate or non-existent health insurance<sup>20</sup>.

Given these racial, ethnic and gender-based disparities, it is hardly surprising that 80% of women in the U.S. living with HIV are women of color<sup>21</sup> and that the rate of HIV infection among African American women is 21 times the rate among white women.<sup>22</sup> As Kai Wright of The Nation Institute observes, “[w]hen people don’t have the economic or emotional resources to protect themselves from a whole host of other threats, they can’t protect themselves from this virus either.”<sup>23</sup>

Research indicates only minor differences between the sexual risk-taking behaviors of white women and women of color<sup>24, 25</sup> but, as Tillerman put it, African-American women “are at high risk even when their behavior is considered low risk.”<sup>26</sup> Or, as Armstrong and del Rio observed, “poverty, intimate partner violence and food insecurity are increasingly recognized as factors significantly associated with increased high-risk sexual behaviors, decreased initiation and retention in care, and worse clinical outcomes. These are not easy challenges to solve, but they represent some of the most important social issues underlying health disparities in the United States.”<sup>27</sup>

For transgender women, health disparities are even more pronounced. As a report from the San Francisco AIDS Foundation states, “Around the world, transgender persons are at elevated risk for HIV infection, yet surveillance, research, programs, and policy pay little attention to transgender populations. This lack of attention is largely due to the extreme social and cultural marginalization such populations experience as a result of their challenges to prevailing notions of sex and gender.”<sup>28</sup>

The urgent need to respond to the worsening HIV epidemic among women and girls is undeniable. Women and girls comprise approximately 25%<sup>29</sup> of the HIV-positive population nationally. But this number does not tell the whole picture. HIV rates for transgender women are among the highest of any population<sup>30</sup> and HIV rates among women in specific age groups or in certain regions of the country such as the U.S. South or Northeast reflect a hard hit and under-resourced population. In Mississippi, for example, 39% of all HIV positive African American

and Latino youth between the ages of 13 and 24 are female.<sup>31</sup>

Secretary Sebelius expressed her own sense of urgency about this in her 2008 speech to the National HIV Prevention Conference when she noted that, if white women were contracting HIV at the same rates as Black women, HIV among women would be a national emergency by now.<sup>32</sup>

This paper highlights the major health disparities experienced by women and girls living with HIV and at high risk of HIV; and proposes actions that can be taken at the federal level to ameliorate them in the near future. The evidence base supporting these proposed actions is summarized briefly in this paper and reviewed in greater depth in Making HIV Prevention Work for Women and Making HIV Care and Treatment Work for Women. This paper focuses directly on three essential areas of action that, if taken now, could demonstrate to women the value of NHAS' promise to show that "serious progress can be made in reducing HIV-related health disparities."<sup>33</sup>

## TAKE ACTION NOW!

### Decrease HIV Related Health Disparities for Women

**1. ACTION NEEDED:** Expand and expedite the provision of women-centered facilitative supportive services and housing services for women living with and affected by HIV.

## WHAT WE PROPOSE

Linking and retaining women in HIV care requires supportive services such as adequate transportation assistance, childcare options, nutritional adequacy (when unmet leads to skipped appointments due to illness), and case management and peer support services to guide efforts to obtain HIV testing, medical and social services. Access to stable housing is an evidence-based HIV prevention strategy, as well as an essential component of effective, sustained medical care. These facilitative prevention and care services keep women in care and help to ameliorate the concrete consequences of the stigmatizing treatment women may experience in their community and from some service providers.

The majority of supportive and housing services are funded by the Health Resources and Services Admin-

istration (HRSA), the Housing and Urban Development (HUD) program Housing Opportunities for Persons with AIDS (HOPWA). HRSA and HUD's models are proven to be effective in linking women to and retaining them in care.

As health care reform is implemented through the Affordable Care Act, critical supportive and housing services must be more robustly funded and scaled up in order to link women living with or affected by HIV to the myriad new models of health care provision in their states. To do this we must ensure the continuation of the Ryan White CARE Act, and in particular services that address the reality of women living with HIV. Continuing supportive services that have been historically provided by the Part D program are critical for women living with HIV, many who have complex family and other obligations and/or challenges, such as mental health and substance use issues.

## WHY?

- HIV-positive women in the U.S. have 20% higher **death rates**<sup>34</sup>, **higher rates of hospitalization**<sup>35</sup>, and experience more than **twice as many HIV-related and AIDS-defining illnesses** per person than their male counterparts.<sup>36</sup>
- In 2008, 64% of women in ongoing HIV care had **annual incomes below \$10,000**, compared to 41% of men.<sup>37</sup> An earlier study showed that 73% of the positive women surveyed had a high school education or less, while only 46% of the men were that poorly educated.<sup>38</sup>
- More than twice as many HIV-positive women (76%) as HIV positive men (34%) are **living with, and caring for, children under 18**.<sup>39</sup> Adherence to a prescribed anti-retroviral treatment (ART) regimen tends to *decrease* among women living with HIV as the number of minor children living in the home *increases*.<sup>40</sup> This is likely due to women's propensity to provide for their children's needs before their own.<sup>41,42,43</sup> In one study, for example, more than 10% of HIV-positive women in treatment reported going without medical care for themselves in order to pay for household food and other necessities.<sup>44</sup> In a study of 700 American women living with HIV, 53% identified themselves as **caregivers** and 43% reported that having HIV made it harder to fulfill these responsibilities.<sup>45</sup>
- **75% of U.S. women living with HIV must house both themselves and their children.** 84% of all homeless families in the U.S. are comprised of single women with children. People whose housing status has worsened are four times

more likely to exchange sex for money or other necessities, while those whose housing situations improve tend to reduce their HIV risk behaviors by half.<sup>46</sup> Stable housing is vital to ARV treatment adherence<sup>47</sup> and highly cost-effective, given that the prevention of even one new HIV infection can save up to \$300,000 in treatment.<sup>48</sup>

- **Case management** services help people with HIV to stay in care and adhere to ARV regimens more consistently.<sup>49,50</sup> In a study conducted in ten U.S. cities, 78% of all participants with case management services were using medical care within six months of enrolment; a rate 30% higher than among those not using case management.<sup>51</sup>
- Lack of a vehicle or money for public **transportation** combined with the sparseness of HIV-experienced health care providers in many areas can be major barriers to accessing care. In one North Carolina study, for example 58% of rural HIV case managers and 30% of urban case managers lack of transportation as the major barrier to care.<sup>52</sup>
- **Food insecurity** compromises the effectiveness of medication prescribed to people living with HIV because adequate daily nutrition is required for effective medication absorption. It also reduces ART-induced side effects, which, in turn, can affect compliance with one's ART regimen. In-home food delivery services ("meals on wheels") cost an average of \$1,507 per person per year<sup>53</sup>, making provision of this or comparable services over three hundred times cheaper than the average \$2,000 per day hospital cost for a person living with HIV.<sup>54</sup>
- Research has shown that these **integrated and facilitative supportive services are ultimately cost-effective** for two reasons: 1) Unlike service delivery designed for individuals, each dollar spent on these services benefits multiple people, given that women are frequently the primary caregivers for their children. 2) Without such services, "treatment as prevention" strategies cannot work because women most in need will be lost to or fall out of critical HIV care.

**2. ACTION NEEDED:** Women-centered integrated care must be more widely and readily available.

## WHAT WE PROPOSE

Relevant agencies must work to integrate service delivery and provider training in the three health care delivery areas of greatest importance to women

living with or affected by HIV: 1) HIV prevention, treatment and care; 2) sexual and reproductive health services; and 3) intimate partner violence prevention and counseling. Siloed provision of these services forfeits opportunities to engage women in HIV testing, improve their prevention behaviors, and assure the access to care and information needed by HIV-positive women.

Healthcare providers who serve women through funding from the Centers for Disease Control (CDC) for HIV testing; Health Resources and Services Administration (HRSA) for supportive and HIV medical services; Centers for Medicare & Medicaid Services (CMS) for Medicaid and Medicare services; the Office of Family Planning (OFP) for Title X family planning services; and the Office of Women's Health (OWH) for intimate partner violence services, serve overlapping populations of women, many of whom are at higher risk for HIV. These healthcare providers must be mandated to collaborate and coordinate with each other to provide integrated health services to women.

The implementation of the Affordable Care Act necessitates immediate action is needed to increase the number of providers with HIV expertise in Federally Qualified Health Centers (FQHCs) and other Medicaid-funded provider sites, particularly in Southern states and rural areas. The AIDS Education Training Centers (AETC) training in cultural competency received by new care givers (as per NHAS plans) must be expanded to include cross-cultural training on gender-related issues including sex roles, intimate partner violence (also called gender-based violence), pregnancy prevention and planning, and the health and service needs of transgender women.

## WHY?

- Nearly **5 million women accessed federally funded family planning** services in 2010, but **fewer than 2 in 10 of them accessed HIV testing** during their clinic visits.<sup>55</sup> This is a missed opportunity. Of the 17.4 million women who needed publicly funded contraceptive care in 2008, 71% either had an income below 250% of the federal poverty level or were, themselves, below the age of 20.<sup>56</sup>
- At least 12% of HIV/AIDS infections among women in romantic relationships are due to **intimate partner violence** (IPV) and this figure is considered by researchers to be an underestimate".<sup>57</sup> Despite this, fewer than 10% of all providers of HIV services routinely screen for intimate partner violence.<sup>58</sup>



■ **Integrating HIV services** into other services commonly used by women results in reaching greater numbers of women and offering them HIV-related care in environments in which they are already comfortable. One 2-year pilot program in Zimbabwe increased its clients' use of male and female condoms significantly and boosted its rate of referrals to HIV voluntary counseling and testing (VCT) centers from less than 50 to more than 2,000.<sup>59</sup> A Nigerian organization's decision to co-locate its family planning and HIV clinics resulted in significant increase in clinic attendance. The providers also noted that women at the family planning clinics who were referred there by the neighboring HIV clinics were more likely to be accompanied by their male partners than were women who had not been referred.<sup>60</sup>

■ Here in the U.S., the Memphis Center for Reproductive Health, known as Choices, created an initiative to **encourage women living with HIV to access sexual and reproductive health (SRH) care through their reproductive health clinics**. It took concerted networking to persuade HIV clinicians and service providers that they could make referrals to Choices without concern that their patients would be stigmatized. Gradually the trust-building paid off and the referrals started. In 2011, Choices provided SRH medical services and counseling to 114 women and men living with HIV, after having served none (to their knowledge) in previous years.<sup>61</sup> Choices also successfully integrated opt-out HIV screening for all those seeking SRH medical services, providing over 3,500 rapid HIV tests annually since 2007.

■ Evidence of persistent of **HIV-related stigma** was documented by a 2007 American Foundation for AIDS Research (amFAR) survey of Americans. One third of respondents said they did not support an HIV-positive woman's choice to become pregnant despite antiretroviral therapy to prevent vertical transmission. Only 14% believed HIV-positive women should be able to have children.<sup>62</sup>

■ A 2008 survey of 181 HIV-positive women of reproductive age in urban health clinics showed that only **31% had discussed their reproductive options with health care providers** and, of those, **64% said they had to initiate that conversation, themselves**.<sup>63</sup> In a national survey of 160 self-identified HIV positive women, only 22% had spoken with their doctor about their reproductive options.<sup>64</sup>

■ Access to care by **providers who can be trusted to be non-stigmatizing and gender-responsive**

**is particularly vital to transgender women and girls** - virtually all of whom have experienced discrimination, and often violence, at the hands of their families, partners, health care providers, and/or a wide range of social institutions. This life experience makes it uniquely challenging for them to access HIV and SRH-related care. Avoidance of such care routinely occurs, according to Sevelius et al., because of "stigma and past negative experiences with providers, prioritization of gender-related health care, and concerns about adverse interactions between antiretroviral medication and hormone therapy".<sup>65</sup> Transgender women and girls are rarely offered transgender-competent care and are also unable to access IPV services at shelters and other programs that exclude transgender participation despite recent policy changes that bar this discrimination. Thus, they have a high unmet need for IPV prevention and treatment services from providers who have received the necessary cross-cultural training to serve them appropriately and with the necessary expertise.

**3. ACTION NEEDED:** Produce better data and more targeted research to identify and address women's needs. All data must be disaggregated by sex and gender. Women-controlled prevention tools must be developed and made available.

### WHAT WE PROPOSE

Available data on service and treatment delivery is rarely disaggregated by gender, making it impossible to accurately quantify existing gaps in services and their impact on women and girls. We do not know, for example, the gender break-out among people living with HIV whose viral load is currently undetectable, or the number of women on ADAP waiting lists, or what percentage of condoms purchased by state health departments are female condoms. Worse, transgender women are often completely missed or not accurately counted in HIV surveillance data due to provider discomfort around talking about gender identity.<sup>66</sup> All reports of federally funded medical care, service delivery, and prevention programming must require data disaggregated by gender to correct this situation.

As yet there are no women-controlled prevention tools available. Male condoms aren't enough and female condoms cannot be used without a partner's knowledge and consent. Women urgently need expanded investment in and research into current

and future HIV prevention tools including female condoms, Treatment as Prevention (TasP), Pre-exposure Prophylaxis (PrEP), microbicides and a better understanding of the impact of hormonal contraception use on HIV risk.

## WHY?

- There is no mention of the need to disaggregate data by sex or gender (or of plans to do so) in the National HIV/AIDS Strategy and its Implementation Plan. The Global Fund to Fight AIDS, TB, and Malaria urges countries to **collect sex-disaggregated data to accurately measure access to HIV services for specific high-risk populations**. The World Health Organization and UNAIDS identify the systematic disaggregation of data by sex and age as one of eight critical steps to improve HIV programming for women and girls.<sup>67</sup> This omission in the U.S. may be explained, in part, by the observation in a 2009 policy analysis that, “countries and regions with low-level or concentrated HIV epidemics lag behind countries with generalized epidemics in integrating women-focused policies into national frameworks.”<sup>68</sup> Correction of this oversight, however, is overdue given that the CDC characterizes several U.S. cities as now having generalized HIV epidemics,<sup>69,70</sup> and has acknowledged that transgender women are likely at higher risk for HIV than any other group, yet there are no national standards for collecting reliable data on HIV and transgender people<sup>71</sup>.
- Research shows that male condom use among African American women ranges from 33%<sup>72,73</sup> to 53%<sup>74</sup> of women surveyed. Factors that render women unwilling or unable to insist on male condom use include **financial dependency, lack of equal power in relationships, the risk that conflict, violence, or loss of relationship may result from requesting condom use**, and the sex-ratio imbalance in African American communities that makes replacement of a relationship more difficult.<sup>75, 76</sup>
- One study among inner-city African-American women showed that participants with multiple sexual partners were **five times more likely to use female condoms than monogamous women, once the product was effectively introduced**

**and provided.**<sup>77</sup> Women who receive female condom skills training have been shown not only to use female condoms more frequently over time but also to have fewer unprotected sex acts overall (that is, use some form of condom -- whether a male or female model -- more frequently.)<sup>78,79</sup> This has been validated in multiple international trials but few domestic trials. More domestic data is needed.

- **Sex differences impact a range of HIV issues and will have serious implications for the treatment and prevention of HIV**<sup>80</sup>. More research is needed to accurately assess the effectiveness of PrEP use by women, as well as its possible impact on pregnancy and breast-feeding. Although the Partners PrEP trial suggested that Pre-exposure Prophylaxis (PrEP) was effective among women participating as part of a sero-discordant, heterosexual couple<sup>81</sup>, this effectiveness was not evident in the Fem-PrEP trial,<sup>82</sup> the tenofovir-only oral PrEP arm of the VOICE trial,<sup>83</sup> or the iPrex trial that included transgender women but lacked significant enough numbers to evaluate transgender-specific efficacy. The CDC’s TDF 2 trial showed effectiveness among participants overall. It was not large enough, however, to show conclusively whether the level of protection provided to women differed at all from the level provided to men.<sup>84</sup>

## Conclusion

The 30 for 30 Campaign was founded to guarantee the unique needs of women living with and affected by HIV, including transgender women, are met in this changing health care delivery and prevention environment. The Campaign is made up of a diverse and far-reaching group of organizations from every region of the United States. We include national and local advocacy and service delivery organizations – all dedicated to ensuring that the health and rights of women living with and affected by HIV/AIDS are upheld. With confidence and urgency the Campaign encourages policy makers to take swift action to implement accountability measures and the HIV prevention, care and treatment programs and services we know work for women.

**Chairperson:** C. Virginia Fields, MSW

**Consultant:** Anna Forbes, MSS

**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 Black Leadership Commission on AIDS, Inc., (NBLCA), National Black Women's HIV/AIDS Network (NBWHAN), National Health Law Program (NHeLP), 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

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