

**A REPORT ON  
WOMEN AND HIV/AIDS  
IN THE U.S.**

**APRIL 2013**

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## INTRODUCTION

The story of women and HIV in the United States (U.S.) spans more than three decades and involves a complex history. Women have been affected since the beginning of the epidemic, yet that impact has not always been recognized. In the early years, high profile – albeit less common – cases of women being infected through blood transfusions attracted headlines as so-called “innocent victims” of the epidemic. Injection drug use (IDU) was in fact the most common initial cause attributed to cases among women.<sup>1</sup> By the mid-1990s, however, heterosexual transmission became – and remains today – the most common means of infection among U.S. women.<sup>2,3</sup>

New infections rose sharply among women during the first decade of the epidemic.<sup>4,5</sup> Women accounted for a rising share of new infections until the early 1990s, after which rates stabilized, remaining stubbornly at the same level for much of the next two decades until recently.<sup>3,4,5</sup> Today, women account for one in four of the more than 1.1 million people living with HIV in this country, and one in five new infections.<sup>3,6</sup> Black women are disproportionately affected, accounting for the majority of new cases among women, as they have since the very early days of the epidemic.<sup>2,3</sup>

In December 2012, the U.S. Centers for Disease Control and Prevention (CDC) reported a significant 21% decrease in new HIV infections among women overall – including a similar decrease among Black women – between 2008 and 2010. While this news is encouraging, rates remain high among women of color. It is estimated that one in 32 Black women today will be diagnosed with HIV at some point in her lifetime.<sup>7</sup>

There are numerous factors that combine to put women at risk for HIV today and can make it more difficult for them to obtain needed care and services. These include issues that are specific to women, as well as those that affect people with HIV generally, including: socioeconomic and structural barriers, such as poverty and cultural inequities; sexual violence; lack of awareness of HIV status; and ongoing stigma. Women also have physiologic differences in HIV acquisition and clinical symptoms.

Insurance coverage, including through the public sector, has been shown to make an important difference in helping to improve access to health care and health outcomes in the U.S., including for people with HIV. Most women with HIV rely on public programs, such as Medicaid and the Ryan White HIV/AIDS Program, including its AIDS Drug Assistance Program (ADAP), for their care and coverage. One in four (23%) have no insurance at all, many of whom rely on the Ryan White Program.

The reduction of mother-to-child HIV transmission is among the notable successes of the past two decades in the fight against HIV. As a result of more routinized screening of pregnant women for HIV and corresponding treatment for those who are positive, mother-to-child HIV transmission is extremely rare in the U.S. today. Another success is the decrease in HIV transmission as a result of intravenous drug use, which today represents a small share of new infections.

### **An Issue That Hits Close To Home for Many Women**

HIV has touched the lives of many Americans. According to a 2011 national survey by the Kaiser Family Foundation, two in five Americans – including more than half of Black Americans – now know someone living with or who has died of HIV; for many, this is a family member or close friend. Women, especially Black women who have been disproportionately affected by the disease, are concerned about HIV both for themselves and their families. One in two Black women say they are *personally* concerned about becoming infected, and those who are mothers of children 21 and younger are even more likely to report concern about their sons’ and daughters’ risk.

*For more about women’s knowledge and attitudes about HIV/AIDS, go to page 21.*

***As mothers, sisters, daughters, friends, partners, activists, researchers, and also people living with HIV, women play a critical role in addressing HIV in this country.***

As the epidemic enters its fourth decade, there is cause for hope, with many experts saying that the end of AIDS, at least scientifically, is possible.

There is now evidence that antiretroviral treatment (ART) not only acts to improve health and extend life for those who are positive, but also significantly reduces the risk of HIV transmission to others – by as much as 96%.<sup>8</sup> The benefits of these treatments, though, are predicated on more people with HIV – including women – knowing their status, getting into regular care, and staying on treatment. This remains one of the greatest barriers to realizing an AIDS free future. Indeed, most people with HIV in the U.S. today, including most women who are HIV-positive, are not on treatment and consequently, not virally suppressed. Only one in four (26%) women with HIV have their virus suppressed through ongoing treatment.<sup>143</sup>

As mothers, sisters, daughters, friends, partners, activists, researchers, and also people living with HIV, women play a critical role in addressing HIV in this country. There are countless examples of strong women leaders in the fight against HIV in all of these arenas, and women’s engagement will continue to be critical in the move toward a future without AIDS.

This report maps the trajectory of the epidemic among women in the U.S., including key historical and epidemiologic trends and the important role played by women in the response over time; the current impact of HIV among women in the U.S., including a profile of those most affected by race/ethnicity, age, transmission risk, geography, and other demographics; major sources of prevention, care, and treatment for women with and at risk for HIV; attitudes toward and knowledge about HIV among women; and ongoing challenges and opportunities. While HIV has impacted women worldwide – globally, women comprise half of all those living with HIV – this report focuses on the impact of HIV on women in the U.S.

## **HISTORY: 1981-2013<sup>9</sup>**

### **1981 – 1984**

On June 5, 1981, the CDC issued its first account about a relatively rare form of pneumonia among a small group of young gay men in Los Angeles, which was later determined to be AIDS-related.<sup>10</sup> Cases began to multiply, and case fatality rates were high. While most early cases were reported among gay men – indeed, one of the first names given to this new illness was “GRID,” or gay-related immune deficiency<sup>11</sup> – women were also being affected, accounting for 8% of new infections by 1981.<sup>4,5</sup>

Public health officials struggled to keep up with increasing cases. Gay men, injection drug users, and, to a lesser extent, hemophiliacs, were identified as being at “highest risk.”<sup>1</sup> Where cases were documented among women, most were attributable to injection drug use and a few higher profile cases to blood transfusions.<sup>1,2,12</sup> Heterosexual transmission was, for the most part, initially not yet on the radar. In 1983, the CDC published its first official report of immunodeficiency occurring among the female sexual partners of men with AIDS, supporting “the possibility that transmission of the putative ‘AIDS agent’ may occur among both heterosexual and homosexual couples” and beginning to establish this as a potential new route of transmission.<sup>13</sup> There was also increasing concern about the possibility of perinatal (mother-to-child) transmission.

Women began to organize in response to the emerging epidemic, both as part of a larger community mobilization effort with gay men, as well as in recognition of the epidemic’s impact on women. In 1983, at the second National AIDS Forum in Denver, the Women’s AIDS Network was established, evolving into an advocacy voice and source of information on AIDS for women going forward.<sup>14</sup>

In 1984, Human Immunodeficiency Virus (HIV), the virus that causes AIDS, was finally identified by scientists, paving the way for the development of the first HIV test.<sup>15</sup>

### **1985 – 1989**

The late 1980s saw an increasing focus on maternal-to-child transmission. In 1985, the first test for detecting antibodies to the newly discovered virus was developed.<sup>16</sup> Later that year, CDC issued guidelines recommending HIV counseling and testing for “at-risk” pregnant women and women who may become pregnant.<sup>17</sup> Routine counseling and testing for any woman not in a risk group was not recommended in these early guidelines. The guidelines further recommended that women who were positive consider delaying pregnancy and warned about the possibility of transmission through breastfeeding.

In 1988, the Pediatric AIDS Foundation was founded by Elizabeth Glaser (the wife of actor Paul Glaser), who had been infected with HIV in 1981 from a blood transfusion during childbirth and unknowingly passed the virus to her two children; it was not until they were tested for HIV in 1985 that they learned of their infection. Today, the Elizabeth Glaser Pediatric AIDS Foundation, renamed for Elizabeth Glaser following her death, continues to play a significant role working to prevent pediatric HIV infection in the U.S. and worldwide.<sup>18</sup>

New infections among women escalated sharply in the second half of the 1980s, peaking by around 1990.<sup>4,5</sup> During these years, high profile women began to speak out more publicly about the epidemic. Elizabeth Taylor, one of the first public figures to address HIV and founder of amfAR (The Foundation for AIDS Research) in 1985 with Dr. Mathilde Krim, played a critical role in drawing public attention to the epidemic in its early years.<sup>19</sup> Madonna held her first AIDS benefit concert in 1987.<sup>20</sup> And, in her first speech as a new member of Congress in 1987, Representative Nancy Pelosi (D-CA) stressed the need for leadership in addressing the emerging AIDS crisis;

soon thereafter, she co-sponsored legislation that helped create HOPWA, the Housing Opportunities for Persons with AIDS program, which provides housing support to low-income people with HIV and their families.<sup>21</sup> Congresswoman Pelosi remains a champion on HIV issues today.

New community organizations were created, such as the Women and AIDS Resource Network (WARN) founded in New York in 1986 by Marie St. Cyr;<sup>12</sup> the New Jersey Women and AIDS Network (NJWAN), the first state-wide organization for women and AIDS, founded in 1988;<sup>22</sup> SisterLove, founded by Dázon Dixon Diallo in Atlanta in 1989;<sup>23</sup> and the HIV Law Project, founded by Terry McGovern in New York in 1989.<sup>24</sup> These organizations continue to address the epidemic among women today.

Even as scientific understanding of HIV was increasing, misconceptions about women's risk still abounded. For example, in 1988, *Cosmopolitan*, the popular women's magazine, published an article<sup>25</sup> claiming that women had virtually no risk for HIV during heterosexual sex, stating that it was "impossible to transmit HIV in the 'missionary position.'"<sup>26</sup> The article prompted protests by women in ACT UP (AIDS Coalition to Unleash Power), an advocacy organization, including a demonstration at *Cosmopolitan's* offices.<sup>27</sup>

Barriers also emerged to understanding the specific needs of women, including the effects of emerging HIV treatments on women. Most notably, U.S. Food and Drug Administration (FDA) regulations limited the inclusion of women of childbearing age in clinical trials.<sup>28</sup> Even when women could be included in trials, few were. Women with HIV and their advocates began to challenge these regulations, eventually leading to important changes.<sup>29</sup>

The first national HIV/AIDS campaigns using television and print advertising also emerged in the late 1980s. In 1987, for example, the CDC launched *America Responds to AIDS*, the first government-sponsored, national public education campaign to address the epidemic.<sup>30</sup> The campaign aimed to reframe the disease from one that only affected gay men to one that affected the country as a whole, including both men and women.

## 1990 – 1994

By the second decade of the epidemic, activism focused on the needs of women with HIV continued to grow, resulting in increased national attention and important changes in HIV-related research and services. In 1990, the National Institutes of Health (NIH) convened the first National Conference on Women and HIV.<sup>31</sup>

Around the same time, activists began calling for an expansion of the CDC's case definition of AIDS, which had primarily been based on infections found in gay men, to include conditions specific to women, as well as injection drug users and other affected groups. It was becoming increasingly clear that women with HIV were at increased risk for cervical cancer as well as other gynecological complications due to HIV-related immunodeficiency, but these conditions were not captured in the case definition. This was of particular concern because other federal agencies, such as the Social Security Administration (SSA), used the CDC's case definition for determining eligibility for services. Led by the HIV Law Project, activists sued the SSA (*S.P. v. Sullivan*) in 1990 to challenge the denial of access to these benefits to women based on the agency's use of the CDC's case definition.<sup>24,32</sup> Three years later, the CDC expanded its case definition to include cervical cancer, among other conditions, and the SSA revised its eligibility determination criteria to include cervical cancer and other conditions specific to women.<sup>32,33</sup>

Several important research developments also occurred during this period. The NIH Revitalization Act of 1993 required the NIH and other agencies to expand the involvement of women and minorities in research studies.<sup>34</sup> That same year, the NIH launched the Women's Interagency HIV Study (WIHS) and the HIV Epidemiology Study (HERS), the first major U.S. federally-funded research studies on women and HIV.<sup>15,35</sup> Also in 1993, the FDA approved the first female condom.<sup>36</sup>

The next year, in 1994, after the release of results from ACTG 076, a trial sponsored by the NIH which showed that AZT taken by pregnant women with HIV reduced transmission of HIV by up to 70% in newborns,<sup>37</sup> the U.S. Public Health Service issued recommendations for universal counseling and voluntary HIV testing of all pregnant women, and treatment for those infected.<sup>38</sup>

Women were also helping to garner more attention to HIV in the political arena. HIV-positive women, Elizabeth Glaser and Mary Fisher, spoke at the 1992 Democratic and Republican National Conventions, respectively. Elizabeth Glaser focused her comments on the inaction of the government in response to HIV.<sup>39</sup> Mary Fisher, one of the first women to speak out publicly about acquiring HIV sexually, helped to move the conversation about HIV and women from an “innocent victims” portrayal to the acknowledgement that women had been contracting HIV sexually since the start of the epidemic. Both women helped to open up public understanding of HIV as a disease that was affecting women.<sup>40</sup> Shortly thereafter, in 1993, President Clinton appointed Dr. Kristine Gebbie as the nation’s first “AIDS Czar.”<sup>41</sup>

Another woman who helped bring national attention to HIV around this time was Jeanne White-Ginder, whose young son Ryan was infected through a blood transfusion and became one of the most recognizable faces of the epidemic. Ryan was expelled from school due to his HIV status and he and Jeanne chose to speak out about the discrimination he faced.<sup>42</sup> The Ryan White HIV/AIDS Program, named after Ryan, was first authorized in 1990<sup>43</sup> and it continues to be one of the most important sources of care for people with HIV in the U.S.

Also in 1990, film and Broadway star Sheryl Lee Ralph started The DIVA (Divinely Inspired Victoriously Aware) Foundation as a memorial to the many friends she lost to AIDS.<sup>44</sup> In addition, Cookie Johnson, the wife of basketball player Earvin “Magic” Johnson, became another female face drawing attention to the importance of combatting HIV as she stood by her husband when he announced to the world he was HIV-positive in 1991.<sup>45</sup> At the time, Cookie was expecting her first child, and both she and the baby remained HIV-negative. Today, Cookie and Magic Johnson are among the most recognizable voices on HIV.

Additional community and non-profit organizations devoted to addressing the needs of women also formed in these years, including WORLD (Women Organized to Respond to Life-threatening Disease), established in 1991 by Rebecca Denison, herself HIV-positive;<sup>46</sup> Women Alive founded by a group of HIV-positive women in Los Angeles in 1993;<sup>47</sup> and Iris House, founded in New York in 1993.<sup>48</sup>

In 1994, Rae Lewis-Thornton, an African-American woman living with HIV, was featured on the cover of *Essence* magazine, and was interviewed about her experience.<sup>49</sup>

## **1995 – 1999**

After declining from its peak around 1990, HIV incidence among women remained relatively stable during the second half of the decade.<sup>4,5</sup> The emergence of combination ART in 1996 dramatically changed the landscape of the epidemic in the U.S., resulting in significant drops in HIV-related morbidity and mortality. Finally some hope could be offered to those who tested positive. However, studies showed that in the first few years of the availability of ART, women were less likely to get access and therefore, lagged in showing an improvement in health outcomes as compared with men.<sup>50,51</sup> While these disparities dissipated over time, and no longer exist today, they raised concerns among public health officials and women affected by HIV.

The first federal treatment guidelines for HIV were published in 1998. While the guidelines included a section on treatment for pregnant HIV-positive women,<sup>52</sup> there was still relatively little guidance for clinicians treating women with HIV in the U.S.

Women's advocates continued to organize to draw attention to the needs of those living with HIV. In 1995, actress Sharon Stone became chair of amfAR's Campaign for AIDS Research, and has continued to work to raise HIV awareness.<sup>53</sup> Additional organizations devoted to addressing the needs of women emerged, including the Women's Information Service and Exchange (WISE), founded by Dawn Averitt Bridge in 1995 who learned she was HIV-positive in 1988, to focus on treatment information and advocacy specifically for women with HIV;<sup>54</sup> and the Women's Collective, founded by Patricia Nalls in 1995, who learned she was HIV-positive in 1987 after losing her husband and daughter to the disease, to provide support and services to other HIV-positive women.<sup>55</sup> In 1996, Rebecca Denison (founder of WORLD), delivered twin girls and became one of the first HIV-positive women to talk about her decision to have children.

In 1995, Dr. Helene Gayle, an early expert in HIV who went to work at the CDC shortly after her residency, was named the first director of the CDC's National Center for HIV, STD and TB Prevention.<sup>56</sup> In 1997, another woman, Sandy Thurman, the Executive Director of AID Atlanta, the Southeast's largest AIDS service organization, was named the nation's second AIDS Czar by President Clinton.<sup>57</sup>

In 1998, as part of a partnership with the Kaiser Family Foundation, MTV produced *True Life: It Could Be You*, a documentary that followed two young HIV-positive women, Rebecca Guberman and Jennifer Jako, as they traveled the country talking to other young people living with HIV/AIDS.<sup>58</sup>

By the late 1990s, there was increasing attention to the epidemic's growing impact on Black Americans, including Black women. In 1998, the Congressional Black Caucus (CBC), led by then Chair Representative Maxine Waters (D-CA), called for a state of emergency in the Black community due the AIDS crisis and helped to establish the federal Minority AIDS Initiative.<sup>59,60,61</sup> Fellow CBC Members Representatives Barbara Lee (D-CA) and Donna Christian-Christensen (D-VI) were also actively involved and remain leaders on combatting the epidemic today.

## **2000 – 2004**

In 2001, twenty years after the first case of AIDS was diagnosed, the U.S. Department of Health and Human Services released the first comprehensive guide to the clinical care of women with HIV. Stating that "[t]he growing number of women living with HIV/AIDS is a dominant feature of the evolving epidemic," the guide brought attention to the challenges faced by women with HIV, including delayed diagnosis and poorer access to care and medications.<sup>62</sup> It also addressed some of the added risks faced by HIV-positive women, such as domestic violence, and highlighted the important role played by women as caretakers for others living with HIV.

In an effort to further address the under-representation of women in HIV clinical trials, in 2000 the FDA issued new regulations, the "Clinical Hold Rule," allowing the agency to delay or suspend any clinical trial found to exclude women (or men) because of their "reproductive potential."<sup>63</sup>

In 2002, The Well Project was formed by Dawn Averitt Bridge and other women living with HIV to advocate for treatment and research specific to the needs of women;<sup>64</sup> in 2003, it established the Women's Research Initiative on HIV/AIDS (WRI), to help expedite HIV treatment and prevention research on women and girls and identify gaps in clinical care and research.<sup>65</sup>

## **2005 – 2009**

In 2006, which marked the 25<sup>th</sup> year of the AIDS epidemic, the CDC updated its HIV testing guidelines calling, for the first time, for routine voluntary HIV testing for all people ages 13-64 in the United States, and strengthening the recommendation for routine HIV testing for all pregnant women.<sup>66</sup> Also in 2006, the first National Women and

Girls HIV/AIDS Awareness Day (March 10) was held to bring attention to the impact of the disease on women, who at that time, accounted for about a quarter of new infections in the U.S.<sup>4,5,67</sup> In 2008, the CDC launched the *One Test. Two Lives.* campaign to focus on ensuring that all women are tested for HIV early in their pregnancy.<sup>68</sup>

Additional key organizations addressing the needs of women with HIV were formed in these years. In 2005, the National Women and AIDS Collective (NWAC), housed at the Ms. Foundation for Women, was created to advocate and build the capacity of women-led and serving organizations.<sup>69,70</sup> In 2007, the National Black Women's HIV/AIDS Network (NBWHAN) formed<sup>71</sup> and in 2008, the U.S. Positive Women's Network (PWN), a project of WORLD, was launched.<sup>72</sup>

Women with HIV continued to speak out. In 2006, Jennifer Jako, who had been infected with HIV 15 years earlier, appeared seven months pregnant on the cover of *Newsweek* to mark the magazine's "AIDS at 25" coverage.<sup>73</sup> The article highlighted her efforts to become pregnant as an HIV-positive woman. Receiving antiretroviral therapy during her pregnancy, she gave birth to an HIV-negative daughter.

In 2006, Regan Hofmann became the first female editor-in-chief of POZ Magazine, a publication for people living with HIV, and publicly announced her own HIV-positive status.<sup>74</sup> In 2005, Marvelyn Brown, a young HIV activist from Nashville, shared her story in a special TV program, co-produced by BET and the Kaiser Family Foundation, as part of the *Rap It Up* campaign. In 2008, Marvelyn published her autobiography, *The Naked Truth: Young, Beautiful and (HIV) Positive*, about her life with HIV.<sup>75</sup>

In 2009, a second generation female condom, the FC2, which is cheaper and easier to use, was approved by the FDA.<sup>36</sup>

By the end of the third decade of the epidemic, momentum began to build among activists for the need for a comprehensive national HIV/AIDS strategy for the U.S. In 2008, then Presidential-candidate Barack Obama pledged that, if elected, he would refocus attention on the U.S. domestic epidemic and create such a strategy, a promise he began to fulfill when he took office in 2009. Many groups provided input on the proposed strategy, including a coalition of 14 U.S. organizations working on issues facing women and HIV.<sup>76</sup> At the end of 2009, the White House held what was heralded as a historic meeting focused on women and HIV.<sup>77</sup>

## **2010 – Present**

On July 13, 2010, President Obama released the first comprehensive strategy for the domestic epidemic.<sup>78</sup> The strategy includes three goals: to reduce HIV incidence, increase access to care and optimize health outcomes, and reduce HIV-related health disparities. While the strategy addresses the impact of HIV on women, some have called for a greater focus, including a coalition of women's groups that developed a gender audit of the strategy and recommendations for its implementation from a gender perspective.<sup>79</sup>

Also in 2010, the President signed comprehensive health reform legislation, the Affordable Care Act (ACA), into law.<sup>80</sup> The ACA will expand health insurance coverage for millions of people, including many women with HIV.<sup>81</sup>

In 2011, Representative Barbara Lee (D-CA), along with Representatives Jim McDermott (D-WA) and Trent Franks (R-AZ), announced the formation of the Congressional HIV/AIDS Caucus, a bipartisan effort to fight HIV at home and abroad (formerly the Congressional Task Force on International HIV/AIDS, founded in 1992).<sup>82</sup>

Prominent female officials in the Obama Administration have also spoken publicly about the importance of addressing HIV and the impact of the disease in their own lives, including Valerie Jarrett, Senior Advisor to the President and Chair of the White House Council on Women and Girls, and Surgeon General Regina Benjamin.<sup>83</sup>

In 2012, the Obama Administration released a Presidential Memorandum creating the “Intersection of HIV/AIDS, Violence against Women and Girls, and Gender-Related Health Disparities Working Group” designed to address gender-based violence and disparities among women with and at risk for HIV in the U.S.<sup>84</sup>

The CDC stepped up efforts to get more Black women tested with its *Take Charge. Take the Test.* campaign in 2012.<sup>85</sup> And in the lead up to National Women and Girls HIV/AIDS Awareness Day in 2013, the Greater Than AIDS initiative launched *EMPOWERED*, a new campaign with Alicia Keys to reach women in the U.S. about HIV/AIDS.<sup>86</sup>

On the research front, several recent developments have brought new optimism for addressing HIV in the future, but also pointed to remaining challenges. In 2010, CAPRISA became the first large clinical trial to provide proof of concept that a topical gel could reduce women’s risk of acquiring HIV during vaginal sex,<sup>87</sup> which many hope will provide a critical new prevention tool for women. However, there is still much research to be done, with a more recent trial (VOICE) finding no protection for women, likely due to low adherence among trial participants.<sup>88,89</sup>

In 2011, an NIH-sponsored trial, HPTN 052, found that antiretroviral therapy reduced the risk of HIV transmission among serodiscordant couples (i.e., couples in which one partner is HIV-infected and the other is uninfected) by 96%.<sup>8</sup> As a result, the federal government revised antiretroviral treatment guidelines to recommend initiation of ART for all patients with HIV infection, regardless of CD4 count.<sup>90</sup> These research findings have also prompted many to call for the very real possibility of achieving an AIDS-Free Generation. In 2011, then Secretary of State Hillary Clinton, in a speech at NIH, stated that achieving an AIDS-Free Generation was now a goal of U.S. policy, and President Obama, on December 1, 2011, World AIDS Day, heralded the “beginning of the end of AIDS.”<sup>91,92</sup>

In December 2012, there was encouraging news about women and HIV when the CDC released new data showing that HIV infections among women in the U.S., including among Black women, declined by 21% between 2008 and 2010 – the most significant decline in incidence among women in almost two decades.<sup>3</sup>

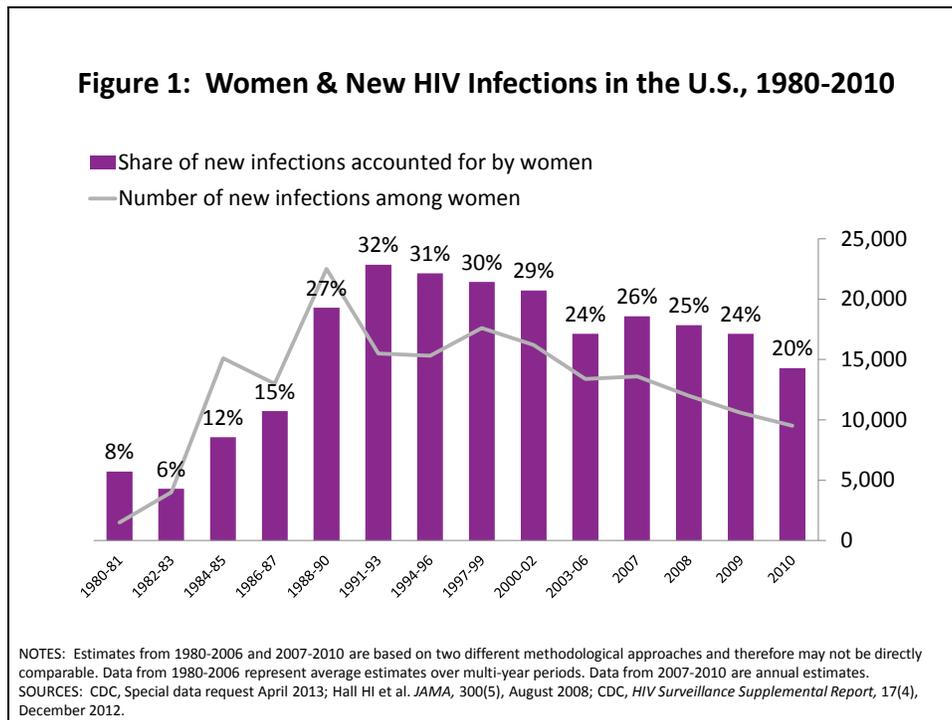
## THE CURRENT EPIDEMIC & KEY TRENDS

Key trends and a current snapshot of the epidemic today among U.S. women by race/ethnicity, age, transmission, geography, and other factors are provided below:

### Trends in New HIV Infections (Incidence)

In first decade of the HIV/AIDS epidemic in the U.S., new infections were largely concentrated among gay and bisexual men, but rose quickly among women. New infections peaked in the 1980s in the U.S.; the peak was somewhat later for women (1988-90) as compared to men (1984-85).<sup>4,5</sup> In 1980-81, 8% of new infections were among women.<sup>4,5</sup>

By 1991-93, women accounted for a high of 32% of new infections in the U.S. The share of new infections among women remained between a third and quarter through 2009.<sup>3,4,5</sup> In December 2012, the CDC reported a significant 21% decrease in new HIV infections among women – including a similar decrease among Black women – between 2008 and 2010, bringing the share of new infections among women to 20%, its lowest in two decades (see Figure 1).<sup>3</sup> The reasons for these declines are not yet fully understood.



### Trends in the Number of People Living with HIV/AIDS (Prevalence)<sup>6</sup>

Today, there are more than 1.1 million living with HIV in the U.S. – including approximately 280,000 women – more than at any time in the three plus decade history of the epidemic. The number of people living with HIV in the U.S. has increased over time, in large part due to advances in treatment that are enabling people to live longer, as well as a stabilizing of new infections beginning in the early 1990s.

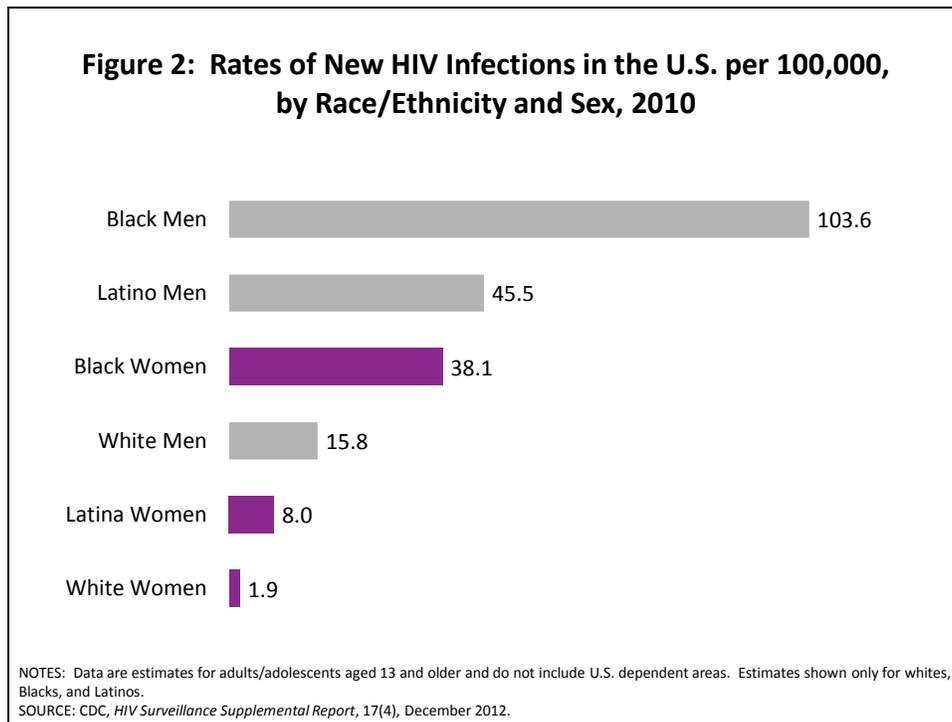
### Trends in HIV Mortality<sup>93</sup>

Prior to the discovery and widespread availability of effective ART, mortality due to HIV was quite high the first 15 years of the epidemic. By 1995, HIV was the 3<sup>rd</sup> leading cause of death among women ages 25-44, and the leading cause of death among men in this age group. The introduction of combination ART in 1996 led to dramatic reductions in HIV-related mortality, allowing people to live much longer and healthier lives. Today, HIV barely ranks as a top cause of death among women overall, although this varies considerably by race/ethnicity, in particular for Black women for which HIV remains a leading cause of death.

From 1993-96, HIV was the number one cause of death among Black women, ages 25-44. As with all people with HIV, mortality rates then began to decline with the advent of ARTs, though HIV death rates are higher for Black women and men than other groups. As of 2009, HIV was the 4<sup>th</sup> leading cause of death among Black women ages 25-44. By comparison, it did not rank among the top 10 leading causes of death for white women in this age group.

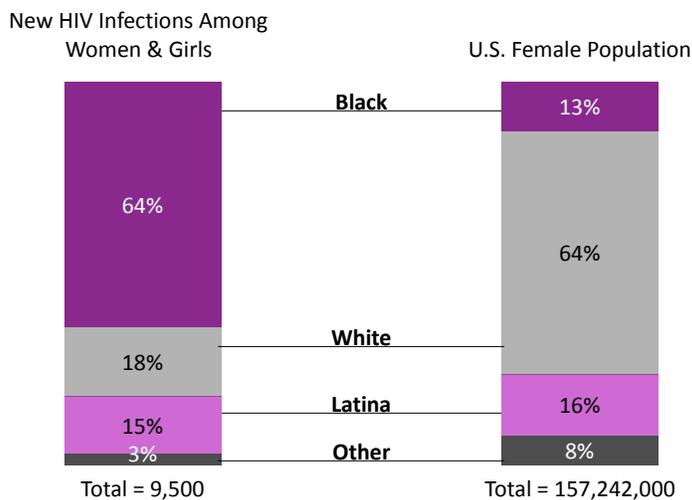
### Race/Ethnicity<sup>94</sup>

Women of color, particularly Black women, are disproportionately affected by HIV, and have accounted for the greatest share of new cases among women since the epidemic's beginning (see Figure 2). This contrasts with the general trend where new infections among Blacks overall did not exceed those among whites until the end of the epidemic's first decade.<sup>95</sup>



Today, Blacks continue to represent a disproportionate share of new infections overall relative to their share of the population, a trend that is even more striking among Black women. Black women account for nearly two thirds of new infections (64%) and HIV-related deaths (65%) among women, and six in ten (60%) women living with HIV, while representing only 13% of the U.S. female population (see Figure 3). White and Latina women represent 18% and 15% of new infections among women, respectively.<sup>3</sup>

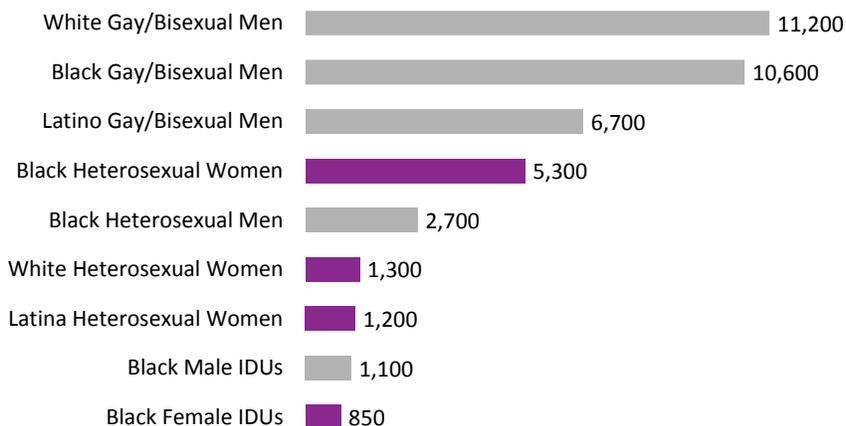
**Figure 3: New Infections Among Women & Girls and U.S. Female Population, by Race/Ethnicity, 2010**



NOTE: HIV data are estimates for adults/adolescents aged 13 and older and do not include U.S. dependent areas.  
 SOURCES: CDC, *HIV Surveillance Supplemental Report*, 17(4), December 2012. U.S. Census Bureau, 2010 Population Estimates.

After gay and bisexual men, the highest number of new HIV infections in the U.S. occurs among Black women (see Figure 4). As with women overall, however, there is encouraging news – new HIV infections among Black women are also on the decline, decreasing by 21% between 2008 and 2010.<sup>3</sup> Despite these gains, Black women remain disproportionately affected by HIV.

**Figure 4: Estimated Number of New HIV Infections in the U.S. for Most Affected Subpopulations, 2010**



NOTES: Data are estimates for adults/adolescents aged 13 and older and do not include U.S. dependent areas. Estimates shown only for whites, Blacks, and Latinos.  
 SOURCE: CDC, *HIV Surveillance Supplemental Report*, 17(4), December 2012.

As of 2010, Black women are still 20 times more likely, and Latinas four times more likely, to become infected with HIV as compared with white women.<sup>3,7</sup> This disproportionate risk translates across a woman's lifespan – the likelihood of a Black woman being diagnosed with HIV in her lifetime is one in 32 compared to one in 526 for a white woman and one in 106 for a Latina.<sup>7</sup>

### **Age**<sup>3,94</sup>

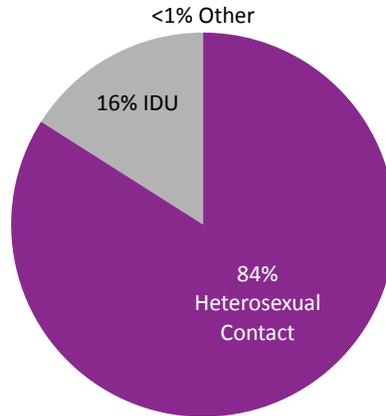
Among women, more than half of new infections occur between the ages of 25 and 44, with those ages 25-34 accounting for 29%, the largest share of any age group. Younger women, ages 13-24, account for 22% of new infections. Black and Latina women are even more likely to acquire HIV at younger ages compared to white women; whereas 16% of new infections among white women occurred between ages 13-24, almost a quarter (23%) of new infections among Black women and 21% among Latinas occurred in those ages 13-24.

### **Transmission**<sup>2,3,94</sup>

Transmission patterns among women have shifted over the course of the epidemic. Until the mid-1990s, most AIDS cases among women were attributable to IDU followed by heterosexual transmission. In 1985, 48% of AIDS cases diagnosed among women were attributable to IDU and 21% were attributable to heterosexual transmission (9% were unknown or unreported risk). Over time, the share of cases due to injection drug use dropped overall in the U.S., which both directly and indirectly led to reductions in cases due to injection drug use among women (who were infected either through their own drug use or through sex with a drug using partner). In addition, some of the early cases reported among women initially classified with “no attributable risk” were later reclassified as heterosexual transmission; indeed, it was not until the mid-1980s that heterosexual transmission was documented as a risk for HIV.

By 1995, the share of AIDS cases diagnosed among women due to heterosexual transmission surpassed those due to IDU (44% to 38%) and has continued to increase. Today, heterosexual transmission accounts for the overwhelming majority of new infections among women in the U.S. (84% overall, including 87% for Black women, 86% for Latinas, and 76% for white women) (see Figure 5). Injection drug use accounted for 16% of new infections among women, although this was higher for white women (25%) compared to Black women (14%) and Latinas (12%).

**Figure 5: New HIV Infections Among Women & Girls in the U.S., by Transmission Category, 2010**



NOTES: Data are estimates for adults/adolescents aged 13 and older and do not include U.S. dependent areas.  
SOURCE: CDC, *HIV Surveillance Supplemental Report*, 17(4), December 2012.

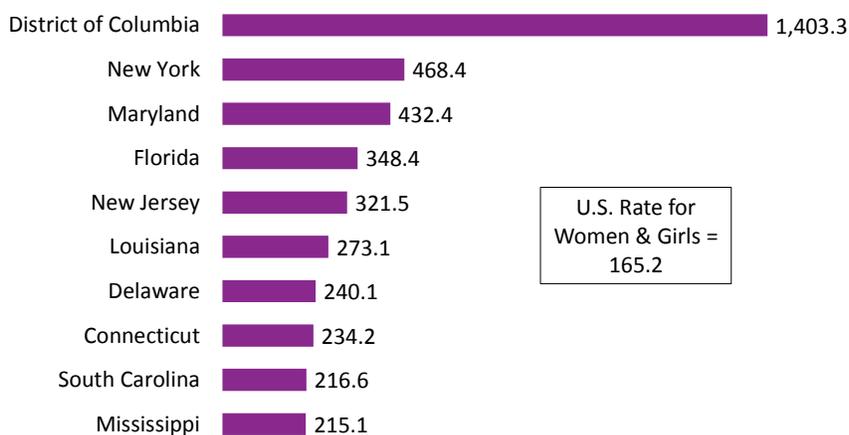
Mother-to-child transmission of HIV (during pregnancy, labor and delivery, or breastfeeding) in the U.S. has decreased dramatically since the early 1990s, due largely to the use of ART during pregnancy. ART significantly reduces the risk of transmission from mother to child by as much as 98%.<sup>96</sup> Today, fewer than 200 children are perinatally infected each year in the U.S., although the majority are Black, reflecting the disproportionate impact of HIV on the Black community.<sup>97</sup>

### **Geography<sup>98</sup>**

The impact of HIV varies across the country. In parts of the U.S., the epidemic is more concentrated among women. Ten states account for the majority (68%) of women living with HIV, with five states (New York, Florida, Texas, California, and New Jersey) accounting for half (49%). Overall, the South (48%) and Northeast (33%) have the greatest shares of women living with HIV, mirroring trends among people with HIV overall. (Washington, DC is included among comparisons of states here. Due to its small population size it does not rank among states based on numbers of people living with HIV, but it does when comparing based on standardized – that is, per 100,000 – population size; see below.)

When standardized to the size of the female population, seven of the top 10 states by highest HIV prevalence rate (per 100,000 women) are in the South; three are in the Northeast. DC has the highest prevalence rate among women in the nation (1,403.3), as compared with other states; more than eight times the national average (165.2) (see Figure 6). The HIV prevalence rate among Black women in DC is 2,595.5 per 100,000.

**Figure 6: Top Ten States by HIV Prevalence Rate Among Women & Girls per 100,000, end of 2010**



NOTE: Data are estimates from all 50 states and the District of Columbia.  
 SOURCE: CDC, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Atlas.

Furthermore, more than half (54%) of women living with HIV live in 10 metropolitan areas, with New York City and Miami having the greatest numbers and highest rates of women living with HIV; of these top 10 cities, six are in the South.<sup>99</sup> Research across the South has identified dense, interlocking sexual networks that increase the vulnerability of low-income Blacks, especially women, to HIV.<sup>100</sup> Washington, DC as a defined city center is compared with states in sections above. As an MSA, the Washington, DC area includes parts of Virginia and Maryland, which have lower HIV prevalence rates, thereby reducing the DC MSA ranking.

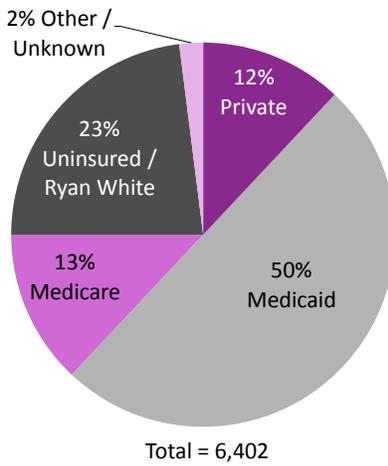
### Transgender Women

Studies have shown that male-to-female transgender women are at particularly high risk for HIV. A recent meta-analysis found that approximately 22% of transgender women in the U.S. are HIV-positive.<sup>101,102</sup> Black transgender women are at especially high risk, with twice the HIV prevalence (56.3%) than those who were white (16.7%) or Latina (16.1%).<sup>101</sup> In addition, data from CDC-funded HIV testing programs has found that a high percentage of newly identified HIV infections are among those who are transgender.<sup>103</sup>

### Insurance Coverage

Due to a combination of factors, including the high cost of HIV care, the difficulty faced by people with HIV in obtaining private insurance under current insurance rules (which will change as a result of the Affordable Care Act – see below), the continuing disabling nature of HIV disease for many, as well as to the link between HIV and poverty, most people with HIV rely on public sector programs for their care.<sup>104</sup> An analysis of data from a network of high-volume HIV clinics<sup>105</sup> found that half (50%) of women with HIV were covered by Medicaid (as compared with 19% of women overall).<sup>106</sup> An additional 13% of women with HIV were covered by Medicare. The remaining 23% had no coverage at all, many of whom rely on the publicly-funded Ryan White Program to obtain needed care and services. Just 12% had private coverage (see Figure 7).

**Figure 7: Insurance Coverage of Women with HIV in Care, U.S., 2011**



NOTES: Based on Patients with HIV Attending Medical Offices Participating in HIVRN. Medicaid includes those with Medicare coverage.  
SOURCE: HIV Research Network (HIVRN) data, personal communication, April 2013.

Women with HIV were much more likely to be covered by Medicaid than their male counterparts with HIV (34%). Men with HIV were more likely to be uninsured (30%), and slightly more likely to be covered by private insurance (19%).<sup>105</sup> For more information on Medicaid and the Ryan White HIV/AIDS program, see section on *Key Prevention, Care, and Treatment Programs*.

## **WHY ARE WOMEN AT RISK FOR HIV?**

A recent national study conducted between 2006 and 2010 found that approximately 8% of women, representing 4.9 million women in the U.S., reported at least one HIV risk-related behavior.<sup>107</sup> Although the study found that risk behaviors among women, and men, had declined somewhat compared to the early part of the decade, numerous factors combine to place women at continued risk for HIV today and/or complicate their ability to obtain needed services. These include socioeconomic and structural barriers, such as poverty, cultural inequities, and sexual violence; ongoing stigma and lack of awareness of HIV status or the risk of partners; competing needs of family; physiologic differences in HIV acquisition and clinical symptoms; and sexual networks.<sup>108</sup> Some of these factors are highlighted here:

### **Biologic Susceptibility**

Women are more biologically susceptible to HIV infection than men during unprotected heterosexual intercourse, due in large part to the substantial mucosal exposure to seminal fluids.<sup>7,109,110</sup> Additionally, several factors can increase the susceptibility of the vaginal (and rectal) mucosa to HIV transmission, such as having a sexually transmitted infection (STI) or any damage to the mucosa.<sup>109</sup> Unprotected anal sex is riskier than unprotected vaginal sex;<sup>111</sup> in a recent national survey, 36% of women ages 25-44 reported having engaged in anal sex at some point.<sup>112</sup>

### **Sexually Transmitted Infections**

Having another STI significantly increases the risk of HIV transmission and acquisition.<sup>113</sup> Women are at particular risk for some STIs and in many cases women are less likely to have symptoms and therefore may not know they are at elevated risk.<sup>114</sup> Black women have substantially higher rates of STIs than white women.<sup>115</sup>

### **Sexual Networks & Background Prevalence**

The structure and characteristics of individual sexual partnerships and broader sexual networks also contribute to the spread of HIV and other STIs among many women. In particular, concurrent partnerships (i.e., partnerships that overlap over time) have long been known to offer an efficient means of linking individuals living with HIV with uninfected partners, facilitating the more rapid spread of HIV within sexual networks.<sup>116</sup> A recent national study involving more than 7,000 women found that the prevalence of concurrent partnerships in the last year was as high as 8.3%; women who were younger, Black, and had a history of drug or alcohol use were more likely to report concurrent sexual relationships.<sup>117</sup> Additionally, the greater the background prevalence (the number of people living with HIV) within a sexual network, the greater the likelihood that someone will come into contact with HIV; this in part explains the higher rates among Blacks (despite not having greater risk behavior compared to whites) – higher HIV prevalence in Black communities combined with the fact that Blacks tend to have sex with partners of the same race/ethnicity means that they are more likely to be exposed to HIV with each sexual encounter.<sup>118</sup>

### **Poverty / Socioeconomic Status**

Poverty also plays a role in HIV risk for women and men, as infection is strongly associated with low socioeconomic status and with the behavioral patterns and life circumstances that accompany poverty. In 2011, women were 20% more likely to be living in poverty than men.<sup>119</sup> A 2006-2007 national survey of more than 8,000 predominately Black and Latino heterosexual adults living in urban areas with high HIV prevalence found that prevalence was more than twice as high for individuals with an annual household income below \$10,000 (2.8%) compared to those with incomes of \$20,000 or greater (1.2%).<sup>120</sup> Individuals who had never completed high

school were more likely to be infected than those with a high school education (3.1% vs. 1.8%). Among the heterosexuals surveyed, individuals who reported having exchanged money for sex in the prior 12 months were more likely to be living with HIV (3.7%) compared to those not reporting transactional sex (2.1%).

### **Competing Needs of Families & Women as Caregivers**

A significant share of women with HIV are parents and/or caregivers, including for others with HIV, and studies have found that women with HIV sometimes put the needs of family members above their own.<sup>110</sup> A recent survey of women with HIV found that 39% reported having children and 52% identified themselves as caregivers.<sup>121</sup> More than four in ten (43%) of the women surveyed reported that living with HIV had made it more difficult for them to take care of their families.<sup>121</sup>

### **Drug Use**

In available studies, drug use consistently emerges as a factor that increases the odds of HIV acquisition for both women and men. A national survey in 2006-2007 found that the likelihood that a person who reported having used crack cocaine in the previous year would be infected (6.3%) was more than triple that of individuals who said they had not used the drug (1.8%).<sup>120</sup> Other studies have found drug use of any kind to be strongly associated with sexual risk behavior.<sup>122</sup> Women who use drugs may face compounded risks for HIV infection because of overlapping sex and drug networks. In addition, studies have shown that female IDUs are more likely than their male counterparts to use drugs with a partner.<sup>109</sup>

### **Sexual Abuse / Gender Based Violence**

Studies have shown that women who have experienced sexual abuse may be more likely to engage in high-risk sexual behaviors, such as exchanging sex for drugs, having multiple partners, or having sex with a partner who is physically abusive when asked to use a condom.<sup>7,123,124,125</sup> While more research is needed, studies have documented the link between sexual violence; particularly intimate partner violence, and HIV.<sup>84,123,125</sup>

### Women and the “HIV Treatment Cascade”

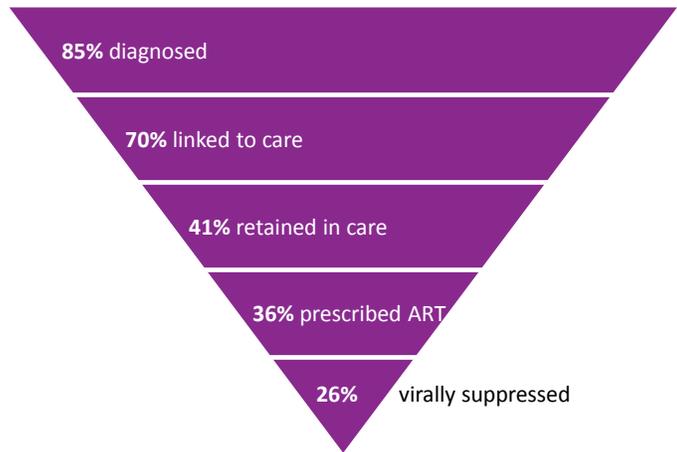
#### *The Continuum from Diagnosis to Viral Suppression*<sup>143</sup>

In recent years, researchers have popularized the concept of an HIV “treatment cascade” to help depict the continuum of care from initial diagnosis of HIV to linkage and retention in care, receipt of ART and, ultimately, viral suppression. The HIV treatment cascade charts the drop-offs, or “cliffs,” that occur at each stage of the cascade, helping to identify opportunities for further intervention. This has become increasingly important now that new research has demonstrated not only the tremendous clinical benefit of ART, but also its ability to prevent HIV transmission by reducing viral load.

The latest national estimates from CDC indicate, however, that, as with people with HIV overall, many women are not on ART and consequently not virally suppressed, due in part to many of the complex socioeconomic and other risk factors described above. While approximately 85% of women with HIV know their HIV status and 70% have been linked to care (compared to 81% and 65% of men, respectively), the biggest cliffs in the cascade occur between linkage and retention in care – only 41% of women with HIV have been retained in care and thus only 36% are on ART. As a result, only about a quarter (26%) of women with HIV in the U.S. are estimated to be virally suppressed (see Figure 8).

**Figure 8: The HIV Treatment Cascade Among Women**

Out of the approximately 280,000 women in the U.S. living with HIV:



SOURCE: CDC, *Fact Sheet – HIV in the United States: The Stages of Care*, July 2012.

## KEY PREVENTION, CARE, AND TREATMENT PROGRAMS

There is a wide range of prevention and treatment programs and services available for people with HIV in the U.S., including women. Some of these are designed specifically for people with HIV, such as the Ryan White HIV/AIDS Program; others are broader programs that serve people with HIV, such as Medicaid. As previously mentioned, most women with HIV rely on Medicaid or the Ryan White HIV/AIDS Program for their coverage and care; very few are privately insured. Insurance coverage, including through the public sector, has been shown to make an important difference in helping to improve access to health care and health outcomes in the U.S., including for people with HIV.<sup>126,127,128,129,130</sup>

A key development in the health care landscape was the passage of the Affordable Care Act (ACA), signed into law in 2010, which will expand access to insurance coverage, and therefore access to care, for millions of Americans, including many women with HIV. While many of the ACA's provisions will have some impact on women with HIV or their care, several are of particular relevance, including the expansion of Medicaid, one of the most important sources of coverage and care for women with HIV; enhanced prevention benefits, including free coverage of annual HIV counseling and screening for all sexually active women; the elimination of pre-existing exclusions and annual and lifetime caps on coverage; and the ability of parents to cover their children up to age 26 on their insurance plans.<sup>131</sup>

Key programs that provide services and other support to people with HIV and those at risk are briefly described here:

### Medicaid

Medicaid is the largest public health insurance program in the U.S., covering health and long-term care services for more than 60 million low-income individuals. Medicaid has played a critical role in HIV care since the epidemic began, and is the single largest source of coverage for people with HIV generally, and for women with HIV specifically. Medicaid covers a broad range of services, many of which are critical for people with HIV, such as prescription drug benefits. Under the ACA, Medicaid eligibility will expand in 2014 to reach millions more low-income Americans, including many people with HIV.<sup>132</sup> A national analysis of Medicaid enrollees with HIV in Fiscal Year 2007 found that 43% were women, who only represent about a quarter of those living with HIV. This in part reflects the fact that women are more likely to be poor than men and that it is easier for women to qualify for Medicaid under current eligibility rules.<sup>133</sup>

### Medicare

Medicare, the federal health insurance program for people age 65 and older, and younger adults with permanent disabilities, is an important source of health coverage for more than 100,000 people with HIV. As of 2006, it includes prescription drug benefits as part of the Medicare Part D program. Most people with HIV on Medicare rely on the program because they are disabled; many also qualify for Medicaid.<sup>134</sup> In 2008, women accounted for 23% of all Medicare beneficiaries living with HIV.<sup>135</sup>

### Ryan White HIV/AIDS Program

First enacted in 1990, the Ryan White HIV/AIDS Program has grown to become a critical part of the HIV health care delivery system in the United States, providing care and services to more than half a million people living with and affected by HIV each year. It is the largest HIV-specific grant program in the U.S., and the third largest source of federal funding for HIV care, after Medicaid and Medicare. The program provides care and support services to

individuals and families affected by the disease, functioning as the “payer of last resort” by filling the gaps for those who have no other source of coverage or face coverage limits. The program provides funding to cities, states, providers, and other organizations throughout the country.<sup>136</sup> In 2010, 30% (nearly 250,000) of Ryan White clients served were women.<sup>137</sup> Ryan White includes several different components, including the AIDS Drug Assistance Program (ADAP), which served more than 30,000 women clients in June 2012,<sup>138</sup> and the Ryan White Part D program which is designed specifically to provide family-centered and community-based services to children, youth, and women living with HIV and their families, including outreach, prevention, primary and specialty medical care, and psychosocial services.

### **Family Planning Services**

As HIV interacts with women’s reproductive health on many levels,<sup>110</sup> sexual and reproductive health services play an important role in HIV prevention and treatment for women. A majority of women of reproductive age (60%) report that a family planning site is their usual source of reproductive and general health care, with 41% indicating it is their only source of care.<sup>139,140</sup> CDC’s current HIV testing guidelines for pregnant women recommend that sites serving women of childbearing age, including family planning clinics, offer voluntary HIV testing to women.<sup>141</sup>

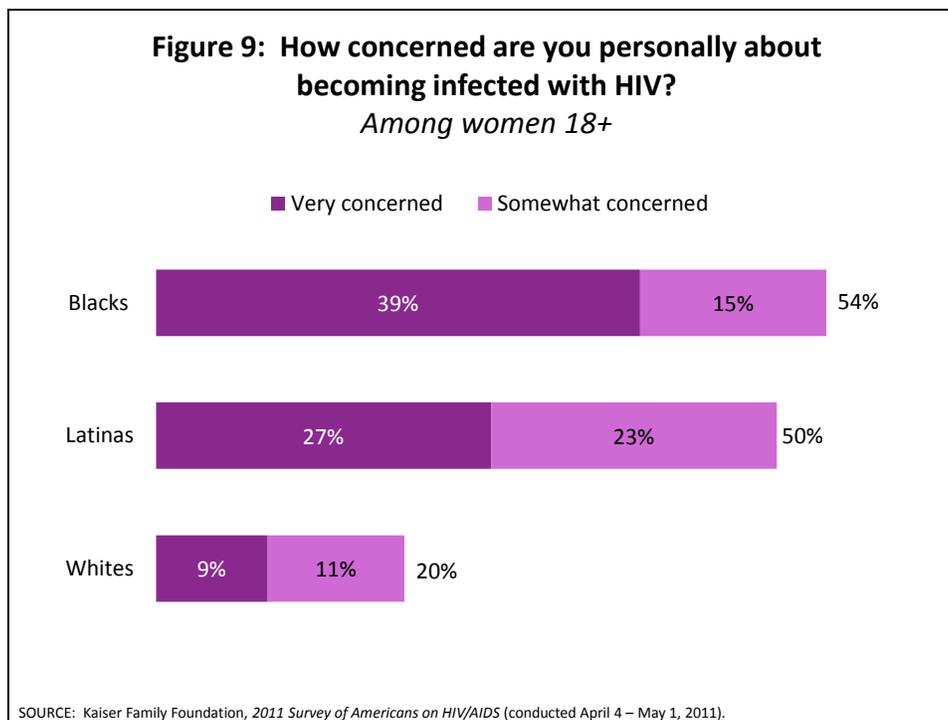
### **HIV Testing and Prevention Services**

Most HIV prevention efforts are carried out by the CDC. The CDC provides funding to states, some cities, and community-based organizations to carry out a variety of HIV prevention activities including surveillance, outreach and education, risk reduction, and HIV testing and linkage to care. CDC recommends routine HIV testing in all health care settings for all adults, adolescents, pregnant women, and newborns whose HIV status is unknown.<sup>66</sup> In addition to testing in association with the delivery of health care, CDC provides support for HIV testing centers and for various community-based testing programs. While over half (57%) of women in the U.S. ages 18-64 report having been tested for HIV at some point, just one in five (20%) report that they were tested in the past year. Black women are much more likely to report having been tested in the past year compared to white women (43% compared to 12%).<sup>142</sup> Among those women who are HIV-positive, 31% were tested for HIV late – that is, diagnosed with AIDS within one year of testing positive, a similar share as men.<sup>97</sup>

## KNOWLEDGE AND ATTITUDES ABOUT HIV/AIDS

### An Issue That Hits Close To Home

More than three decades in to the epidemic, American women express significant concern around HIV/AIDS. According to national surveys by the Kaiser Family Foundation, 30% of American women – and one in two (54%) Black women, who have been disproportionately affected by HIV – say they are *personally* concerned about becoming infected (see Figure 9). Younger women, especially those of color, also worry about HIV. Among youth ages 15-24, Black females (66%) and Latinas (50%) were considerably more likely to say that they are personally concerned about HIV/AIDS, as compared to white females of the same age (33%).



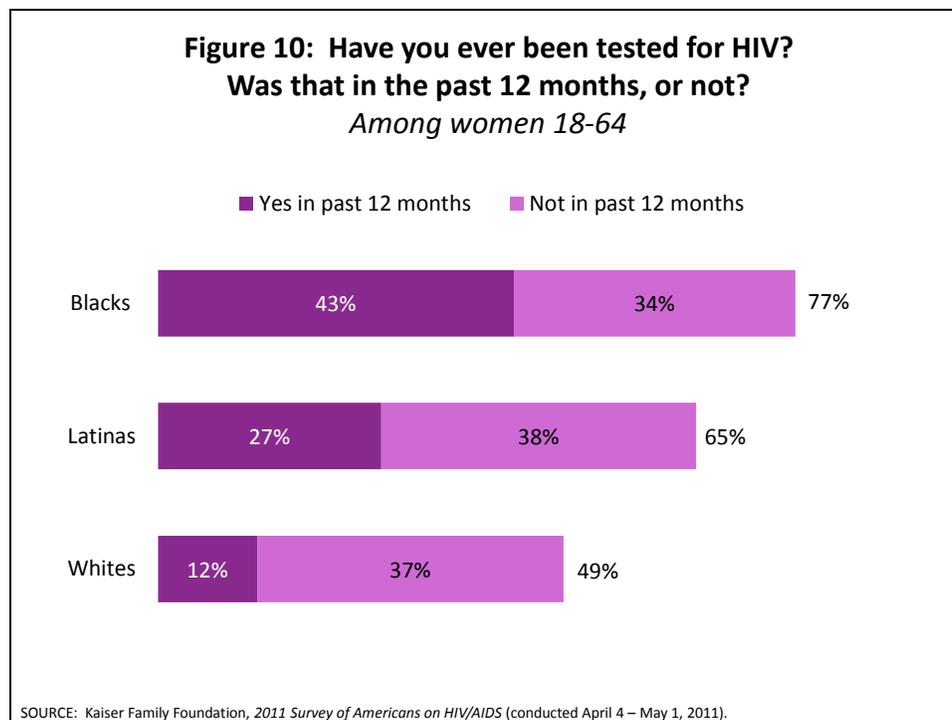
These differences in outlook by race also extend to broader concerns expressed by women about HIV/AIDS. Reflecting the disproportionate impact of HIV on women of color, many more Black (38%) and Latina (38%) women say that AIDS is a “very serious” problem for people they know, than white women (22%). Similarly, nearly twice as many teen and young adult Black females (61%) and Latinas (63%) say HIV/AIDS is a “very serious” problem for people their age today, as compared with white females (35%) of the same age.

Women of color are also more likely to express concern about their family, especially their children, becoming infected with HIV. Three out of four (75%) Black women say they are concerned about an immediate family member becoming infected with HIV, twice as many as among white women (37%). Black mothers of children 21 and younger are especially worried about their sons’ and daughters’ risk (57% “very” and 21% “somewhat”).

The greater sense of concern may stem from the fact that Black females are more likely to have a personal connection to the issue than their white or Latina peers. More than half (56%) of Black women report knowing someone living with or who has died of HIV, for most a family member or close friend. Fewer though still significant percentages of white women (41%) and Latinas (30%) also report knowing someone affected by the disease.

## Black Women More Likely To Be Tested For HIV

Over half (57%) of non-elderly women report having ever been tested for HIV. Black women ages 18-64 are more likely to report having been tested as compared to white women (77% vs. 49%), and more than three times as likely to say they have been tested in the past 12 months (43% vs. 12%) (see Figure 10).



However, at least some of the women who report being tested may be mistaken in believing the test was done, as 22% say they did not actually discuss it, rather just assumed it was a routine part of the exam. Black women are more likely to say that they asked to be tested (57%), as compared to white women (44%) or Latinas (35%). Most of those nonelderly women who say they have been tested for HIV indicate that it was part of another health visit, such as a routine check-up (79%); another 18% of women say they went specifically to get tested.

For nonelderly women who report having been tested, four in 10 (39%) say having a health care provider recommend they do so was a motivator in their decision. Yet relatively few women report that their health care providers are suggesting testing. Only 34% of women ages 18-64 say that a doctor or other health care provider has ever suggested they be tested for HIV. Black women (45%) and Latinas (52%) are more likely than white females (27%) to report that a health care provider suggested they be tested. Similarly, about half of women (49%) say they have ever talked with a doctor or health care provider about HIV or AIDS, with Black women (72%) more likely to report having talked with a doctor or health care provider as compared to Latinas (53%) or white women (43%).

Most nonelderly women (77%) say that they have been tested for HIV because “it just seemed like a good idea.” For those women who have not been tested, most say the reason they have never been tested is because they don’t think they are at risk (63%).

## **Stigma and Misconceptions Persist**

While the majority (89%) of women (as well as 82% of teen and young adult females) recognize that “it is possible for people with HIV to lead healthy, productive lives,” they also say that stigma around the disease remains a significant issue. Most (81%) women think that there is still a lot or some prejudice and discrimination against people living with HIV in this country today. Similarly, most (82%) teens and young adult females say that there is at least some stigma in the U.S. today around HIV/AIDS, including 32% who say “a lot.”

When pressed on their own feelings about HIV, although decreasing over time, still significant shares of women (and similar percentages of men) express discomfort at the idea of interacting with people living with HIV. For example, 45% of women ages 18 and older say they would be uncomfortable having their food prepared by someone who is HIV-positive, 37% having an HIV-positive roommate, 28% having their child in a classroom with an HIV-positive teacher, and 19% working with someone with HIV. Fully 84% of teen and young adult females say they would be uncomfortable being in a relationship with someone who is HIV-positive, reflecting a lack of understanding at some level about options to protect against sexual transmission.

Women and men are equally likely to be misinformed about how HIV is (and is not) spread, potentially fueling stigma. One in three (34%) women mistakenly believes that a person can become infected with HIV by sharing a drinking glass, touching a toilet seat, and/or swimming in a pool with someone who is HIV-positive. Women are more likely than men to say that a pregnant woman who has HIV can take certain drugs to reduce the risk of her baby being born infected (57% vs. 48%). Notably, Black women (72%) are more likely than Latinas (57%) or white women (55%) to know that there are drugs to reduce the risk of having a child born with HIV.

## **Women Want To Know More**

Substantial shares of women (65%) – and even larger shares among Black women (84%) and Latinas (85%) – say they would like to have more information on any of a variety of HIV-related topics, including how to prevent the spread of HIV, how to know whether to get tested and where to go to do so, and how to talk with children, partners, and doctors or health care providers about the disease.

To better understand the views of Americans on HIV/AIDS, the Kaiser Family Foundation routinely conducts nationally representative surveys of the public’s attitudes toward and experiences with HIV. Results presented here reflect some of the key findings from a nationally representative telephone (landlines and cell phones) survey conducted in 2011 of 2,583 adults ages 18 and older (including 1,297 females) and a nationally representative web-based survey conducted in 2012 of 1,437 teens and young adults ages 15-24 (including 748 females). For the purposes of this report, only the views of females are listed except where noted although both surveys collected data on men as well as women. For more information and the full methodology, please refer to [www.kff.org](http://www.kff.org).

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- <sup>1</sup> CDC. *MMWR*, Vol. 32, No. 35; September 1983. See: <http://www.cdc.gov/mmwr/preview/mmwrhtml/00000137.htm>.
- <sup>2</sup> KFF analysis of data from CDC, AIDS Public Information Data Set (AIDS), US Surveillance Data for 1981-2002, CDC WONDER Online Database; December 2005. See: <http://wonder.cdc.gov/aids-v2002.html>. Data on HIV infections by transmission were not available at this time.
- <sup>3</sup> CDC. *HIV Surveillance Supplemental Report*, Vol. 17, No. 4; December 2012.
- <sup>4</sup> Hall HI et al. "Estimation of HIV Incidence in the United States." *JAMA*, Vol. 300, No. 5, 300:520-529; August 2008.
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- <sup>7</sup> CDC. *Fact Sheet: HIV Among Women*; March 2013.
- <sup>8</sup> Cohen MS et al. "Prevention of HIV-1 Infection with Early Antiretroviral Therapy." *New England Journal of Medicine*, Vol. 365: 493-505; August 2011.
- <sup>9</sup> For additional details and timelines, see: KFF, *The Global HIV/AIDS Timeline*, [www.kff.org/hivaids/timeline](http://www.kff.org/hivaids/timeline); AIDS.gov, *A Timeline of AIDS*, <http://www.aids.gov/hiv-aids-basics/hiv-aids-101/aids-timeline>; and *The Body, A Timeline of Women Living with HIV: Past, Present and Future*, <http://www.thebody.com/content/16568/a-timeline-of-women-living-with-hiv-past-present-a.html>.
- <sup>10</sup> CDC. *MMWR*, Vol. 30, No. 21; June 1981. See: [http://www.cdc.gov/mmwr/preview/mmwrhtml/june\\_5.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/june_5.htm).
- <sup>11</sup> New York Times. "New Homosexual Disorder Worries Health Officials"; May 11, 1982. See: <http://www.nytimes.com/1982/05/11/science/new-homosexual-disorder-worries-health-officials.html?pagewanted=all>.
- <sup>12</sup> *The Body. A Timeline of Women Living with HIV: Past, Present and Future*. See: <http://www.thebody.com/content/16568/a-timeline-of-women-living-with-hiv-past-present-a.html>.
- <sup>13</sup> CDC. *MMWR*, Vol. 31, No. 52; January 1983. See: <http://www.cdc.gov/mmwr/preview/mmwrhtml/00001221.htm>.
- <sup>14</sup> Online Archive of California (OAC). See: <http://www.oac.cdlib.org/findaid/ark:/13030/kt7199r07h/>.
- <sup>15</sup> KFF. *The Global HIV/AIDS Timeline*. See: [www.kff.org/hivaids/timeline](http://www.kff.org/hivaids/timeline).
- <sup>16</sup> FDA. *HIV/AIDS Historical Time Line 1981-1990*. See: <http://www.fda.gov/ForConsumers/ByAudience/ForPatientAdvocates/HIVandAIDSActivities/ucm151074.htm>.
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- <sup>18</sup> Elizabeth Glaser Pediatric AIDS Foundation (EGPAF). See: <http://www.pedaids.org/>.
- <sup>19</sup> amfAR, The Foundation for AIDS Research. See: <http://www.amfar.org/>.
- <sup>20</sup> New York Times. "Pop: Madonna Benefit for AIDS at the Garden"; July 15, 1987. See: <http://www.nytimes.com/1987/07/15/arts/pop-madonna-benefit-for-aids-at-the-garden.html>.
- <sup>21</sup> Congresswoman Nancy Pelosi. 25 Years of Leadership on HIV/AIDS. See: <http://pelosi.house.gov/about/25-years-of-leadership-on-hivaids.shtml>.
- <sup>22</sup> New Jersey Women and AIDS Network (NJWAN). See: <http://www.njwan.org/index-int.html>.
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