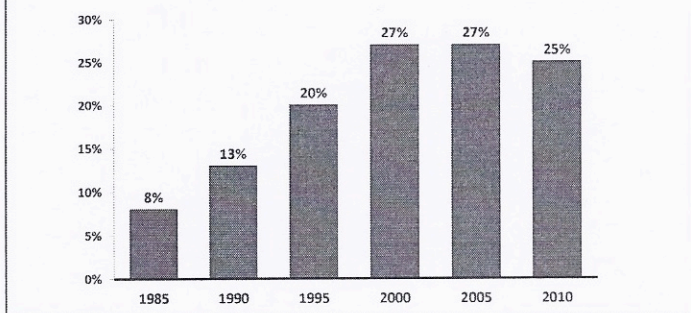


Women have been affected by HIV/AIDS since the beginning of the epidemic, an impact that has grown over time.^{1,2,3,4,5} Women of color, particularly Black women, have been especially hard hit and represent the majority of new HIV infections and AIDS diagnoses among women, and the majority of women living with the disease.^{1,4} Many women with HIV are low-income and most have important family responsibilities, potentially complicating the management of their illness. Research suggests that women with HIV face limited access to care and experience disparities in access, relative to men.^{6,7,8,9} Women also experience different clinical symptoms and complications.¹⁰ Given these trends and issues, efforts to stem the tide of the U.S. HIV/AIDS epidemic will increasingly depend on how and to what extent its effect on women and girls is addressed.

Snapshot of the Epidemic

- Although men represent the majority of new HIV infections and AIDS diagnoses as well as people living with the disease, the impact on women has grown since the beginning of the epidemic. For instance, women represented 8% of new AIDS diagnoses in 1985, 20% in 1995 and 27% in 2000, a similar share as today (Figure 1).^{1,2,11} HIV incidence among women rose gradually until the late 1980s, but then declined in the early 1990s and has remained fairly stable since that time.^{4,12}
- Today, there are more than 1.1 million people living with HIV/AIDS in the U.S., including nearly 280,000 women.¹³
- In 2009, there were 11,200 new HIV infections and in 2010 there were 8,422 new AIDS diagnoses among women.^{1,4,5}
- There were 4,693 deaths among women with AIDS in 2009.¹

Figure 1: Women as a Proportion of New AIDS Diagnoses, 1985–2010^{1,2,11}



Key Trends and Current Cases

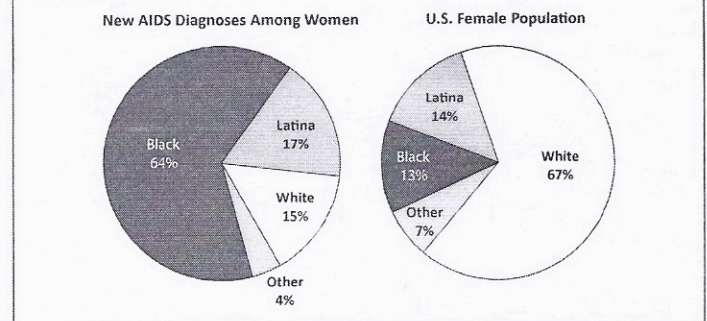
Race/Ethnicity: Women of color, particularly Black women, are disproportionately affected by HIV/AIDS (Figure 2).

- Black women accounted for 64% of new AIDS diagnoses among women, ages 13 and older, in 2010, but only 13% of the U.S. population of women. Latinas accounted for 17% of new AIDS diagnoses, compared to 14% of the female population ages 13 and over.^{1,14,15} Black women also accounted for the majority of new HIV infections among women in 2009.^{4,5}
- Rates per 100,000 illustrate the severe impact on women of color. HIV incidence and prevalence rates as well as the rates of new

AIDS diagnoses for Black and Latina women are higher than those of white women. The rate of new AIDS diagnoses for Black women in 2010 was 33.7 per 100,000, or 22 times the rate for white women (1.5). The rate for women of multiple races (13.1) was 9 times the rate for white women, while the rate for Latinas (7.1) was 5 times as high. The rate was 5.4 for Native Hawaiian/Other Pacific Islander women, 4.6 for American Indian/Alaska Native women, and 1.2 for Asian women.^{1,16} HIV incidence and prevalence rates for women by race/ethnicity show a similar pattern.^{1,4}

- An analysis of 1999–2006 data from a national household study found that 1.49% of Black women in the U.S. (among those ages 18–49) were HIV positive, higher than women of other racial/ethnic groups, but lower than Black men.¹⁷
- Among women, the number of HIV-related deaths and HIV death rates are highest for Black women. In 2008, HIV was the 4th leading cause of death among Black women ages 25–44, compared to 5th for women overall in the U.S.¹⁸ In 2008, the HIV death rate per 100,000 women, ages 25–44, was 15.0 for Black women, higher than the rate for other women and most men in this age group, and second only to the rate among Black men.¹⁹

Figure 2: New AIDS Diagnoses and U.S. Female Population, by Race/Ethnicity, 2010^{1,11,14,15}



Age: The impact of HIV on younger women is particularly notable. More than 6 in 10 new HIV infections among Black women and Latinas were among those ages 13–39 in 2009—over one third were ages 13–29.⁴

Transmission:

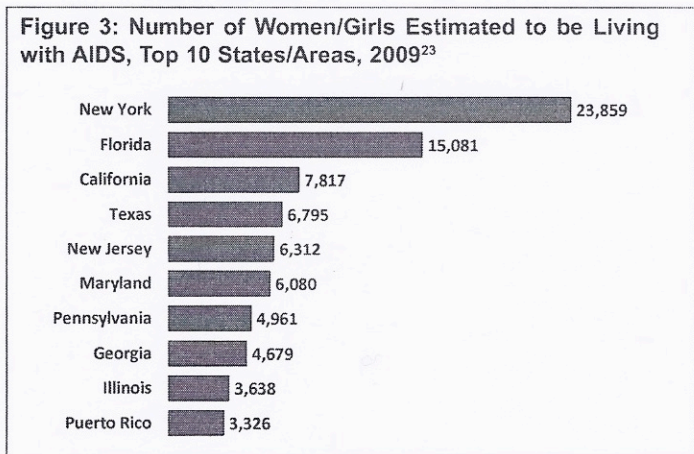
- Women are most likely to be infected through heterosexual sex, followed by injection drug use.¹ This pattern is consistent across racial and ethnic groups, although heterosexual transmission accounts for a greater share of new HIV infections among Black women and Latinas (85% and 82%, respectively) compared to white women (72%); injection drug use accounts for a greater share of new infections among white women (28%).⁴
- Mother-to-child transmission of HIV in the U.S. has decreased dramatically since its peak in 1992 due to the use of antiretroviral therapy (ART), which significantly reduces the risk of transmission from a woman to her baby (to less than 2%). Still, perinatal infections continue to occur each year, the majority of which are among Black Americans.^{1,20,21}

- A CDC study found that most pregnant women with HIV (81%) and most babies born to HIV-infected women (93%) have received ART.²²

Reproductive health: HIV interacts with women's reproductive health on many levels:¹⁰

- In the United States, studies have shown that the virus is transmitted more efficiently from men to women during sexual intercourse. Having another sexually transmitted infection may increase risk for contracting HIV.
- Women with HIV are at increased risk for developing or contracting a range of conditions, including human papillomavirus (HPV), which can lead to cervical cancer, and severe pelvic inflammatory disease (PID).
- There are a number of new HIV prevention technologies under research which could be particularly beneficial for women, such as cervical barriers and microbicides.

Geography: The epidemic in some states is more likely to have a woman's face. About a third of those estimated to be living with AIDS in the Virgin Islands, Maryland, New Jersey, and Connecticut are female (compared to 24% nationally). New York has the highest number of women living with AIDS (Figure 3).²³ Regionally, the concentration of new AIDS diagnoses among women, as measured by the rate of new AIDS diagnoses per 100,000, is highest in the Northeast and the South. The District of Columbia tops the list at 79.9 per 100,000, or over 12 times the national rate for women (6.4).²³



Income: The HIV Cost and Services Utilization Study (HCSUS), the only nationally representative study of people with HIV/AIDS receiving regular or ongoing medical care, found that women with HIV were disproportionately low-income. Nearly two-thirds (64%) had annual incomes below \$10,000, compared to 41% of men.⁶

Family responsibilities: HCSUS also found that most female parents with HIV/AIDS receiving medical care had children under age 18 in their homes (76%), which may complicate their ability to manage their illness.²⁴

Access to and Use of the Health Care System

Studies have indicated that women with HIV/AIDS may encounter barriers to treatment and do not receive optimal levels of care compared to men.

- HCSUS found that women with HIV were less likely to receive combination therapy and fared more poorly on other access measures than men.⁷
- Women with HIV were also more likely to postpone care because they lacked transportation or were too sick to go to the doctor than men.⁸
- An analysis of data from 2000–2002 in 11 HIV primary and specialty care sites in the U.S. found higher rates of hospitalization and outpatient visits among women with HIV/AIDS compared to men.⁹

Health Insurance: Having health insurance, either public or private, improves access to care. Medicaid, the nation's health insurance program for low-income Americans and the largest source of public funding for AIDS care, is a critical source of coverage for people with HIV/AIDS. HCSUS found that women with HIV receiving care were:^{6,25}

- more likely than their male counterparts to be covered by Medicaid (61% compared to 39%) because they qualified for Medicaid as pregnant women or as parents of a dependent child.
- less likely to be privately insured (14% of women compared to 36% of men).
- as likely to be uninsured (21% of women and 19% of men).

Insurance status also varies at the time of HIV diagnosis. Analysis of 1994–2000 data from 25 states found that women were less likely than men to be privately insured and more likely to be covered by Medicaid at the time of their HIV diagnosis. Black and Latina women were more likely to be covered by Medicaid than white women, and Latinas were the most likely to be uninsured of any group.²⁶

HIV Testing:

- One in 5 (20%) non-elderly women (ages 18–64) report that they have been tested for HIV in the last 12 months, with higher rates among Black women (37%) and Latinas (25%) compared to white women (10%).²⁷
- Among those who are HIV positive, 31% of women were tested for HIV late in their illness—that is, diagnosed with AIDS within one year of testing positive (in those states/areas with HIV name reporting).¹
- The CDC recommends routine HIV screening for all adults, ages 13–64, in health care settings, including women, and repeat screening at least annually for those at high risk. The CDC also recommends that HIV screening be included in the routine panel of prenatal screening tests for all pregnant women, unless the patient declines to be tested, and repeat HIV screening in the third trimester for women at high-risk for HIV. HIV testing of newborns is recommended if the mother's status is unknown.²⁸

Concern About HIV/AIDS²⁷

When asked how concerned they were personally about becoming infected with HIV, a recent survey found that 30% of women say they are "very" or "somewhat" concerned. Black women are much more likely to say they are concerned (54%) as are Latinas (50%). Over half of female parents (55%) say they are "very" or "somewhat" concerned about their children becoming infected.

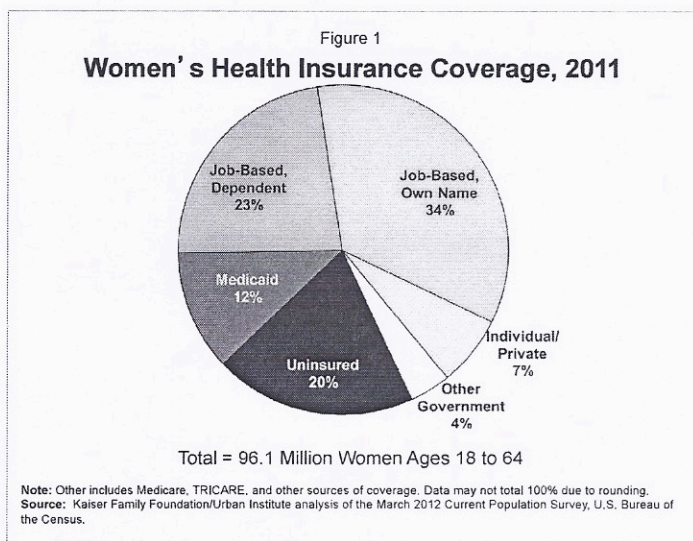
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¹² Hi Hall et al. "Estimation of HIV Incidence in the United States." *JAMA*, Vol. 300, No. 5; August 2008.
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¹⁵ Calculations based only on data for which race/ethnicity data were provided.
¹⁶ Estimates do not include diagnoses from the U.S. dependencies, possessions, and associated nations, and diagnoses of unknown residence.
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²⁰ CDC. *MMWR*, Vol. 55, No. 21; 2006.
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WOMEN'S HEALTH INSURANCE COVERAGE

Health insurance coverage is a critical factor in making health care accessible to women. Women with health coverage are more likely to obtain needed preventive, primary, and specialty care services, and have better access to new advances in women's health. Among the 96 million women ages 18 to 64, most have some form of coverage. However, the patchwork of different private sector and publicly-funded programs in the U.S. leaves one in five women uninsured. The Affordable Care Act (ACA) of 2010 includes several measures that will change the profile of women's coverage between now and 2014, when the new law is scheduled to be implemented fully.

Sources of Health Insurance Coverage

Employer-sponsored insurance covers 58% of women between the ages of 18 and 64 (Figure 1). Women are less likely than men to be insured through their own job (34% vs. 45%, respectively) and more likely to be covered as a dependent (23% vs. 14%).¹



Medicaid, the state-federal program for the poor, covers 12% of non-elderly women. Typically, only very low-income women who are pregnant, have children living at home, or who have a disability have been able to qualify for the program.

Individually purchased insurance is used by just 7% of women. This type of insurance often provides more limited benefits than job-based coverage and can be costly. Also, pre-existing medical conditions can trigger coverage denials in the individual market, depending on the insurer and state regulations.

Medicare and other government health insurance covers a small fraction (4%) of women under age 65. For non-elderly women, coverage is limited to women who either have a disability (Medicare) or are covered through the military (TRICARE).

Uninsured women account for 20% of women ages 18 to 64. They typically do not qualify for Medicaid, do not have access to employer-sponsored plans, and either cannot afford or do not qualify for individual policies.

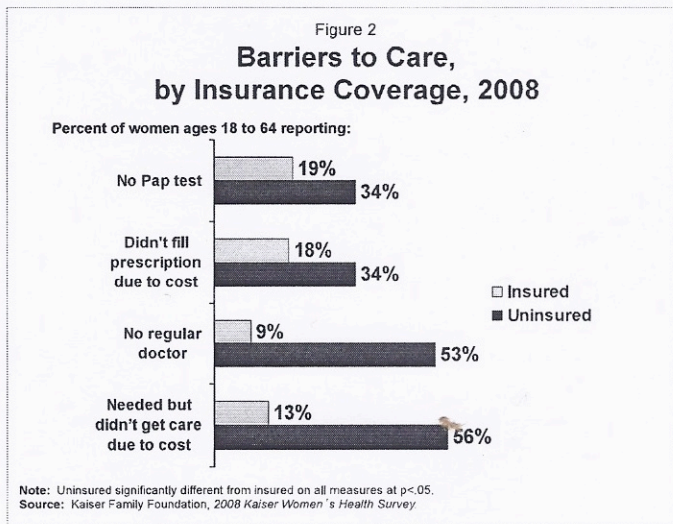
Employer-Sponsored Insurance: Approximately 56 million non-elderly women in the U.S. receive their health coverage from their own or their spouse's employer. Historically, full-time employment has provided the greatest opportunity for obtaining job-based coverage.

- Women in families with at least one full-time worker are more likely to have job-based coverage (71%) and less likely to be uninsured (16%) than women in families with only part-time workers (34%) or without any workers (30%).¹
- Women are more vulnerable to losing their insurance compared to men, as they are more likely to be covered as dependents. This places a woman at greater risk of losing coverage if she becomes widowed or divorced, her spouse loses a job, her spouse's employer drops family coverage or increases premium and out-of-pocket costs to unaffordable levels.
- In 2012, annual insurance premiums averaged \$5,615 for individuals and \$15,745 for families, nearly doubling in cost over the past ten years. Workers currently pay for an average of 18% of premiums for individual coverage and 28% for family coverage.²

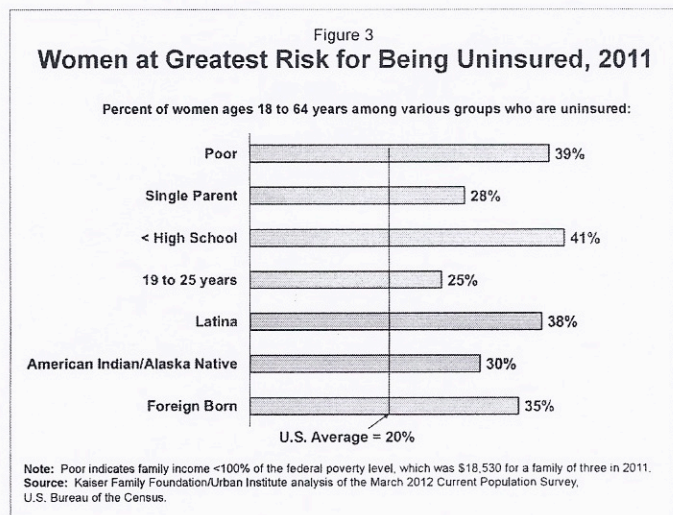
Medicaid: According to Medicaid program statistics, in 2009, 18.2 million low-income women (18 to 64 years) were enrolled in Medicaid.³ Women make up three-quarters of the adult Medicaid population, but only low-income women who are pregnant, mothers of children who are 18 years or under, disabled, or over 65 can qualify for Medicaid. Women without children and disabilities typically are not eligible no matter how poor. This will change after 2014 when Medicaid eligibility is broadened to more people.

- Among all insurers, Medicaid disproportionately carries the weight of covering the poorest and sickest population of women. Approximately 81% of non-elderly women on Medicaid have incomes below 200% of the Federal Poverty Level (FPL). Three in ten (31%) women on Medicaid rate their health as fair or poor, compared to 10% of low-income women covered by employer-sponsored insurance and 14% of low-income, uninsured women.¹
- Medicaid finances nearly half of all births in the U.S.⁴, accounts for 75% of all publicly-funded family planning services⁵ and nearly half (43%) of all long-term care spending.⁶
- Over the past decade, several states (31 states) have expanded Medicaid eligibility to cover the costs of family planning services for low-income women and all states have established Medicaid programs to pay for breast and cervical cancer treatment for certain low-income uninsured women.⁷

Uninsured Women: Approximately 19 million women are uninsured.¹ Uninsured women are more likely to have inadequate access to care, get a lower standard of care when they are in the health system, and have poorer health outcomes.⁸ They are more likely to postpone care and to forgo filling prescriptions than their insured counterparts and often delay or skip important preventive care such as mammograms and Pap tests (Figure 2). One study attributed nearly 45,000 excess annual deaths to lack of health insurance.⁹



Women who are younger, poorer, and of color (especially Latinas) are particularly at risk for being uninsured (Figure 3). However, the ACA included a provision allowing dependents to be covered up to age 26, and it is estimated that more than 3 million young adults have been insured as a result of this policy.¹⁰



- Six in ten (60%) uninsured women are in families with at least one adult working full-time and 78% of uninsured women are in families with at least one part-time or full-time worker.¹
- There is considerable state-level variation in uninsured rates across the nation, ranging from 30% of women in Texas to 5% of women in Massachusetts.¹

Health Reform and Women's Coverage

Expanding Coverage: One of the ACA's primary goals is to expand access to insurance coverage, significantly reducing the number of uninsured. The law requires that nearly everyone carry health insurance by 2014, through a combination of changes in private and public coverage. Most employers will be required to offer coverage to employees or pay a penalty. There are also numerous reforms that will go into effect in 2014, that will prohibit insurance companies from denying coverage based on pre-existing conditions, and will not allow insurers to vary premium rates based on gender or health status.

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The ACA was written with the intention that individuals with very low incomes (< 138% of poverty) would qualify for Medicaid through an expansion of the program in all states, and that other uninsured individuals would be able to purchase policies through state-based exchanges or mini-marketplaces offering a choice of plans. However, in July 2012, the Supreme Court issued a ruling that effectively made the Medicaid expansion optional for states. Under the ACA, individuals with incomes between 100% and 400% of poverty can receive assistance with the premium costs of plans in state-based exchanges through a graduated system of tax credit subsidies. However, subsidies are not available to individuals with incomes below 100% of poverty, making a state's decision about whether it will expand Medicaid to all individuals in this income bracket even more important.

Addressing Affordability: Affordability of care is a concern for many women, not just those who are uninsured. In 2008, one in seven privately insured women reported she postponed or went without needed care because she couldn't afford it.¹¹ The new law includes some measures directed at controlling system costs as well as individual out-of-pocket spending. These include caps on out-of-pocket spending for certain low-income individuals, coverage for many preventive services without cost-sharing, an emphasis on reducing unnecessary treatments and improving quality of care, as well evaluating the cost-effectiveness of medical treatments.

Scope of Coverage: The ACA mandates that plans in state-based exchanges cover broad categories of "essential benefits," including outpatient and hospitalization care, maternity care, prescription drugs, rehabilitation, and mental health care. The law also requires that new private plans now cover preventive services and vaccines recommended by federally-sponsored committees without co-payments or other cost sharing. This includes pap tests, mammograms, bone density tests, as well as the HPV vaccine. As of August 2012, new private plans were also required to cover an additional set of preventive services for women, including contraceptives as prescribed by a provider, breastfeeding supplies and supports such as breast pumps, screening for domestic violence, well woman visits, and several counseling and screening services. Some religious employers (houses of worship) are exempt from the contraceptive coverage requirement altogether and other religiously affiliated employers (such as religiously affiliated universities) were granted a one year delay before having to provide contraceptive coverage, as more policy details are developed.¹²

Health reform holds the potential to greatly expand access to coverage for millions of currently uninsured women and stabilize coverage for many more. Many important details will be determined over the next few years during the implementation phase, particularly whether states opt to expand their Medicaid programs to more poor people, including low-income women. The decisions that the federal government, states, insurance companies, policymakers and individuals make over the next few years will have a major impact on access to coverage and care for millions of women across the nation in the years ahead.

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