

WOMEN IN PERIL
HIV & AIDS
THE RISING TOLL ON WOMEN OF COLOR

DECEMBER 2005

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The Rising Toll on Women of Color**

**A Report of the New York State
AIDS Advisory Council
December 2005**

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Introduction

For the past two years, the New York State AIDS Advisory Council has explored HIV and AIDS prevention, care and services relating to women across New York State. We met with a range of individuals: consumers, health care practitioners and social service providers about current trends, successful service models and effective methods for reaching and serving women at highest risk for contracting HIV. This report highlights our findings and makes recommendations for further action.

The seriousness of the HIV and AIDS epidemic in New York State is well known. New York continues to be the epicenter of the epidemic nationally. Women in New York State represent 30 percent of all AIDS cases statewide; 85 percent of these cases occur among poor women of color, including immigrant and migrant women. Our state health care delivery systems for persons living with HIV and AIDS is supported by a broad range of women-oriented supportive social services with the goal of providing holistic HIV prevention and care for women infected and affected by HIV and AIDS and their families. Despite the best efforts of funders and service providers, the numbers of HIV infection and AIDS cases among New York women continue to grow, and not all women have access to the care and services they need.

We have come a long way from the exclusionary policies and total dearth of research, treatment and services for women and other special populations infected by HIV and AIDS. Indeed, in this third decade in the fight against HIV and AIDS, we know much more about HIV seroprevalence rates among U.S. women, gender-specific AIDS-related conditions, medical and social co-morbidities and the complexity of creating effective HIV prevention and care models that are responsive to the needs of women. Yet, even with these significant advances, we remain at a loss when it comes to creating significant and sustained reductions in new HIV infection rates in the United States. New York State is no exception.

Stigma, discrimination and the lack of coordinated systems of services for women remain the most significant barriers to effective HIV prevention and care for women across New York State. Drug abuse (intravenous and other drugs), coercive or survival sex and sexual violence make adult and adolescent women vulnerable to HIV infection. Poverty among women, especially in communities of color, create struggles to meet basic life needs, including employment, education and health care, as women try to balance self-care, care for family members and others in the extended community. Across all income levels and classes, persistent HIV stigma and discrimination prevents important public and private discussions about meeting women's sexual health needs.

It is our hope that the recommendations in this report will be the beginning of a long overdue call to action to explore the issues and take new approaches to destroy the seemingly inextricable link between HIV infection and the simple reality of being a young woman or woman of color in New York. Our report is based primarily on epidemiological data and the knowledge and experience of key informants, deriving its recommendations from women living with HIV and AIDS, service providers, and researchers. The report reflects a rich and diverse

experience and it is the Council's hope that it will aid greatly in efforts to address a devastating disease that has and continues to challenge all of us concerned about women's health. The Council will continue to evaluate the issues raised in this report and other related issues that emerge as a result of further exploration of these topics.

The New York AIDS Advisory Council extends its heartfelt thanks to all of the individuals who gave their time, knowledge and expertise in the formation of this report.

Executive Summary

The goal of the New York State AIDS Advisory Council in developing this report is to focus attention on the continuing and escalating impact of HIV and AIDS on New York's most vulnerable women and to serve as a call to action for health officials, health care providers, community based organizations and representatives of the communities most affected.

Megan McLaughlin, D.S.W.
Vice Chairperson
New York State AIDS Advisory Council

Alarmed by the increasing toll of HIV and AIDS on New York women, particularly women of color, the New York State AIDS Advisory Council undertook an in depth exploration of the societal, biological and cultural factors that put women at risk for infection and limit women's access to HIV prevention, health care and support services. This 18-month investigation primarily took the form of presentations to the Council by key informants, including HIV-infected women, community based organizations, social service and health care providers serving women and families affected by HIV and AIDS.

This report highlights the Council's findings, including the persistent and growing threat of HIV to women of color and the socio-economic, cultural and gender issues that increase the risk of HIV infection for women. Presentations to the Council also identified gaps in HIV-related services for women and their families, as well as successful program models that have proven effective in reaching the highest risk women and bringing them into prevention and care services. Involvement of past and present members of the New York State Prevention Planning Group (PPG) made possible the integration of PPG perspectives and needs, interventions and models of service delivery for women at risk of acquiring or transmitting HIV.

The Council's recommendations address a wide range of pressing needs identified by individuals and organizations that appeared before the Council. The Council's recommendations should not be viewed as exhaustive, but rather as a starting point for concrete action. The recommendations encourage the establishment of public/private partnerships to carry out strategic planning, identify resources and better coordinate HIV prevention and care services for women and families. It is anticipated that the information contained in this report will prompt renewed focus on the special challenges facing at-risk and infected women and families, and generate creative and coordinated services to more effectively address their needs. It should also be considered as an overarching fact to frame this report that in New York State, a single case of HIV infection is now estimated to result in more than \$246,800 in medical costs – costs that can be reduced through effective and comprehensive community-based services and avoided altogether through comprehensive prevention education initiatives. Stated another way, each additional dollar in HIV prevention resources in New York would return over \$6 in savings in HIV/AIDS medical treatment costs.

Findings

Throughout the Council's presentations and discussions, a number of consistent, cross-cutting issues emerged that heighten the risk of HIV infection for adult and adolescent women, and create special challenges to their ability to gain access and remain connected with the health care system. These issues, cited by virtually all of the presenters, are outlined below.

HIV Threatens New York's Most Vulnerable Women, Particularly Poor Women of Color

The toll of HIV and AIDS on women has increased dramatically -- globally, nationally and in New York State. The proportion of newly reported AIDS cases among women has more than tripled in New York, rising from 12 percent in 1986 to 34 percent in 2003. The increase in HIV infection among young women and teens is even more alarming. In New York, females now account for 48 percent of new HIV infections among teens ages 13-19, and 43 percent of new infections among young adults, ages 20 to 24. An increasing number of HIV/AIDS cases are also being seen in women over 50 years of age.

The concentration of the HIV epidemic among women of color is striking. African American and Hispanic women together represent 86 percent of the 53,500 women who have been diagnosed with HIV and AIDS in New York. The rate of HIV infection among African American women in New York is more than 27 times higher than that of white women; the rate for Hispanic women is 13 times higher than white women. Also at increased risk for HIV infection are Asian/Pacific Islander women, Native American women and immigrant women from regions where HIV is endemic, including Africa, Haiti and the Dominican Republic.

By far, the largest group of women affected by HIV and AIDS are poor women and women who are marginalized in society. Many of the women at greatest risk for HIV are also struggling with drug and alcohol use, mental illness, low educational levels, poor nutrition, sexually transmitted diseases, teen pregnancy and lack of culturally appropriate and accessible health and social services. Many are homeless, incarcerated, mentally ill or engaged in prostitution to meet subsistence needs for themselves and their families.

Sexual Transmission of HIV has Become the Major Risk for Young and Adolescent Women

The Centers for Disease Control estimates that more than two-thirds of new HIV infections in women and female teens results from unprotected sexual contact with infected partners. While the number of women becoming infected by personally injecting drugs has declined in recent years, non-injecting poly-drug use and alcohol abuse play a major role in women engaging in high-risk sexual activity, including trading sex for money or drugs.

A woman is twice as likely as a man to contract HIV infection during unprotected vaginal intercourse with an infected partner, and the presence of sexually transmitted disease greatly

increases this risk. Women, especially young women, may not be aware of the history of high-risk behaviors of their partners or have the ability to negotiate condom use with a male partner. One quarter of female HIV cases attributed to heterosexual contact are due to sex with an HIV-infected injection drug user. In addition, men who consider themselves as heterosexual but secretly have male sex partners (a phenomenon colloquially referred to as being “on the down low”) also put women at risk for HIV and other sexually transmitted diseases.

Gender Inequality, Violence, Cultural Norms & Stigma Put Women at Risk

Cultural and gender issues play a powerful role in the lives of minority and ethnic women, and increase their risk for HIV. Many cultures are patriarchal; women are considered subservient to men, and women are totally dependent on men, emotionally, socially and financially. In many cultures masculinity is associated with having multiple sexual partners. Women are expected to accept, or at least not to question the lifestyle of male partners.

Male dominance and power – expressed through violence and coercion – also play a critical role in increasing the risk of HIV infection to women. Many HIV-infected women have a history of childhood sexual abuse, rape, incest and domestic violence from adult male partners. The threat of violence deters many women from attempting to negotiate safer sex or to resist unprotected sex with a high-risk partner. Women may also face violence as a result of being HIV positive. In addition to beatings, abusers may threaten to reveal the woman’s status to family, friends and employers, or use her HIV status as grounds for paternal custody.

There is widespread stigma concerning HIV and AIDS in most cultures. Secrecy and denial surround risk activities such as homosexuality, intravenous drug use, prostitution and infidelity. Discussion of sexual matters is often taboo. Women often fear that seeking HIV testing or care will lead to social stigma and blame for infecting their partners.

Cultural issues also limit access to health care for many women. Immigrant women frequently face language and literacy barriers and may be suspicious of treatments that are different from their own cultural beliefs and practices. Undocumented immigrant women or those who have violated the law may avoid contact with the health care system out of fear of arrest or deportation.

Women’s Caretaker Responsibilities Impact Access to Care

Women infected with HIV face a host of challenges in carrying out their family responsibilities and managing their illness. Traditionally, women have the primary responsibility for care of children, and they often put the needs of their children ahead of their own. Health care may not be a high priority for women at risk or infected with HIV. They are often living in poverty-ridden, urban neighborhoods and are struggling to meet the basic subsistence needs of their families for food, clothing and shelter. They may lack health insurance, childcare and transportation. In addition to managing her own health issues, an HIV-infected woman may be caring for an HIV-infected child, partner or an ill elderly parent.

Engaging and retaining at risk and HIV-infected women in the health care system requires holistic, family-centered and culturally competent health care services that recognize the role of women as primary caregivers and address the multiple health care needs of all family members. Women also need a wide array of auxiliary support services to help them stay connected with the health care system and adhere to complex medical regimens.

Recommendations

In response to the findings identified above, the New York State AIDS Advisory Council developed a series of recommendations directed to stemming the escalating rate of HIV infection among women, particularly focusing on adult and young women of color, and increasing their access to needed health care and support services. The Council's recommendations call for developing more effective prevention strategies targeted to women and teens, expanding and strengthening community based outreach and support services, and tailoring health care services to meet the needs of women and families. Many of these recommendations grew out of the presentations to the Council by community groups, health and social service providers and HIV-infected women. In refining prevention interventions and strategies, providers and planners may also want to refer to the work of the New York State Prevention Planning Group (PPG) and, in particular, the specific recommendations of the PPG's Women's Committee.

The nine major recommendations listed below are supported by specific implementation actions (listed in the body of the report) to be carried out by federal, State and local health officials, health care providers and institutions, and community based organizations.

- 1. Promote Public/Private Partnerships to Address the Full Range of HIV Services Needed by Women and Their Families**
- 2. Prioritize and Increase Resources for HIV Prevention Strategies Directed to Adult and Adolescent Women, Particularly Women of Color**
- 3. Expand and Strengthen Community-Based Outreach, HIV Prevention and Support Services for Women and Adolescents**
- 4. Tailor Health Care, Mental Health and Substance Abuse Services to Meet the Needs of Women and Families**
- 5. Expand Access to Substance Abuse Treatment for Women and Women with Children**
- 6. Create Culturally Competent Health Care Services for Immigrant Women**
- 7. Increase the Availability of Supportive Housing for HIV-Infected Women and Families**
- 8. Encourage Greater Public/Private Funding to Speed Microbicide Research and Development**
- 9. Improve Data Collection Relating to Female HIV and AIDS Cases**

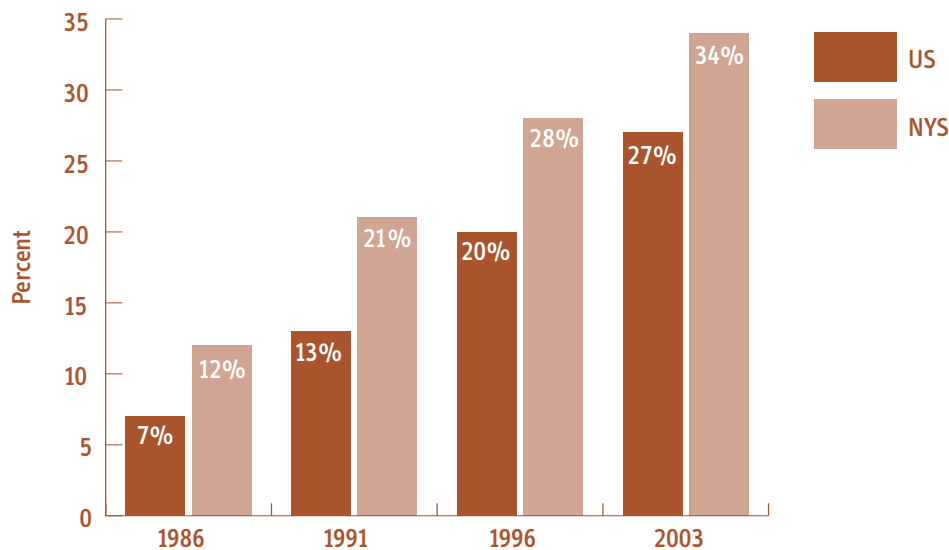
The New York State AIDS Advisory Council and the New York State Department of Health AIDS Institute will provide advice and consultation to community based organizations and health care providers in working toward implementation of these recommendations and achieving our common goals.

Women and HIV & AIDS: An Alarming Picture

Through graphs and tables, this section of the report dramatically illustrates the escalating impact of HIV and AIDS on women, especially women of color.

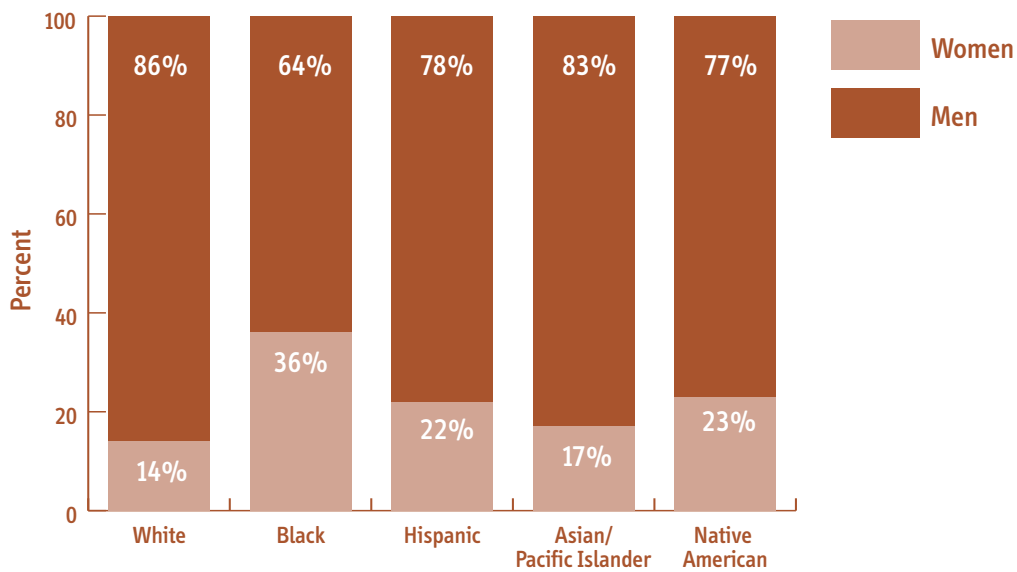
- More than 53,500 New York women have been diagnosed with HIV or AIDS since the beginning of the epidemic; 22,224 of them have died.
- More than 31,200 New York women and female teens are currently known to be living with HIV or AIDS. This number is an undercount as not all women and adolescent females know their infection status because they have not been tested.
- Note: The data category “Black” includes African American women as well as immigrant women from Africa and the Caribbean.

Women as a Proportion of Newly Reported AIDS Cases in the United States and New York State 1986-2003



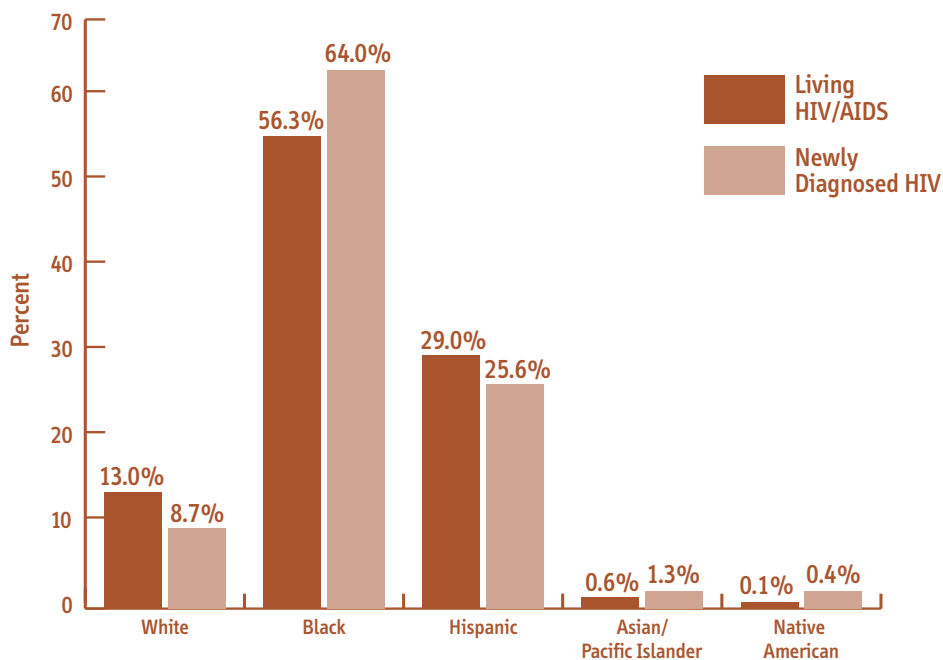
The impact of the HIV epidemic on women has increased dramatically, both in the United States and in New York State. Women now represent 34 percent of newly reported AIDS cases in New York State, compared to 27 percent nationally.

Newly Reported AIDS Cases in the United States by Sex and Race/Ethnicity 2003



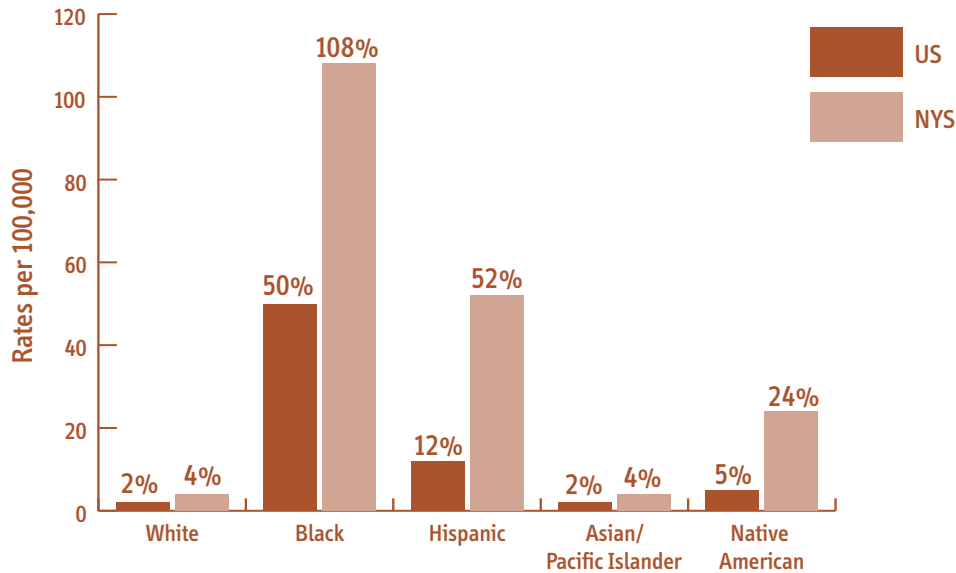
The proportion of AIDS cases among women is much greater among women of color.

Females Living with HIV/AIDS and Females Newly Diagnosed with HIV through 2003 by Race/Ethnicity in New York State



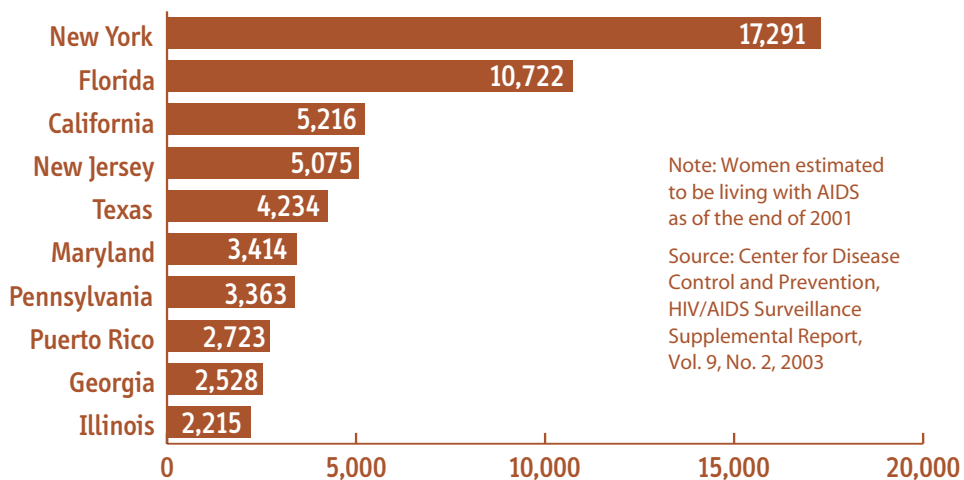
The proportion of females living with HIV/AIDS is greatest among Black women; the proportion of Black women newly diagnosed with HIV is even greater.

AIDS Case Rates per 100,000 Women in the United States and New York State by Race/Ethnicity 2003



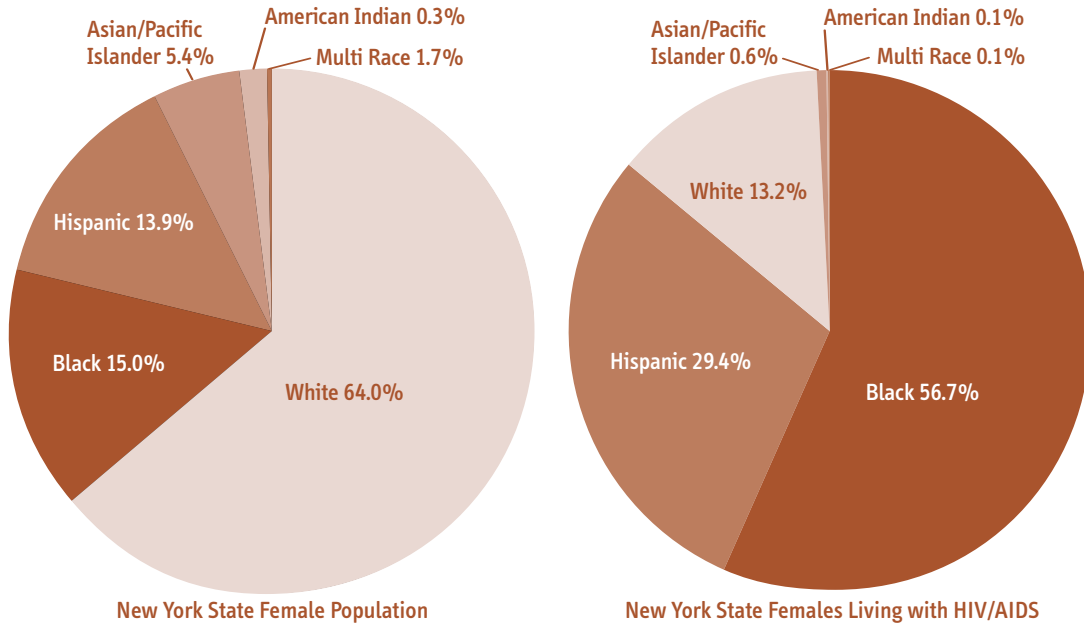
The severe impact of the HIV epidemic on New York's women of color is striking. The AIDS case rate for Black women is more than 27 times higher than for white; the rate for Hispanic women is 13 times higher.

Number of Women Estimated to be Living with AIDS Top 10 Jurisdictions, 2001



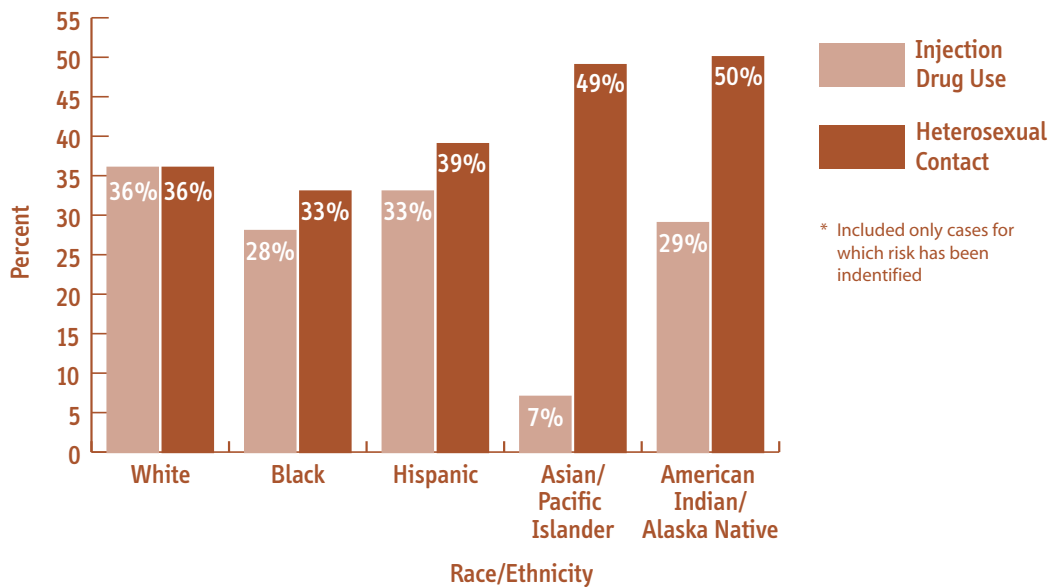
By a wide margin, New York State continues to lead the nation in the number of women living with AIDS.

New York State Female Population, by Race/Ethnicity Compared to New York State Females Living with HIV/AIDS



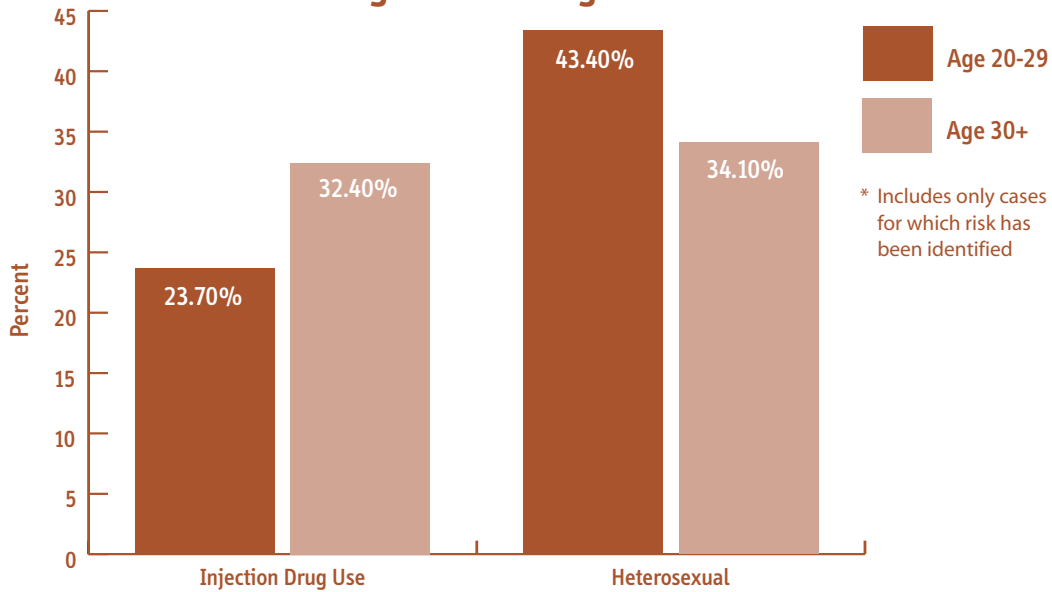
Black and Hispanic women account for only 29 percent of the New York female population. However, together they represent 86 percent of New York women living with HIV/AIDS.

New York State Women Living with AIDS by Race/Ethnicity and Exposure Category Diagnosed through 2003



Almost all women contract HIV through heterosexual contact or injection drug use.

Proportion of Women Living with AIDS in New York State by Age Group and Major Risk Category* Diagnosed through 2003



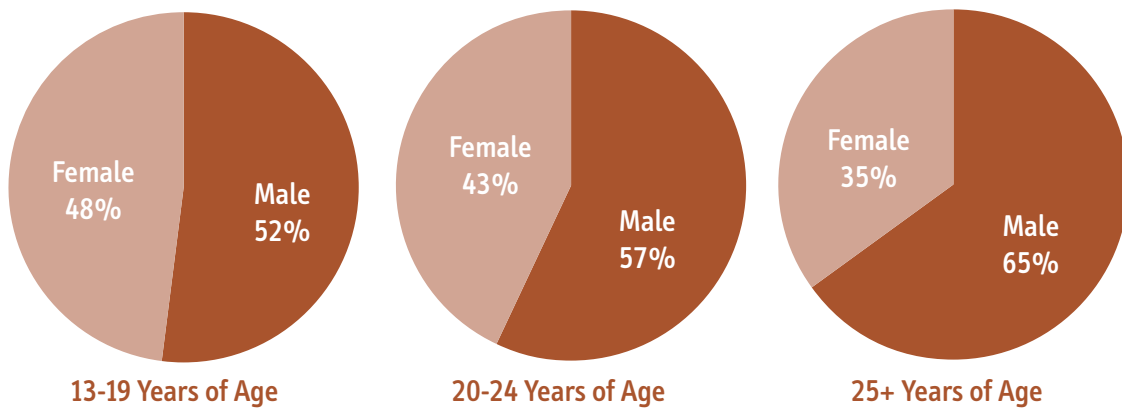
The majority of younger women living with AIDS became infected with HIV through sexual contact. Among older women, AIDS cases linked with injection drug use and heterosexual contact are nearly equal.

Females Living with HIV/AIDS by Age Group Diagnosed through 2003 New York State

Age	HIV (N=12,476)	AIDS (N=18,804)
	%	%
<12	7.1	2.2
13-19	3.3	1.5
20-24	8.4	4.1
25-29	12.5	11.3
30-49	59.0	70.4
50+	9.3	10.5
Unk	0.4	0.00
Total	100.0	100.0

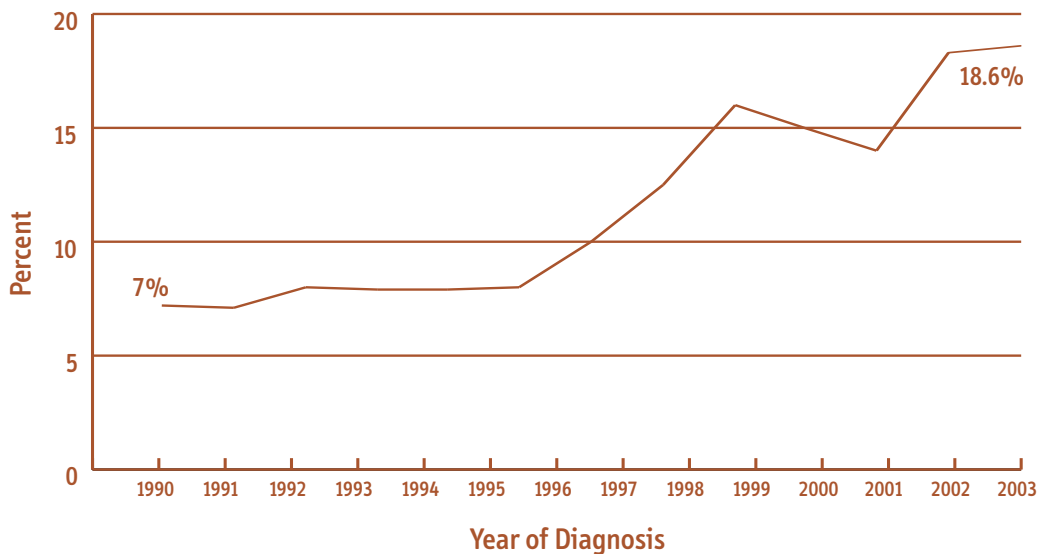
While the greatest number of women living with HIV and AIDS are 30-49 years of age, there is concern that the percent of HIV infections among young women and female teens is significantly higher than AIDS cases. This may reflect increased risk-taking behavior by young women and female adolescents.

Newly Diagnosed HIV Cases by Age Group and Gender Diagnosed 2001-2003 New York State



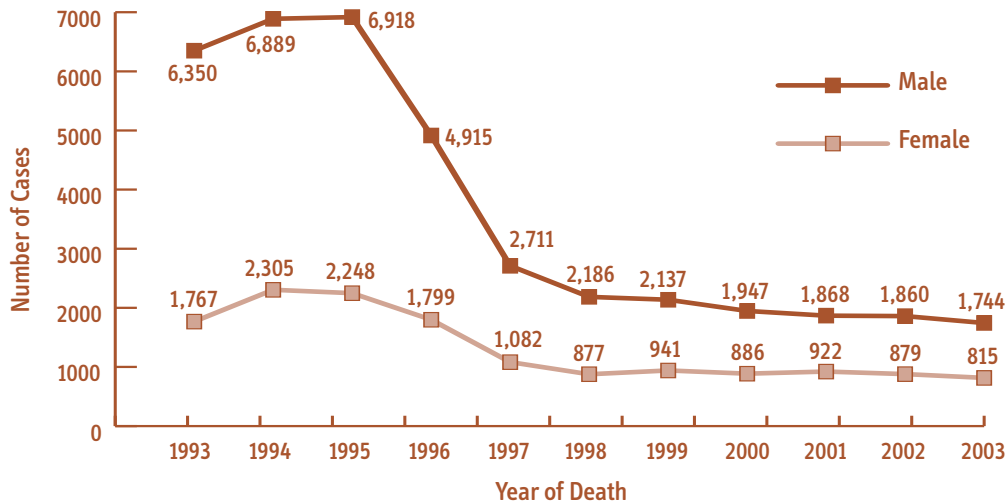
Female teens and young women represent nearly half of newly diagnosed HIV cases in their age groups. The increased impact of HIV on young women and teens may be a harbinger for the epidemic's future course: a trend toward equalization of male and female cases.

Proportion Female AIDS Cases 50+ Years of Age by Year of Diagnosis New York State



An increasing share of AIDS cases are being diagnosed among women over age 50.

Trends in AIDS Deaths by Sex, 1994-2003 New York State

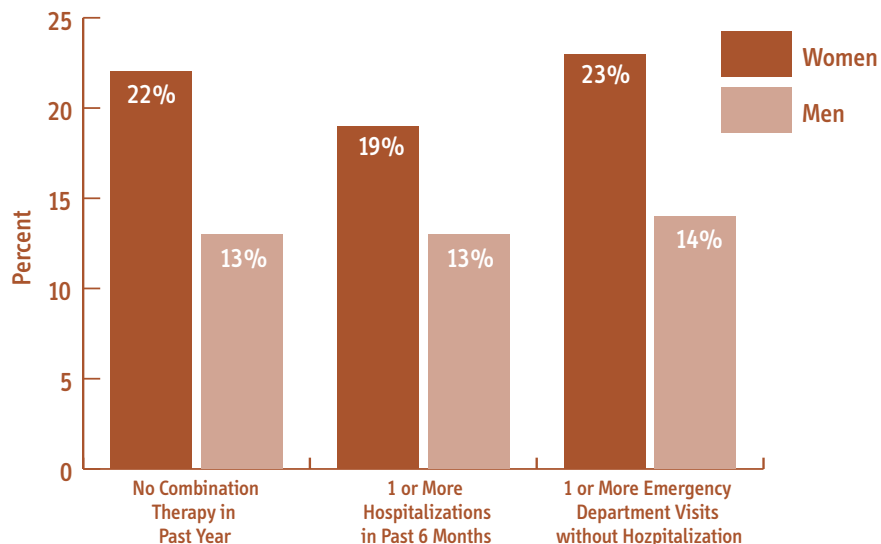


Advances in treatment have led to a significant reduction in AIDS deaths. However, the rate of decline among women has been proportionally somewhat less than among men. Deaths among New York women with AIDS declined by 64 percent, compared to 75 percent among men from a peak in 1995 to 2003.

Differential Access to Care Among People with HIV/AIDS in Care, by Sex, 1998

Note: All results shown are significantly different from men ($p < .05$) after adjustment for CD4 count. Includes persons 18 years and older. Higher hospitalization rates result from failure to receive indicated outpatient therapy.

Source: Shapiro, et. al., "Variations in the Care of HIV-Infected Adults in the United States," Journal of the American Medical Association, Vol. 281, No. 24, 1999.

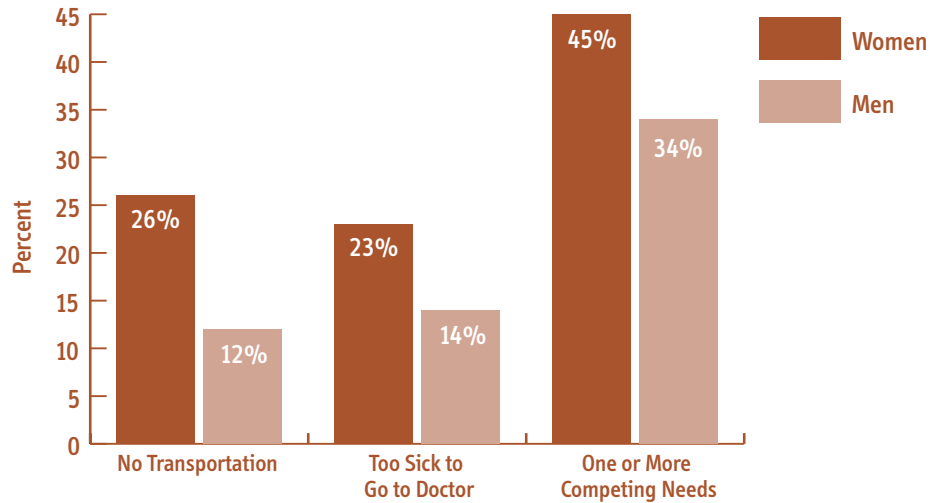


Nationally, women fare more poorly than men on several access and quality of care measures. For example, women were less likely than men to have received combination therapy and more likely to have more hospitalizations and emergency room visits.

Reasons for Postponing Care Among People with HIV/AIDS in Care, by Sex, 1996

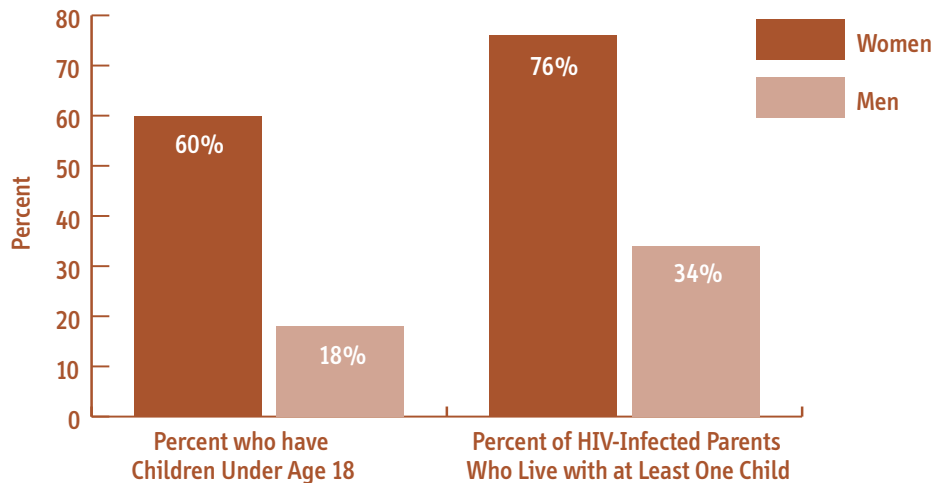
Note: All results are significant at $p < 0.01$. Includes persons 18 years and older.

Source: Cunningham, et. al., "The Impact of Competing Subsistence Needs and Barriers on Access to Medical Care for Persons with Human Immunodeficiency Virus Receiving Care in the United States," Medical Care, Vol. 37, No. 12, 1999.



Women may face greater barriers to care than men. A higher proportion of women than men with HIV report postponing medical care due to the lack of transportation, or because they were too sick to go to the doctor or had competing needs.

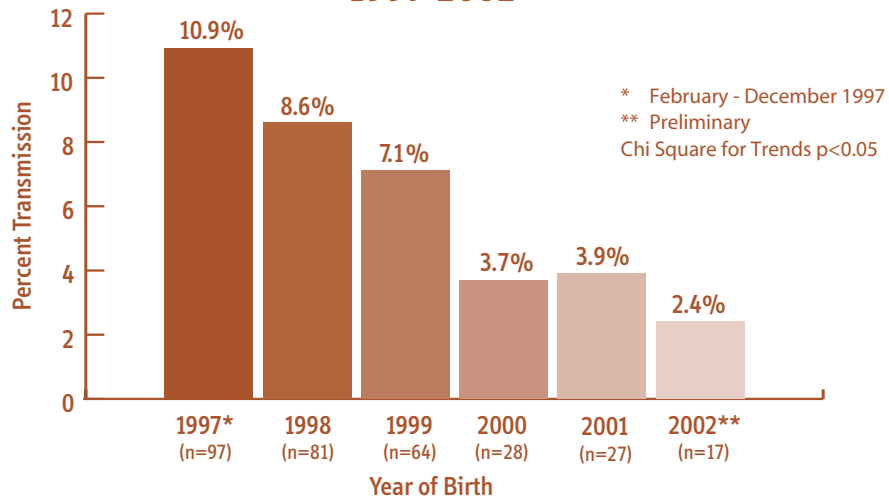
Child Rearing Responsibilities of People Living with HIV/AIDS in Care, by Sex, 1996-1997



Source: Schuster, et. al., "HIV-Infected Parents and Their Children in the United States." American Journal of Public Health, Vol. 90, No. 7, 2000.

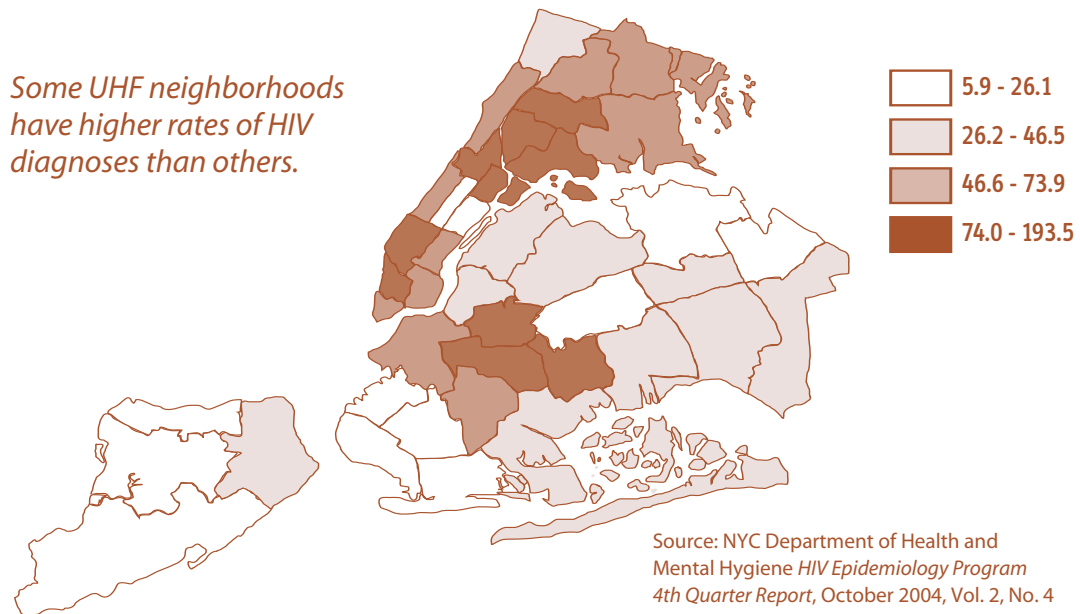
Women with HIV/AIDS are much more likely than men to have child care responsibilities. In addition to managing their own illness, women are responsible for their children's health needs and well being. Some HIV infected women are also caring for their infected spouses and for parents.

Perinatal HIV Transmission Rate New York State 1997-2002



New York State has achieved a remarkable reduction in the number of infants infected with HIV through perinatal transmission. This is a result of routine HIV counseling and voluntary testing during prenatal care, and offering any pregnant woman who tests positive antiretroviral therapy to reduce the risk of HIV transmission to her child.

HIV Diagnosis per 100,000 in 2002



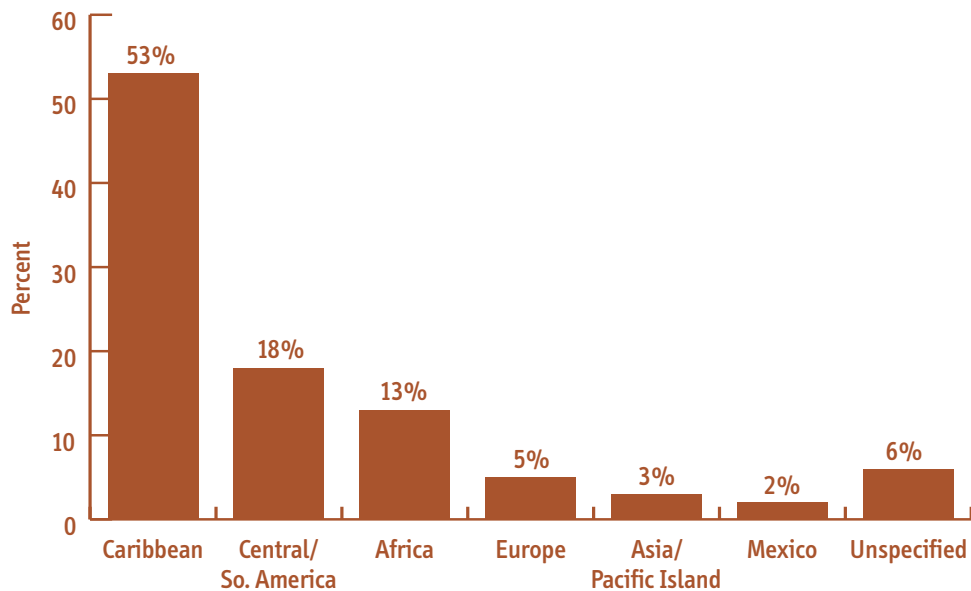
The HIV epidemic is concentrated in New York City low-income neighborhoods that have high numbers of minority and immigrant residents.

New York City Neighborhoods with the Highest Rates of HIV Infection

	HIV/AIDS Rate/100,000
Manhattan	
Chelsea-Clinton	223.6
East Harlem	181.3
Central Harlem- Morningside Heights	180.7
Bronx	
High Bridge-Morrisania	150.7
Crotona-Tremont	132.3
Hunts Point-Mott Haven	131.3
Brooklyn	
Bedford Stuyvesant- Crown Heights	127.3
Williamsburg-Bushwick	102.4

Source: 2002 Census Data New York City Department of Health & Mental Hygiene HIV Epidemiology Program

Distribution of HIV & AIDS Cases Among Foreign Born Women in New York State with Known Country of Origin



Includes 2540 cases diagnosed through December 31, 2003. Does not include Puerto Rico or U.S. Virgin Islands.

Socio-economic, Cultural and Gender Issues Put Women At Increased Risk for HIV

Throughout the course of the New York State AIDS Advisory Council’s exploration of HIV and AIDS in women, a number of societal, biological, and cultural factors emerged that put women at greater risk of HIV infection, and challenge their ability to gain access to prevention and care services. These circumstances must be recognized and considered in developing effective HIV prevention strategies and health care services for women.

HIV Threatens New York’s Most Vulnerable Women

“The HIV epidemic in New York State and the nation is fueled by socio-economic factors, including poverty, low educational level and substance abuse.”

Miguelina Ileana Leon
Health Policy Consultant

- By far, the largest group of women affected by HIV and AIDS are poor women, women of color and women who are marginalized in society. Many of the women at greatest risk for HIV are also struggling with drug and alcohol use, low educational levels, poor nutrition, sexually transmitted diseases, teen pregnancy, and lack of culturally appropriate and accessible health and social services. Many are homeless, mentally ill or engaged in prostitution to meet subsistence needs for themselves and their families.
- Many vulnerable women come from a background of multi-generational violence and abuse. A significant majority of women who are infected with HIV have a history of childhood sexual abuse, rape, incest and domestic violence from adult male partners.
- Nearly two thirds (65 percent) of women diagnosed with HIV in care are living below the poverty level, with annual incomes under \$10,000¹. At risk women are likely to be unemployed, and have limited education. The lack of employment options drives many women into prostitution and liaisons with high-risk men. Many women end up homeless, living on the streets, or incarcerated for drug related crimes.
- HIV infection is particularly elevated among women incarcerated in New York State prisons, most of whom are in custody for drug-related crimes. Studies show that women entering prison are three times more likely than men to be infected with HIV and hepatitis C. Most of these women are poor women of color.²
- HIV-infected women often lack familial and social supports. Women engaged in drug use or prostitution may be disavowed by their families and friends. Recently arrived immigrant women may be cut off from their cultural support systems and isolated by language barriers.
- Given the immediate and overwhelming stresses with which these women must cope, it is understandable that HIV prevention and health care may take a back seat. Competing subsistence needs for themselves and their children — money, food, housing, clothing, — can drain their energy and resources, leaving them vulnerable to high-risk situations.

Limited Early Focus on Women's HIV Risks and Care Needs

“Women were largely invisible during the first decade of the HIV/AIDS epidemic in terms of the attention of policy makers, researchers, service providers and public health officials.”

Miguelina Ileana Leon
Health Policy Consultant

- For the most part, women were absent in early HIV/AIDS clinical and social research, policy decisions and program planning. Researchers and public health officials were primarily focused on women as vectors or carriers of HIV infection through prostitution or maternal transmission to infants.
- Only recently has more extensive research activity been directed to identifying and measuring the gender specific variables related to women's risk of infection, response to treatment and access to care. Several studies are now underway to investigate gender specific differences in HIV disease progression, complications and treatment in women.³
- It is likely that many women died of AIDS without ever being diagnosed prior to 1993 when the federal Centers for Disease Control and Prevention (CDC) expanded the AIDS case definition to include infections and conditions specifically related to women.
- Women suffer from many of the same infections and complications of HIV that afflict men, but women also experience female-specific manifestations of HIV disease, such as recurrent vaginal yeast infections, severe pelvic inflammatory disease, and human papilloma virus infection, which increase their risk of cervical cancer. Women may also react differently to antiretroviral therapy.³
- Major advances in HIV treatment, coupled with prevention efforts, have led to a decline in the number of new AIDS cases and deaths. However, national studies suggest that compared to men, women with HIV experience disparities in access to and utilization of preventive care, and are 12 percent less likely to receive prescriptions for the most effective treatments for HIV infection.⁴

Sexual Transmission of HIV is Now the Greatest Threat to Women

“Abstinence and monogamy cannot be relied upon to protect women. Women are socially and biologically vulnerable to sexual transmission of HIV and there are limits on women's ability to protect themselves, especially when they have little or no control over sexual behavior of male partners or are in abusive relationships.”

Sue Klein, Director
AIDS Institute Division of HIV Prevention

- Sexual transmission of HIV has become the primary route of infection for women and adolescent females. The CDC estimates that nearly 80 percent of new HIV infections diagnosed in women and female teens in 2003 resulted from unprotected sexual contact with infected male partners.⁵

- HIV is transmitted more efficiently from men to women during unprotected sexual intercourse due to the higher concentration of HIV in semen compared to female genital fluids, and the greater exposure of mucosal surfaces in the woman’s vagina. These biological factors put younger women at particular risk.³
- A woman’s risk of infection is also greatly increased if she is infected with other sexually transmitted infections (STIs), especially those that cause ulcerations of the vagina (for example, genital herpes, syphilis and chancroid). Further increasing the risk is that many reproductive tract infections in women are asymptomatic which makes women less likely to seek timely treatment.³
- Women may not be aware of the high-risk behaviors of their partners. One quarter of female HIV cases attributed to heterosexual contact are due to sex with an injection drug user. Men who consider themselves heterosexual but secretly have male sexual partners (colloquially referred to as “on the down low”) may put women at risk for HIV and other sexually transmitted diseases. In a recent study of HIV-infected men, 34 percent of African American men who have sex with men (MSM), 26 percent of Hispanic MSM, and 13 percent of white MSM reported also having had sex with women.⁵

Gender Inequality and Violence Put Women at Risk

“We encouraged women to talk to their partners about condom use. One week later a number of women came back with their eyes all black and blue because their partners thought that the women were the ones out there being unfaithful and how dare they suggest that their partner who is in control of the situation use a condom.”

Yvonne Graham
Brooklyn Borough Deputy President

- Socially constructed concepts of masculinity and femininity define the roles and position of men and women and their relationships to each other. Traditional sex roles, in which women are passive and men lead, keep women from voicing their sexual needs and limit their ability to prevent HIV infection. A woman’s hesitation to discuss safer sex with a male partner is based on her understanding of power and lower perception of control in sexual relationships.⁶
- Male dominance and power – expressed through violence and coercion – plays a critical role in increasing the risk of HIV infection to women. The threat of violence deters many women from negotiating safer sex or resisting unprotected sex with a high-risk partner. If a woman brings up condom use she may be concerned that her male partner will accuse her of being unfaithful, ignore her request and force unprotected intercourse, or physically abuse in the belief that she is a carrier of HIV or other sexually transmitted diseases.⁷
- Women may also face violence as a result of being HIV positive. Women who are diagnosed with HIV are often afraid to tell their male partners or to encourage their sexual partners to be tested for HIV. Abusers often use the woman’s HIV status as an excuse for physical and psychological abuse. In addition, abusers may threaten to reveal the woman’s HIV status to

children, family, friends and employers, or use the woman's HIV status as grounds for paternal custody.⁷

- HIV-infected women in poverty are at particular risk. They may be reluctant to leave abusive partners because they are dependent on their partners for housing, food and money to pay for costly medications and treatment. Women with children may be particularly reluctant to leave out of concern for the care of their children should they become incapacitated by the disease.⁷

Cultural Norms and Stigma Increase the Risk to Women

- Cultural and gender issues play a powerful role in the lives of women and increase their risk for HIV. Many cultures are patriarchal; women are considered subservient to men, and women are dependent on men, emotionally, socially and financially. In many cultures masculinity is associated with having multiple sexual partners. Women are expected to accept, or at least not to question, the lifestyles of male partners.
- There is widespread stigma concerning HIV and AIDS in most cultures. Secrecy and denial surround risk activities such as homosexuality, intravenous drug use, prostitution and multiple partners. Discussion of sexual matters is often taboo.
- As a consequence of the extreme stigma and oppression associated with homosexual contact in many cultures, some men who have sex with men may not openly identify as gay or bisexual for fear of rejection by their families and community. In some cultures men have female partners as a cover; some marry to have children.
- Cultural factors also limit access to health care services for many women. Women may be suspicious of treatments that are different from their own cultural beliefs and traditional practices. Women often fear that seeking HIV testing or care will lead to social stigma and blame for infecting their partners. In some cultures, there is a belief that disease is a means of divine retribution, or results from witchcraft or violation of taboos.

Women's Caretaker Responsibilities Impact Access to Care

- Women infected with HIV face a host of challenges in carrying out family responsibilities and managing their illness. Traditionally, women have the primary responsibility for care of children. A woman who is coping with HIV or AIDS may lack the energy, resources or ability to care for her children and also attend to her own health care needs.
- As primary caretakers, women often put the needs of their children and family members ahead of their own health care needs. HIV may affect several generations and extended family members. In addition to managing her own health issues, an HIV infected woman may be caring for an HIV- infected child, partner or an ill elderly parent.
- HIV-infected women have the added burden of disclosing their health status to their children, and planning for the future care and custody of children during their illness or after death. A woman who is unable to adequately care for her children may be forced to make the wrenching decision to give them up for adoption, resulting in extreme feelings of guilt and loss.

Recommendations

The Council's recommendations for future action address the most pressing needs identified by individuals and organizations that testified during the Council's exploration of HIV and AIDS in women. These recommendations should not be viewed as all-inclusive or exhaustive, but rather as a plan for concrete action. It is anticipated that these recommendations will prompt renewed focus on the special challenges facing at-risk and HIV-infected women and families, and generate creative and coordinated services to more effectively address their needs. The recommendations outline specific action steps to be taken by government, health and social service providers, and community based organizations. The Council will continue to evaluate issues raised in this report and that emerge as a result of discussions and actions generated by the report and its recommendations.

1. Promote Public/Private Partnerships to Address the Full Range of HIV Services Needed by Women and Their Families

- Federal, State and local health officials, health care providers and a wide range of community organizations and representatives from affected communities should establish partnerships to carry out strategic planning, identify resources, and implement coordinated HIV prevention and care services for women and families. This approach is particularly important in an era of level or diminishing resources.
- Strategic plans should involve creative integration of HIV education, testing, support services and treatment into a wide range of settings, including: hospitals, clinics, community health centers, private practice and medical groups, community-based organizations, substance abuse programs, maternal and infant care programs, family planning and STD clinics, social service agencies, schools, after school programs, faith based initiatives and programs conducted by civic, neighborhood and business groups.

2. Prioritize and Increase Resources for HIV Prevention Strategies Directed to Adult and Adolescent Women, Particularly Women of Color

- Increased public and private resources should be identified to mount an aggressive, multi-faceted campaign to promote risk behavior reduction and HIV testing among women and female youth. This initiative should include consumer input and involve the active and coordinated participation of local health departments, community based organizations, health care providers, churches, schools and the public media.
- Effective HIV prevention strategies and messages must be designed to reach all women and also targeted to women and female youth who are most at risk, including young women of color, recent immigrants, transgender women and those who are mentally ill, homeless, incarcerated or engaged in substance abuse or prostitution. It is important to maintain a focus on both the at-risk and infected populations of women.
- Social marketing techniques, that involve target audiences in the design of effective messages, should be employed to develop woman-focused HIV prevention strategies

and programs. Cultural, social, religious and generational factors should be taken into account.

- Support should be provided to community-based organizations serving immigrant women to develop culturally and linguistically competent HIV prevention materials and activities to reach the growing and diverse immigrant population in New York State.
- HIV prevention activities should be directed to lesbian, bisexual and transgender women who may not perceive themselves at risk and may avoid the health care system due to fear of discrimination.
- The AIDS Institute should work with the New York State Department of Education and the New York City Board of Education to assess the adequacy of HIV prevention education currently being provided to New York school children. HIV prevention education addressed to adolescents must be explicit and developmentally appropriate. Information should be designed to help teenagers develop the skills necessary to initiate and maintain HIV prevention behaviors. If necessary, additional training should be provided for teachers, school nurses and others who discuss HIV issues with students.
- All programs that serve young people at increased risk should provide ongoing HIV prevention and risk reduction education, and encourage HIV counseling and testing with appropriate adult support based on the needs of the young person. This includes the availability of HIV counseling and testing in after-school programs, runaway shelters, family planning clinics, teen pregnancy and maternal/child health programs, STD treatment clinics, and juvenile justice facilities. Organizations that work with youth should be encouraged and assisted to train a statewide cadre of female adolescents to serve as peer educators.

3. Expand & Strengthen Community-Based Outreach, HIV Prevention and Support Services for Women and Children

- As the number of women and families affected by HIV/AIDS continues to escalate, agencies struggling to meet their needs are becoming overwhelmed. Existing community-based prevention and support services for women and families need to be expanded and new programs created for women living in underserved rural areas of the State.
- Increased, stable federal, state, local and private funding should be made available to ensure that community-based agencies providing HIV-related services to women and families have the necessary resources to support infrastructure, staff, management and information systems to respond to the unique health and social support needs of women and their families. Funding should provide for annual cost of living salary increases to help these organizations hire and retain qualified staff. Funding provided for only one year at a time prevents organizations from hiring staff and implementing needed services.

- Programs should be encouraged to involve women of the affected communities — who speak the same language, understand the cultural backgrounds, and have had similar life experiences — in the design, development and implementation of HIV prevention strategies and support programs for women and their families.
- On-going training should be provided to ensure that the staff and volunteers working in community organizations are up-to-date on the most recent information about HIV transmission and treatment. Community-based educators and counselors need to have current, easy to understand, non-technical information designed for a lay audience that they can convey effectively to their clients.
- The Community Action for Prenatal Care (CAPC) initiative -- which includes targeted outreach, enhanced follow-up by trained peer outreach workers and collaboration among service providers -- should be expanded to all areas of the State with high rates of HIV among women of child bearing age. Elements of the CAPC model should also be applied to helping women stay in care and adhere to complex medication regimens. This successful service delivery model should also be expanded to establish trust with other high-risk women, including runaway youth, homeless women, sex workers and substance users.
- Enhanced outreach efforts should be targeted to recent immigrant women and trans-women, especially those from regions with high rates of HIV infection such as Africa and the Caribbean and those who encounter significant language barriers, to encourage them to receive HIV counseling and testing, and to help them gain access to prenatal care and HIV-related health care and support services.
- Greater coordination is needed between community-based agencies and health and social service providers to ensure that women gain prompt access to needed HIV-related services and stay connected with the health care and support systems. The AIDS Institute should work with community-based organizations and health and social service providers to encourage and assist them in forming more meaningful collaborative arrangements and working referral agreements.
- Technical assistance should be provided to community- based programs to help them acquire the computer and data analysis skills needed to more effectively develop statistical reports and carry out program analyses that will aid in planning, evaluating and improving their services, and obtaining the resources needed to support service provision.
- Federal, state and local support is needed for programs that provide support to families who are caretakers of children and adult family members with HIV and AIDS.

4. Expand Family-Centered Health Care, Mental Health & Substance Abuse Services for Women & Children

- The linked epidemics of HIV infection, substance abuse and mental illness call for greater coordination and integration of the mental health, substance treatment and HIV

- service delivery systems. It is critical that these systems of care work together to minimize harm and maximize successful outcomes for at-risk and HIV-infected women and their families.
- Co-located HIV health care, mental health and substance abuse treatment services need to be developed in multiple settings serving women at risk for HIV infection. These settings include: medical centers, community health centers, drug treatment programs, mental health facilities, family shelters and HIV supportive housing sites.
 - Training should be provided to develop a cadre of health care professionals who understand the full range of services and social supports needed by multiply diagnosed patients.
 - Primary care physicians should be equipped to screen and identify women with mental health disorders and substance use problems and refer them to appropriate services.
 - Psychiatrists, psychologists, psychiatric nurses and other mental health professionals need information concerning HIV-related care, including antiretroviral therapy, drug interactions, and substance abuse issues.
 - Substance abuse counselors need to be knowledgeable about HIV symptoms and treatment regimens, including the potential interaction of HIV medications with methadone and other medications used in treating addiction.
 - Training should be made available for health care providers, social workers, case managers and other staff who deal with at-risk and HIV-infected women to help them understand the women's life challenges, multiple needs, and the barriers that prevent women from gaining access to and staying in care. All health care and community-based organizations providing HIV/AIDS related services should receive training in the dynamics of domestic violence, identifying women at risk of violence, assessing a woman's need for protection and support, and referring abused women to appropriate services.
 - A full continuum of mental health services for women and women with children needs to be developed to include: psychiatric evaluation and treatment, psychotherapy (individual, family and group), medication evaluation and management, peer support groups, and crisis intervention.
 - Government oversight and funding agencies, medical research institutions and pharmaceutical companies should adopt policies and standards to ensure that women have equal access to HIV-related research programs and clinical trials to evaluate new drugs for treatment of HIV. Physicians and community-based organizations serving HIV-infected women should educate women about the benefits of early treatment and encourage and help women enroll in HIV research studies. Women's participation in clinical drug trials is critical to evaluate how medications affect women differently from men, how hormonal changes may affect a drug's efficacy or safety and whether women require different dosages than men.

- With the availability of rapid HIV testing methods, HIV counseling and voluntary testing should be provided in non-traditional community settings and should become a routine part of medical care for women and adolescents. Physicians should be alerted to the increasing rate of HIV infection among young women as well as women over 50 years of age.
- Intensive monitoring and follow-up necessary to help HIV-infected women who are also suffering with mental illness and substance abuse stay connected with the health care system and maintain adherence with treatment regimens needs to be expanded.
- The State Health Department should work with the State Medical Society and regional AIDS Care Centers to expand access to comprehensive HIV- related health care services for women living in rural areas of New York State through distance learning, telemedicine, and links between primary care providers and HIV/AIDS treatment centers. Due to a lack of trained health care providers, HIV-infected women and families in some rural areas must travel hundreds of miles to reach medical providers with experience in HIV diagnosis and antiretroviral therapy.
- The State Health Department should work closely with the State Department of Corrections to ensure that all incarcerated women receive prompt access to HIV- related services, including counseling, testing, and medical care that is consistent with current treatment standards. Incarcerated women also need counseling and treatment for substance abuse and mental health problems, and linkages to needed health care and community services when they are released from prison.

5. Expand Access to Substance Abuse Treatment for Women and Women with Children

- Increased availability of family-focused residential substance abuse treatment programs for women and women with children, particularly children over the age of five, would help to bring women with children into treatment. Once established, the availability of these services needs to be promoted among eligible women. In the past, women have been reluctant to seek such services for fear of losing their children to foster care placement.
- Non-residential drug treatment and harm reduction programs should be encouraged and assisted in developing woman-focused services that address the special health care and psycho- social supports women need to remain drug free and reduce drug-related risk behaviors that can lead to HIV infection.
- Substance abuse treatment providers should reach out to community based organizations as well as medical providers and social support agencies to establish referral arrangements for services needed by women in treatment. Likewise health care providers and community-based HIV and AIDS service organizations need to reach out to drug treatment programs to establish a functioning and appropriate regional network of coordinated services.

6. Create Culturally Competent Health Care Services for Immigrant Women

- The AIDS Institute should foster collaborative linkages between community based organizations that serve immigrant women and health care providers to help Western trained physicians develop immigrant sensitive services that recognize the cultural, language, legal, economic and generational factors that serve as barriers to health care access for immigrant women. Likewise, traditional practitioners that serve immigrant women — including herbalists and acupuncturists — should receive HIV-related training to enable them to counsel their patients about HIV transmission risks, recognize HIV-related symptoms and refer at-risk patients to HIV testing and care providers.
- Intensive outreach efforts are needed to educate and convince undocumented immigrant women that health care providers will not report them to immigration officials. Immigrant women also need information about the health care benefits and services they are eligible for, including pre-natal care and ADAP Plus (primary medical care available through New York State’s HIV Uninsured Care Program).
- The AIDS Institute should encourage and support health care providers to bring HIV and AIDS care and treatment services into immigrant neighborhoods. Lack of nearby health care services can be a major barrier to care for immigrant women who do not speak English and lack transportation.

7. Increase the Availability of Supportive Housing for HIV Infected Women and Families

- The lack of safe, affordable housing is one of the most pressing needs for HIV-infected women and families in New York State. Addressing this public health concern requires a renewed effort by all levels of government (federal, state, & local) to increase resources for development of additional supportive housing units to meet the needs of low-income women and families living with HIV.
- The State Health Department AIDS Institute should work with local health departments and community based organizations to document the current and estimated future need for HIV and AIDS supportive housing throughout New York State.
- Additional research should be undertaken to identify what models of supportive housing are the most effective for women and families with a member with HIV or AIDS.
- New York State should work to increase the rental allowance for HIV and AIDS housing in order to increase the availability of open market rentals. The need is particularly pressing in New York City where the housing boom is pricing low-income tenants out of the market.
- Federal HOPWA (Housing Opportunities for Persons with AIDS) funding should be expanded to serve the growing number of low-income women and families who are living with HIV and need housing assistance. State funding should be increased through the Homeless Housing Assistance Program (HHAP) specifically for persons with HIV and AIDS.

8. Encourage Greater Public/Private Funding to Speed Microbicide Research & Development

- While surveys show that women feel an urgent need for a female controlled method to protect themselves from sexual transmission of HIV, it could take five to ten years before such products become available at current funding levels. As the state with the largest number of women at risk and infected with HIV, New York should actively collaborate with national and worldwide organizations that are working to encourage greater public/private investment to accelerate microbicide research and development.
- New York’s political leaders and health policy makers should strongly advocate for greater participation by the federal government in microbicide research and development. They should also foster dialogue among public funding agencies, research institutions and the biotechnology and pharmaceutical industries in New York State to encourage greater participation in anti-microbial research and development.
- The New York State AIDS Advisory Council and AIDS Institute should continue to highlight the urgent need for microbicides as an HIV prevention technology to advisory bodies, providers, consumers, members of the public, policy makers and potential funders.
- In advance of microbicides reaching the market, resources should be provided for social science research into the beliefs and attitudes that are likely to affect the understanding, acceptance, access and use of this new technology.

9. Improve Data Collection Relating to Female HIV & AIDS Cases

- To more accurately determine the magnitude of heterosexual transmission in the HIV epidemic, the Centers for Disease Control should add a risk category of “probable heterosexual exposure.” Under the current CDC risk hierarchy, an individual with HIV or AIDS for whom all but heterosexual contact risk has been ruled out can be classified as heterosexually exposed only if s/he knows the partner’s risk and/or HIV status. In the absence of such information, the case is classified as having an “undetermined exposure category.” Both New York State and New York City have begun to collect information on “probable heterosexual exposure.”
- The Centers for Disease Control should work with the Indian Health Service and the National Alliance of State and Territorial AIDS Directors to develop a uniform HIV data collection system for Native Americans. There is minimal HIV testing in Native American communities and Native Americans may be misclassified by health workers as white, Asian or Hispanic. In addition most Native American tribes do not report HIV or AIDS diagnoses to the Indian Health Service, state health departments or the federal government.
- Due to the very low rates of HIV testing among Asian/Pacific Islander women, surrogate markers for HIV infection — including sexually transmitted diseases, hepatitis and TB — should be employed to project infection trends in this population. More intensive data

collection efforts are also needed to identify the HIV transmission route in the very high number of cases that fall in the “unidentified risk” category.

- The New York State Health Department should conduct HIV seroprevalence studies to determine the rate of infection in women and female adolescents being treated for sexually transmitted diseases.
- The Centers for Disease Control should conduct studies to identify and quantify the actual risk of female-to-female sexual transmission of HIV. Failure to scientifically evaluate this issue is putting some lesbian women at risk for HIV in the mistaken belief that they are at low risk for infection, regardless of their risk behaviors.
- The Centers for Disease Control should establish uniform guidelines for recording HIV and AIDS cases among transgender women. The common practice of assigning these cases to the MSM category regardless of gender-identity, genitalia or behavior obscures the actual risk factors involved. The resulting inability to track data concerning trans-women negatively impacts funding, outreach and prevention efforts.

Testimony Presented to the Council

The following sections of this report reflect key testimony presented to the New York State AIDS Advisory Council over the course of its investigation of the increasing toll of HIV and AIDS on women and adolescent females. The presenters included:

- Women who are living with HIV;
- Medical and mental health professionals caring for HIV- infected women and families;
- Directors of community-based organizations providing HIV prevention and support services to women and families;
- Peer counselors and outreach workers striving to reach high risk women;
- Representatives of organizations serving culturally diverse immigrant women;
- Directors of substance abuse treatment programs for women; and
- Past and present members of the NYS PPG, including the Co-Chair of the PPG’s Women’s Committee.

Informative testimony offered by the presenters focused on the impact of HIV on various sub-populations of women*, the social and cultural factors that bear on women’s risk of infection and access to care, special health care and supportive services needed by women and families and the current gaps in services. The presenters also highlighted effective HIV prevention strategies and programs that have proven successful in reaching high-risk women.

Please note that the presenters represent a sample of providers and other key informants on the subject of women and HIV/AIDS. Their presentations express a wide range of experience and expertise but may not be an exhaustive representation of all experience and expertise.

* The source of all statistical data and information provided during the oral presentations to the Council has not been identified or confirmed by the New York State Department of Health or the Centers for Disease Control.

The Increasing Toll of HIV on Women – Particularly Women of Color

African American and Hispanic Women

“Race and ethnicity are not, themselves, HIV risk factors, but correlate with other more fundamental determinants of health status such as poverty, access to quality health care, health care seeking behavior, illicit drug use and living in communities with high prevalence of HIV and other sexually transmitted diseases.”⁸

Centers for Disease Control & Prevention

- Women of color, particularly African American women, are severely impacted by HIV and AIDS. In New York State the rate of infection among African American women is 27 times higher than that of white women, the rate for Hispanic women is 13 times higher than that of white women.⁹
- While the number of new HIV infections stemming from intravenous drug use has declined among African American and Hispanic women, women who use non-injection drugs (e.g., crack cocaine, methamphetamines) are at greater risk of acquiring HIV sexually, especially if they trade sex for drugs or money.
- Of great concern is the escalating rate of heterosexually acquired HIV infection among young and adolescent African American and Hispanic women. Young women are at particular risk for HIV infection, not only because of physiological factors but also by engaging in sexual activity with older male partners whose drug use, sexual history and HIV status are unknown. Young women are less likely to have the skills to question an older partner about his past history or to negotiate condom use.
- A Centers for Disease Control study of urban high school students, found that more than one third of African American and Hispanic female teenagers had their first sexual encounter with an older man. These teenagers, compared with teenagers whose partners were also teenagers, were younger at first sexual intercourse, were less likely to have used a condom during first and most recently reported intercourse, or were less likely to have used condoms consistently.⁵
- The high rate of sexually transmitted infections (STIs) among sexually active young people also puts young women at risk for HIV. According to the Planned Parenthood Federation of America, Inc., every year, an estimated 15 million people in the U.S. contract one of more than 25 infections spread through sexual activity. Nearly two-thirds of all STIs occur in people younger than 25 years of age.¹⁰
- The extreme stigma associated with homosexuality within African American and Latino cultures also puts women at heightened risk. Black and Latino men who secretly have sex with men (referred to as “on the down low”) may also have girlfriends or wives. In a recent study of HIV- infected men, 34 percent of African American men who have sex with men (MSM), 26 percent of Hispanic MSM and 13 percent of white MSM reported having had sex with women.⁵

Immigrant Women

- New York State is home to the second largest immigrant population in the nation. Twenty percent (3.8 million) of the State's population is foreign-born, twice as high as the national average. Immigrants living in New York represent 150 ethnicities, and speak almost as many languages and dialects.¹¹
- The most foreign-born New Yorkers live in New York City (2.9 million) where they represent 36 percent of the city's population. Foreign-born women represent 43 percent of women in New York City, and over half of all births in the city are to immigrant mothers. Together with their U.S. born offspring, immigrants comprise 55 percent of the city's population.¹²
- Approximately 11 percent of all documented AIDS cases in New York City occur among foreign-born residents, however, this may represent a significant undercount since country of birth is frequently not recorded on HIV and AIDS reports.¹³
- Many immigrants come from areas of the world where HIV is endemic (Africa, Asia, the Caribbean) and access to HIV testing and treatment is limited. Some immigrants travel back and forth from their birth countries and the U.S. on a regular basis, potentially increasing the risk of disease transmission.
- Persons immigrating to the U.S. are required to have an HIV test, and those who test positive are denied entry to the country.¹⁴ However, it is recognized that a large number of immigrants enter the U.S. without official documentation. These "undocumented" immigrants are not eligible for most government funded health care and social services, and their fear of deportation often prevents them from accessing prenatal care and HIV- related health care services that are available to all New York residents.
- Cultural mores and gender inequality increase the risk of HIV for immigrant women. Many cultures are patriarchal and masculinity is associated with having multiple sexual partners. Women are usually dependent on men and lack decision-making powers, especially in sexual matters.
- Cultural factors may also limit access to health care for immigrant women. Many immigrant women avoid seeking medical care until they are very ill. Women may be suspicious of treatments that are different from their own cultural beliefs and traditional practices. Immigrant women may also have great difficulty navigating the U.S. health care system due to language and literacy issues. As a result, a high percentage of immigrant women are first diagnosed with HIV when the infection has already progressed to AIDS.

Caribbean Women

"HIV and AIDS is still very dreaded and tabooed and held in secrecy in the Caribbean and in the Caribbean community in New York City."

Yvonne Graham
Brooklyn Borough Deputy President

- Approximately 600,000 non-Hispanic Caribbean immigrants and 370,000 immigrants from the Dominican Republic were living in New York City in 2000, representing 33 percent of the city's foreign-born population.¹²
- Women born in the Caribbean account for 53 percent of all AIDS cases diagnosed among foreign-born women living in New York State whose country of origin is known.⁹ The high rate of HIV infection in some Caribbean countries puts women at significant risk. Haiti has the highest HIV infection rate outside of Africa, with 5.6 percent of the adult population afflicted. More than 150,000 women and 19,000 children in Haiti were estimated to be living with HIV and AIDS in 2003. In the Dominican Republic, where the adult infection rate is 2.8 percent, an estimated 88,000 Dominican women and 2,000 children are living with HIV and AIDS.¹⁵
- Caribbean women tend to migrate to the U.S. first during their childbearing years, often leaving family members behind with hopes of reunification. This factor and the proximity of Caribbean countries to the U.S. results in extensive movement back and forth between the two locations, greatly increasing the risk of disease transmission.
- Heterosexual contact is the primary route of HIV infection for Caribbean women, yet socio-cultural barriers often prevent women from discussing their partners' sexual activities or suggesting safer sex practices. The negative consequences of doing so can be domestic violence, divorce or abandonment. For many people from the Caribbean, the contraceptive effect of condoms prevents their use due to religious prohibitions.
- Caribbean women typically present for medical care in late stages of HIV disease. There is extreme stigma and discrimination regarding HIV and AIDS in Caribbean cultures. Many women fear that seeking HIV testing or treatment will lead to social stigma and blame for infecting their partners. There is also distrust of health care provided outside of their communities due to the continuing fear of genocide.
- Caribbean women may also avoid accessing health care and other government services for fear it will lead to deportation or jeopardize their ability to sponsor relatives coming to the U.S.

African Women

“Lack of social support for HIV infected persons and associated stigma negatively affects prevention efforts, making people reluctant to acknowledge risk behaviors, avoid seeking prevention information and testing, and delay treatment.”

Kim Nichols
African Services Committee

- According to the New York City Department of Planning, 92,000 African immigrants were living in New York City in 2000, representing 3.2 percent of the foreign-born population.¹² It is estimated, however, that more than three to four times as many undocumented African immigrants also have migrated to the city in the last decade.¹⁶

- In the predominant countries of origin of African immigrants, HIV seroprevalence ranges from less than one percent to as high as 40 percent. In sub-Saharan Africa, an estimated 25.4 million people were living with HIV in 2004.¹⁵
- More than 90 percent of HIV infections among men and women in sub-Saharan Africa are heterosexually transmitted. Women represent 57 percent of HIV-infected persons in Africa, with 13 infected women to every 10 infected men. Among African teenagers and young adults, the ratio is 20 infected females to every 10 infected males.¹⁵
- African immigrants, like Caribbean immigrants, often maintain strong ties to their countries of origin and frequently travel back and forth. This results in the potential for continuous sexual exposure to HIV between Africans living in the U.S. and those in African areas with explosive HIV infection rates. There is also increasing sexual networking and intermarriage between African immigrant women and African American men.
- In general, there are strong socio-cultural barriers to African women discussing sexual matters or questioning a partner's sexual activities. The consequences of women raising the subject of safer sex can be domestic violence, blame for being a carrier of HIV, and abandonment. The practice of female genital mutilation in some African countries also puts women at increased risk for HIV infection and other medical complications.
- The extreme stigma and discrimination associated with HIV and AIDS in most African cultures prevents people from acknowledging risk behaviors or seeking testing, and leads to fear of disclosure, isolation and despair for HIV- infected African women. Outside of immediate family members, there is little sympathy or community support for those who are infected. Many believe that disease is a means of divine retribution as a result of witchcraft or violation of cultural taboos.

Asian/Pacific Islander Women

“I think sexual shame and modesty have and will continue to influence Asian/Pacific Islander women to underestimate our sexual and reproductive health risk or to utilize preventive care services.”

Sumon Chin
Chinese American Planning Council

- The term Asian/Pacific Islander (API) describes about 40 countries, representing more than 100 languages and dialects that vary widely in area of origin, tradition and religion. In 2000, approximately 690,000 Asian/Pacific Islander immigrants were living in New York City, representing 24 percent of the city's foreign-born population. Chinese immigrants, totaling 261,550, were the second largest foreign-born group living in the city.¹²
- Asia is one of the regions where HIV infection is rampant. The United Nations estimates that about one million people in Asia and the Pacific acquired HIV in 2003, bringing the total number of people living with the virus to an estimated 7.4 million.¹⁵

- While the rate of HIV and AIDS among Asians/Pacific Islanders (A/PI) in the United States remains low compared to other immigrant groups, there is concern that the numbers are increasing and may be significantly underestimated. Some fear that an incubating HIV epidemic among A/PI women may be hidden due to their traditional reluctance to seek medical care until it is a medical emergency. A/PI women have the lowest HIV testing rate of any ethnicity, and most first learn of their HIV infection when it has already progressed to AIDS.¹⁷
- There is widespread stigma concerning HIV and AIDS and reluctance to recognize that the disease exists within the Asian/Pacific Islander community. In general, sex is a taboo subject in A/PI cultures. Many A/PI cultures don't even have names for sexual organs and use euphemisms to describe them. Asian women and men lack access to sex education, and discussion of sexual matters is not shared by married couples, parents and adult children, or even among women confidants.
- Heterosexual contact is the primary source of HIV infection for A/PI women. A/PI men who have sex with men may serve as a sexual bridge to women. Due to the strong cultural stigma concerning homosexuality, many A/PI men who have sex with men do not openly identify as gay or bisexual for fear of rejection by their families and community. Many of these men marry to remain socially accepted and to have children.
- A/PI women at highest risk for HIV infection include:
 - Women whose partners have unprotected sex with men or women outside of the relationship;
 - Women who have been smuggled into the U.S. and are forced into sex work to pay back the cost of their passage;
 - Women forced to work in the sex trade due to lack of job skills and limited employment opportunities; and
 - "Mail order brides" living with controlling and abusive husbands.¹⁸
- Preventive health care is not widely practiced in Asian countries. Taking care of their own health is generally not a priority for Asian/Pacific Islander women. Many A/PI women are acculturated to believe that their needs are secondary to those of their male dominated extended families. Even women who are very ill may refuse to be hospitalized, as that would take them away from their family responsibilities.

Mexican Women

"The powerlessness of Mexican women, combined with the lack of health services and information in rural areas of Mexico may spread the infection, reaching epidemic proportions."

**Dr. Gabriel Rincon
Mixteca Organization, Inc.**

- The Mexican population in New York State more than tripled in the 1990s; many are undocumented. Estimates of the number of Mexicans living in New York range from 200,000 to more than 500,000.¹⁹
- Most Mexican immigrants are young men who enter the U.S. illegally in order to work and send money home to their families. Many of the Mexican men are working in unskilled, low-

paying jobs that no one else wants, including restaurant and farm labor jobs. They often live in overcrowded apartments or migrant housing facilities and many engage in high-risk activities including drug and alcohol abuse, sharing needles, sex among men and prostitution.

- Mexican women typically remain at home in rural Mexican areas and the men travel back and forth between the U.S. and their communities of origin, bringing HIV and other ailments with them. American and Mexican authorities believe that the rate of HIV and AIDS and other sexually transmitted diseases in rural Mexican areas has increased by 80 percent since 1994 due to the temporary return of infected Mexican men.¹⁹
- Mexican women are often powerless due to the “machismo” Mexican culture. Alcohol consumption is high among Mexican men and domestic violence is prevalent. Traditionally, there is no discussion of sexual matters between men and women. Culturally, men expect to engage in extramarital affairs and to have unprotected sexual intercourse with their wives to produce children.
- Fatalism often dominates attitudes of Mexican women concerning health problems. Many delay seeking care hoping the problem will go away, in the belief that what happens to oneself is bound to happen and that the hands of fate cannot be controlled.²⁰

Native American Women

“When I started outreach and education activities in Native American communities in rural New York State, it was met with a lot of denial. People didn’t want to believe that HIV and AIDS was a problem, and if it was, it certainly did not affect them because they knew why people got HIV, and as far as they were concerned, whoever those people were they were not part of their community.”

Cissy Elm

American Indian Community House

- It is highly probable that the prevalence of HIV and AIDS among Native Americans is higher than that reported by CDC. In general, there is minimal HIV testing in Native American communities and the Indian Health Service typically does not report HIV or AIDS cases to state health departments or the federal government.²¹
- The Native American population is disproportionately affected by many social and behavioral factors that contribute to an increased vulnerability for HIV, including high rates of poverty, sexually transmitted diseases, family violence and drug and alcohol abuse. Among Native American women with, or at risk for, HIV physical and sexual assaults and histories of childhood sexual abuse are alarmingly high.²¹
- The extreme stigma and secrecy surrounding HIV and AIDS within Native American communities severely limits women’s access to HIV prevention and care. There is long-standing resistance by native health providers and clinics to even discuss HIV risk reduction with their patients or to offer HIV counseling and testing. Many Native American women live on reservations or in rural communities that are far from major hospitals and trained health providers experienced in providing HIV and AIDS diagnosis and related care.

Substance Users & the Mentally Ill

“HIV infected women and their children represent a population who have experienced multi-generational patterns of insults and have often been ignored by service systems. They are particularly vulnerable to psychiatric and substance abuse problems.”

Dr. Warren Y.K. Ng

New York Presbyterian Hospital

- Directly and indirectly, substance abuse drives the HIV epidemic in New York State. While the estimated number of women personally injecting drugs has declined, non-injecting poly drug use and alcohol abuse play a major role in women engaging in high-risk sexual activity, including trading sex for money or drugs. Among female HIV and AIDS cases attributed to heterosexual contact, about one quarter are due to sex with an injection drug user.
- Many women suffer from the triple diagnoses of substance abuse, mental illness and HIV. A high percentage of these women come from a background of multi-generational substance abuse and mental illness. They were often neglected as children due to their parents’ substance abuse and/or mental illness. Many of these women were sexually abused by family members or their mother’s sexual partners. Many left home at an early age to get away from their disruptive and dangerous home environments. Many ended up as homeless teenagers, living on the streets.
- A study of HIV-infected women in New York City found up to 36 percent suffered from major depression, 34 percent had anxiety disorders, 25 percent were drug dependent or abused drugs, and 35 percent displayed signs of post traumatic stress disorder. The women often have co-morbidity with more than one mental illness.²²
- Children of HIV-infected women suffering from mental illness and drug abuse are equally psychiatrically affected. They frequently exhibit severe behavioral and psychiatric problems stemming from neglect, abuse and exposure to unsafe living conditions and traumatic events. Many of the children have spent long periods in foster care (often moving from home to home) due to their mother’s illness, drug addiction, and/or incarceration. Some children of infected mothers are also coping with developmental delays, frequent illness and disabilities related to their own HIV infection from perinatal transmission.

Case history of a woman living with HIV reveals the traumatic life events and complex mental health issues affecting women and families.

EC is a 49-year-old African American mother of two boys. Due to her long history of substance abuse, she had never parented her children who spent many years in kinship and foster care. After five years, she finally graduated from a substance abuse treatment program, and her sons, who were now pre-adolescent, were returned to her.

The level of stress and frustration she experienced in trying to parent her boys, who clearly had mental health issues and needs of their own, finally prompted EC to accept mental health services. She was diagnosed with anxiety, bipolar mood disorder, obsessive-compulsive disorder, panic disorder with agoraphobia and a history of substance abuse.

She was often depressed or manic, and the children were very affected by her suffering and erratic behavior. Her obsessive-compulsive disorder caused her to clean her house constantly. Every time the boys used the bathroom she would rush in after them to scrub the toilet and sink with bleach. She was also so frightened of leaving her home because of her anxiety and panic attacks that it was difficult for her to attend medical appointments or adhere to her medication regimen.

Both boys had been in psychiatric care in the past and had been hospitalized for psychiatric disorders. The family centered clinic was able to engage her in working with her sons around the family issues. A year after entering treatment, she finally experienced a resolution of many of her psychiatric symptoms and began to adhere to her antiretroviral regimen.

Just as she was feeling better, a major setback occurred when one of her sons, who had a diagnosis of bipolar disorder, became depressed, suicidal and was hospitalized. As a mother she experienced guilt at not having parented her child for nine years of his life and for possibly sharing her own psychiatric disorder with him.

These issues have increased EC's depression and negatively affected her adherence to antiretroviral therapy as well as her psychiatric medications. She is now very fearful that she might relapse, and also fears that the Administration of Children's Services will take her children away again.

Incarcerated Women

“Tragically, 98 percent of female inmates we see have been victims of some type of abuse: childhood sexual abuse, domestic violence, and incest. These issues have actually influenced their high-risk behaviors, including drugs, alcohol, sexual experiences, and prostitution.”

**Ken Siegel
Rural Opportunities, Inc.**

- According to United States Department of Justice statistics, the New York State prison system has the highest number of prisoners infected with HIV, including the largest number of HIV positive female inmates, of all prison systems in the country.²³
- A recent New York State Department of Health study found that women entering state prisons were three times more likely than men to be infected with HIV and hepatitis C (HCV). Nearly 14 percent of women versus 4.7 percent of men were HIV positive; 23 percent of women and 13 percent of men were infected with HCV.²
- More than 80 percent of women in New York State prisons report having a substance abuse problem prior to arrest. As of January 2004, nearly 87 percent of women in custody for a drug offense were African American or Hispanic, most of whom come from impoverished inner-city neighborhoods. For substance using women, addiction and criminality are intertwined. Nearly 30 percent of women released from prison will return to custody within three years.²⁴

- Over 25 percent of women in State prisons are being treated for mental health issues, but many more may suffer from depression and other mental disorders. Many incarcerated women have histories of physical, emotional and sexual abuse and would benefit from counseling and treatment to address these traumatic life circumstances.²⁵

Women Over Age 50

“AIDS incidence among older women is a new nightmare for HIV care. Many of these women already battle other chronic illnesses such as diabetes, hypertension, obesity and a host of social and financial ills facing women on fixed incomes. Many of them have no idea of their risk until diagnosis.”

Marie Saint Cyr
Executive Director, Iris House

- A recent disturbing trend, both nationally and in New York State, is the increasing impact of HIV/AIDS on women over 50 years of age. Despite myths and stereotypes, many seniors are sexually active and some are drug users.
- Women are at heightened risk for heterosexual transmission of HIV after menopause. The use of condoms for birth control is no longer necessary and normal changes associated with the aging process, such as a decrease in vaginal lubrication and thinning vaginal walls, can put them at higher risk during unprotected sexual intercourse.²⁶
- Many health care providers and older adults themselves do not realize that seniors who engage in risk behaviors are at the same risk as younger people. Health care providers are less likely to question women over age 50 about their sexual activity, discuss HIV risk reduction, or recommend HIV testing. Also, HIV/AIDS educational campaigns and programs are not usually targeted to older persons.²⁶
- Misdiagnosis of HIV infection is frequent in older people because the symptoms are similar to those associated with aging (fatigue, weight loss, dementia, swollen lymph nodes). Older people often become ill with AIDS-related complications and die sooner than younger people, due to late diagnosis and immune systems that naturally weaken with age.²⁶

Lesbian, Bisexual & Transgender Women

“Rather than just looking at gender or sexual orientation, it may be more useful in categorizing risk for HIV infection to look at a person’s social context. Social context recognizes more multiple behaviors, and includes the spaces where people congregate, a multifaceted sense of identity, cultural and ethnic influences, and the roles cultural oppression and stigma play.”

Carrie Davis
The Lesbian, Gay, Bisexual & Transgender
Services Center

- Lesbians, bisexual and transgender women are made invisible in the HIV and AIDS epidemic through risk factor reporting methodologies that prioritize behavior over social or cultural identity. Over-reliance on a behavioral approach ignores other risk factors and erects powerful barriers to HIV prevention, unique to each of these three communities.
- The CDC reporting methodology does not categorize or count female-to-female sexual contact. If a lesbian acknowledges that she has ever had sex with men she is typically counted under heterosexual contact; if she has ever used intravenous drugs, then that becomes her risk category. The actual risk of HIV infection through female-to-female sexual contact remains unknown with only one documented case, since there has been minimal research on this issue. This gap in understanding has led some lesbians to maintain an “immunity belief” and perceive that they are at low risk for HIV infection regardless of their behavior.
- Identity and community may not correlate with behavior, and many lesbians do not exclusively have sex with women. Surveys have shown that up to three-quarters of women who identify as lesbian have had sex with men at some time, many recently, including unprotected vaginal and anal intercourse with gay and bisexual men.²⁷ The identities of bisexual women are often conflated with lesbian or heterosexual women, complicating identity or community-specific prevention. In addition, women with bisexual identities are often invalidated and subjected to stigma within both the lesbian and heterosexual communities.
- Many transgender women (trans-women), or women with transgender histories, are at elevated risk for HIV infection. The U.S. Surgeon General’s Office, summarizing numerous HIV and AIDS assessments and sexual risk behavior studies, estimates HIV infection rates for trans-women range from 14 to 69 percent.²⁸ The majority of women surveyed in these studies are trans-women of color. Low socio-economic status, cultural transphobia and stigma, injection drug use, as well as injection of hormones and silicone are also cited as significant concerns for trans-women.
- Trans-women are also made invisible through the HIV and AIDS reporting system. There is lack of agreement about what constitutes gender, gender-identity and sex. For reporting purposes, the identities of trans-women are typically negated. Trans-women are classified as men, typically as men who have sex with men (MSM), regardless of gender-identity, genitalia or behavior.
- Cultural stigma associated with lesbian, bisexual and transgender women complicates HIV prevention efforts, especially within communities of color. Many are reluctant to seek medical care, acknowledge their sexual orientation or gender identity, or discuss HIV prevention practices. Those who do seek medical care are either frequently asked inappropriate questions about their sexual behavior or not asked relevant questions about behavior or identity that would inform the practitioner about risk.

Women Living in Rural Areas

“People do not want others to know their status or even to know they are going to be tested. There is a lot of denial going on, that we don’t have HIV in our community. People are traveling out of their communities to get care.”

Becky Smith

Southern Tier AIDS Program

- Six percent of New York women with HIV and AIDS live in rural areas of the State. Isolation is a major cause of depression and hopelessness for rural women infected with HIV due to the strong stigma surrounding AIDS. Some women can’t even tell their parents or partners about their diagnosis. Rural residents also have higher rates of alcohol abuse, and infant and maternal mortality. They are less likely to have health insurance and lack knowledge about entitlement resources.
- Due to close social networks in small rural communities, women avoid seeking HIV testing out of fear of stigma and discrimination. Women who do seek testing often travel to urban centers to protect their confidentiality. Community-based organizations offering HIV risk reduction counseling and support services are available in some rural urban centers, but women living in remote areas have little access to these services.
- Rural women are often diagnosed late in the disease due to a general lack of awareness that HIV exists in rural communities and very few trained health care providers experienced in HIV diagnosis and therapy. Many rural areas are designated as physician shortage areas, and even regional hospitals may lack infectious disease specialists. This requires many HIV infected women and children, who may be seriously ill, to travel hundreds of miles to reach medical providers who have the expertise to treat their complex medical conditions.
- Transportation is a critical need for HIV infected women living in rural areas. Many families do not have automobiles, or telephones. Using rural buses to get to medical appointments can take a full day and be exhausting for infected women and children.

Women-Focused HIV Prevention Strategies

Given the continuing and increasing rate of HIV infection in women and adolescent females, it is apparent that existing prevention efforts are not reaching and motivating all women and female teens to avoid high-risk behaviors. Developing and carrying out effective HIV prevention strategies for women and female adolescents requires a coordinated, long term commitment at all levels: government, health care providers, community based organizations, schools, churches and the public media.

- Effective prevention strategies and messages must be designed to reach all women and also targeted to women and female youth who are most at risk, including young women of color, recent immigrants, transgender women and those who are mentally ill, homeless, incarcerated or engaged in substance abuse or prostitution. It is important to maintain a focus on both women at risk for HIV and those who are already infected.

- HIV prevention efforts must be extensive, designed to reach adult and young women through a variety of means and in a wide range of settings, including health care clinics, churches, shelters, drug treatment programs, prisons and youth detention facilities, school and after-school programs, community based outreach efforts, Internet web sites and multi-media campaigns.

Target Audiences Should be Involved in Developing Prevention Strategies

- Women and female youth who represent the target audiences should be involved in developing, carrying out and evaluating woman focused HIV prevention strategies. Focus groups of women from the target populations should ensure that the messages being conveyed are clearly understandable and culturally acceptable.
- To gain the attention of women and promote behavior change it is important to highlight the benefits and to identify real or perceived barriers that may prevent women from adopting a new behavior. For example,
 - A teenager who does not think she is at risk for HIV may be more receptive to a safer sex message as a means of preventing pregnancy or avoiding other STIs;
 - A pregnant woman may be more motivated to change risk behavior to protect the health of her child rather than her own;
 - An intravenous drug user may be more interested in learning where to obtain free clean needles than in entering drug rehabilitation;
 - An immigrant woman needs prevention information that is linguistically appropriate and respects her cultural and religious customs concerning sexual activity and substance abuse.

Women Need a Female-Controlled Method to Protect Themselves from Sexual Transmission of HIV

“Microbicides offer a real possibility for helping women protect themselves from HIV/AIDS and other STDs. We need to invest far more resources and energy if we are to make this possibility a reality.”

**Peter Piot, Executive Director
Joint United Nations Program on HIV/AIDS**

- Sexual transmission of HIV is the greatest threat to women, including female adolescents. Women are particularly at risk because they must rely on the cooperation of their male partners to engage in safer sex. For a wide variety of reasons including cultural factors, many women, particularly young women, cannot effectively negotiate condom use with male sex partners.
- Female condoms have been available for several years, but they have not been widely marketed to nor used by women. Female condoms are expensive (about \$1.00 each) which puts them out of reach of the poor women who are at greatest risk. Even for those women who would purchase them, due to their limited use, they are not stocked by most drug stores. Female condoms that are available are primarily distributed through community-based organizations or local health departments.

- Microbicides, which are now in various stages of development, could offer women the advantage of taking independent, unobtrusive action to protect themselves from transmission of HIV and other sexually transmitted infections (STIs) during sexual intercourse.
- Microbicides are chemical or biological compounds that can block or disable the organisms that cause HIV and other STDs. They may be in a gel, cream or suppository form that women could apply intra-vaginally prior to sexual intercourse. Ideally these products would be non-irritating to both women and men, inexpensive enough to encourage widespread use, and available in both contraceptive and non-contraceptive formulas.²⁹
- So far, the private pharmaceutical sector has not invested the resources needed to bring microbicides to market, and the current level of public funding is insufficient to accelerate the process. More than twenty years into the worldwide HIV epidemic, there are only a handful of anti-microbial products that are beginning lengthy clinical trials to test their efficacy, side effects and acceptability. At the current rate, scientists believe it may take up to ten more years before microbicides become widely available.^{30, 31}

Adolescent Females Need HIV Prevention Information at an Early Age

- It is vital for adolescent females to receive sustained and explicit HIV prevention information, starting at an early age, even before they reach puberty.
- Surveys conducted by the federal Centers for Disease Control and Prevention (CDC) show that by 12th grade, 65 percent of students are sexually active and one in five has had four or more sexual partners. Each year, 3,000,000 adolescents contract sexually transmitted diseases, indicating that many teens are engaging in unprotected sex.³²
- Focus groups have shown that teenage females often have misinformation about HIV transmission and risk. Some teens think that oral sex is risk-free. Others say that you can tell if someone is infected by looking for sores on the skin or tongue. Many teens report that the decision to use condoms during sex comes down to whether they know and trust a partner.³³
- Parents are often reticent and embarrassed to talk with their adolescent children about sexual issues. Parents may themselves have limited or incorrect information about the risks for HIV transmission.
- Schools are an obvious resource for reaching adolescents, but too frequently the amount of class time devoted to HIV education is limited and the messages are imprecise and weakened by school boards and school officials. A CDC survey found that only a third of teachers discussed the role of condoms in preventing sexual transmission.³²
- The teens at highest risk for HIV infection may not be in school. Young people at highest risk include homeless or run away youth, those in jail or detention centers, sex workers, teens that have been sexually or physically abused and youth in social networks whose members engage in high risk behaviors, including gay and transgender youth.

- Since 1987, the New York State Education Commissioner’s regulations have required that public schools throughout the state provide AIDS education to students in grades K-12. Many school systems need assistance to implement the State and City HIV/AIDS educational requirements. With the estimates of 50% of all new HIV infections nationwide being among people under age 25 and that two Americans between the ages of 13 and 24 are infected with HIV every hour (CDC), it is imperative that more young people receive HIV/AIDS education and resources. The school system is a natural and logical venue for reaching youth.
- In early December 2005, the New York City Department of Education released a revised HIV/AIDS education curriculum for grades K-12. Additional steps need to be taken to assist other localities to develop comprehensive sexual education curricula that includes HIV and AIDS information and to train teachers to implement the curricula.

Community-Based Outreach, HIV Prevention and Support Services for Women and Children

Reaching out to at-risk women and bringing them into prevention and care is a daunting challenge that requires ongoing, intensive effort by caring, sensitive workers who recognize and understand women’s vulnerabilities. Community-based organizations provide a safe and caring environment for women and their children, where they can gain access to the full range of medical, social and educational services needed to build self-esteem, reduce their risk of HIV infection and improve their quality of life.

According to the Women’s HIV Collaborative of New York that convened focus groups with 96 HIV positive women, community-based outreach, prevention and support services are critical for both HIV positive women and women at risk for HIV. Through focus group discussions they heard that the burden of ensuring adequate care is often placed on the consumer and that the quality of an HIV positive woman’s care is linked to her own self-esteem, access to support networks and environments where women empower women. Women reported waiting between two and nine years to enter care after testing HIV positive and entered care only when they had support to gain acceptance and education.

Community-Based Organizations Are Key Public Health Partners

“CBOs have developed a model of care that subscribes to many of the theories in social work, and that has made them important partners in the spectrum of health care delivery. CBOs are neighborhood based, they provide culturally sensitive services, they are available to the community at convenient hours, their employees reflect the characteristics of the populations they serve and their programs are designed, developed and implemented with consumer input. And most of all they have community ownership of the problem and are essential partners in the solution.”

Yvonne Graham
Brooklyn Borough Deputy President

Women Need A Broad Spectrum of HIV Related Support Services

“We need to look at and address the critical issues that arise beyond HIV and AIDS that are affecting the lives of these women, particularly domestic violence, sexual abuse, lack of adequate housing, and financial resources to care for themselves and their children. If we cannot at least meet the survival needs of the women, we cannot retain them.”

Marie Saint Cyr
Executive Director, Iris House

- Engaging and retaining women in HIV prevention and health care services requires a broad spectrum of support services that address the complex needs of women and their families. These “enabling services” help women get the care they need for themselves and their families and help women stay in care. These services include:
 - Individual and group HIV prevention activities;
 - HIV counseling and testing;
 - Family centered case management;
 - Peer education and support groups;
 - Domestic violence counseling & referral;
 - 24-hour crisis intervention;
 - Childcare and children’s services;
 - Nutrition education, food bank and home delivered meals;
 - Emergency financial assistance;
 - Transportation and escort service to health care and other appointments;
 - Housing assistance;
 - Mental health and substance abuse counseling and treatment;
 - Legal services; and
 - Educational & vocational counseling.

Peers Are Most Effective in Reaching At-Risk Women

“Being a person who is HIV positive myself, I can relate to a lot of what the women go through and the services they need because at one point in time I needed those same services. If I don’t share my status in a lot of the cases, women just won’t approach me because they feel I don’t know what I am talking about and I’m not on their level.”

Angel McGee
Peer Educator, Life Force

- Community-based programs that are designed, developed and conducted by women from the affected communities are best able to recognize and respond to the special needs of at-risk women. Peer educators who have the same cultural and ethnic background, speak the same language and have had similar life experiences are the most successful in communicating with and gaining the trust of at-risk women.

- Peer-based programs have evolved into a career enhancement resource for many women infected and affected by HIV and AIDS. Women who initially entered the programs as clients in need of services have progressed to full or part- time employment as peer educators and counselors helping others.
- Women who are themselves HIV positive make powerful educators who can go out into their communities and share their personal life stories to develop rapport with and gain the trust of women at risk or infected with the virus. Getting involved in community based HIV prevention activities empowers women by giving them self-confidence and added purpose and meaning to their lives.

Repeated Contact & Follow-up Needed to Gain Women’s Trust

“Women bring a whole slew of problems in addition to their HIV positive diagnosis that other members of our communities don’t. Unless we’re able to address these issues in a comprehensive manner and a holistic manner and realize that people are not living with HIV in a vacuum, I think we’re going to always have problems.”

Gwen Carter

Executive Director - Life Force

- Outreach to women at risk for HIV often requires repeated, long-term contact to gain their trust and attention. Given the immediate and overwhelming stresses with which these women must cope, it is understandable that HIV prevention and health care may not be their first priority. Other issues may need to be addressed first, such as the need for substance abuse treatment, food or shelter for their children, or getting away from an abusive partner.
- Helping women address their immediate needs builds trust that may ultimately draw them into the health care system. By focusing on the woman’s agenda rather than the agency’s, outreach workers may be able to develop a trusting relationship that allows an at-risk woman to accept HIV prevention, counseling and testing. It may take months or even years of on-going contact to convince a woman who abuses drugs or is a sex worker to address her high risk behavior and enter the treatment and health care systems to obtain the help she needs.

Programs That Work

CAPC - A Comprehensive Outreach/Case Management Model

“If a woman calls the hotline, she doesn’t come to us; we go to her. We are trained to go to her and meet her where she is at, where her immediate needs are at.”

Ruth Mitchell
Outreach Worker, Bronx CAPC

The Community Action for Prenatal Care initiative has proven highly successful in reaching out to at-risk pregnant adolescents and women and bringing them into early prenatal care and HIV counseling and testing. CAPC is currently operating in high newborn seroprevalence neighborhoods in Central Brooklyn, the South Bronx, Northern Manhattan and in the City of Buffalo.

Community Coalitions: CAPC brings together health care facilities and community based organizations that coordinate their resources and efforts to locate pregnant women and connect them with the health care system. Outreach workers, case managers and health care providers from the coalition agencies receive training on the life stresses that prevent high risk women from entering and staying connected with the health care system, including substance abuse, mental illness, domestic violence, cultural and language barriers.

Enhanced Peer Outreach: Efforts are made to match women with peer outreach workers who speak their language, understand their cultural issues, and may have experienced similar life challenges. Outreach workers are trained to focus on the woman’s agenda rather than the agency’s. A pregnant woman’s immediate goal may be to get a subway token or food for her children or to get away from an abusive partner. A pregnant adolescent may be most concerned about how to tell her parents that she is pregnant.

Social Marketing: A 24-hour staffed hotline — advertised through radio, subway cards, posters and other means — informs pregnant women that free prenatal care is available, and puts a woman in direct touch with an outreach worker who can help her get the help she needs.

Internal Navigators: By establishing strong linkages with health care providers, CAPC workers can facilitate a woman’s access to prenatal care and other needed health services. Case managers who serve as “internal navigators” inside prenatal care clinics arrange an immediate appointment for a high-risk woman and meet her at her first appointment. If a pregnant woman drops out of care, the health care agency can ask CAPC outreach workers to find her and try to motivate her to return.

Strong Linkages Essential Among Collaborating Agencies

“Agencies like Life Force need to be able to refer clients to agencies that we feel are going to give them the services they need. And sometimes what happens when we refer clients is they get lost in the system and don’t really get the services they need. It’s important that we work very hard to collaborate as agencies serving women to make sure that they don’t get lost in the system.”

Gwen Carter
Executive Director, Life Force

- It is crucial for community-based agencies serving women to have strong, working partnerships and meaningful referral agreements with health care and social service providers. Agencies must have confidence that when they refer a woman elsewhere for services, those services will be provided in a timely and respectful manner. If a woman falls through the cracks because she was not given prompt attention or was treated in a judgmental way by a referral agency, it is often impossible to get her back into the system of care.
- Community-based agencies need to work closely with health and social service agencies to which they refer clients to ensure that all staff that have direct contact with clients (medical personnel, social workers, case managers, receptionists) understand and are sensitive to the life stresses and barriers that prevent women from gaining access to needed services and staying in care.

“If a woman is referred to a medical setting and the receptionist says, ‘we are not going to talk to you because you are drunk’ or ‘you are high’ or ‘you are late’ all of our outreach efforts may be wasted and the woman may be lost to care.”

Patricia Doyle
Director, CAPC Program

Flexibility Needed to Adapt to Women’s Changing Needs

Medical advances in treating HIV have significantly increased the life expectancy and quality of life for those who are infected. Service providers must be ready to reshape their programs to meet the changing and evolving needs of women and families.

- Women who are HIV-infected need access to the most current information about HIV transmission and treatment, presented in easy to understand, non-technical terms. They also need on-going support to help them stay connected with the health care system and to comply with complex treatment regimens.
- HIV-infected women, who only a few years ago might have been too ill to leave the house or care for their children, now need education and vocational counseling to prepare them to seek appropriate employment. They also need information about their rights to health insurance and reasonable workplace accommodations related to their medical needs. Women may also need assistance with accessing quality childcare services as well as transportation.

Housing for HIV-Infected Women is a Critical Need

- Safe, affordable and supportive housing for HIV infected women and their families is a critical and expanding need, particularly in New York City where the housing boom is pricing low income tenants out of the market. Additional research should be done to identify specific models of supportive housing that work best for women and families with a member(s) with HIV or AIDS.
- Studies have shown that stable and medically appropriate housing for people with HIV and AIDS reduces costly inpatient hospitalizations and emergency room visits, and allows for more successful adherence with complex medical and medication regimens. Supportive housing has also proven to benefit clients with psychosocial functioning, helping them achieve self-determination and self-care.³⁴

Programs That Work

IRIS House - A Center for Women Living with HIV

“When HIV strikes families already burdened by poverty, inadequate medical care, substandard housing and fragmented support systems, the consequences are devastating.”

Marie Saint Cyr
Executive Director

Iris House is the nation’s first community-based organization created by women living with AIDS. Established in 1993, Iris House provides comprehensive services to women and their families in a safe environment. The Iris House philosophy is holistic and family-centered, with services ranging from childcare to nutrition, from legal advocacy to spiritual counseling.

The number of women and children receiving services through Iris House has grown from 131 in 1994, to more than 2,500 in 2003; ninety-nine percent are women of color (African American and Latino). Iris House serves women from all boroughs of New York City.

Case management is the core service of the program, through which an individualized plan is developed to meet each woman’s needs, including appropriate medical, social and educational services for the woman and her children.

Children’s services include school advocacy and counseling, family-centered educational and recreational activities, summer camp, field trips and holiday celebrations.

Nutritional services are a key component of the Iris House program. In 2003, over 100,000 meals were provided through congregate meals, food pantry, hospital and home bound visits. Cooking classes and nutritional counseling sessions focus on medication and food interactions.

Scattered site housing is available to 66 homeless and displaced women and families living with AIDS.

Educational seminars are offered weekly on such topics as access to clinical trials, enhancing intra-family communication, public entitlements, legal issues, domestic violence and strategies to increase self-esteem.

Peer outreach conducted by trained Iris House clients brings HIV education and counseling door-to-door in high-risk neighborhoods.

Coordinated Health Care Services for Women & Families

Advances in medical care and treatment have significantly reduced the number of deaths from HIV allowing many people who are infected to live healthier, longer lives. Early diagnosis is critical to link infected people with life-extending health care and treatment. In spite of these advances, many women do not access care early in their infection. Women are often diagnosed late, when HIV infection has already progressed to AIDS, or they develop AIDS within a year of initial testing.

Women Face Many Barriers to Health Care

- The same vulnerabilities that place women at risk for HIV infection — poverty, domestic violence, substance use, cultural norms, and mental illness — are often barriers to health care and adherence to medical advice and treatment regimens.
- Health care may not be a high priority for women at risk or infected with HIV. They are likely to have children, and may lack health insurance, adequate housing, childcare and transportation. They are often living in poverty-ridden, urban neighborhoods and are struggling to meet the basic subsistence needs of their families for food, clothing and shelter. In addition to managing her own health issues, an HIV-infected woman may be caring for an HIV infected child, partner or an ill elderly parent.
- Cultural issues also limit access to health care services for many women. Immigrant women often face language and literacy barriers and may be suspicious of treatments that are different from their own culture, beliefs and practices. Undocumented immigrant women or those who have violated the law may avoid contact with the health care system out of fear of arrest or deportation. Preventive medical care is not practiced in many immigrant cultures, another potential cause of women's late entry into care.

Women Need Family-Centered, Co-located Health Care Services

“Family centered health care programs are designed to promote a holistic approach to family health care, integrate medical care with psycho-social support services, and provide a supportive, respectful care environment with collaboration between families and professionals.”

Beth Woolston
Division of HIV Health Care
AIDS Institute

- In New York State, HIV is a disease of families with multiple needs. HIV may affect several generations and extended family members. There is no family member who is not affected by the diagnosis of HIV infection within the family. Family centered, co-located health care services that recognize the role of women as primary care givers and that address the multiple needs of all family members are critical to engaging and retaining at-risk women in the health care system.

- Many women suffer from the triple diagnoses of HIV infection, mental illness and substance abuse stemming from a history of poverty, homelessness, physical and mental abuse. Their children frequently exhibit severe behavioral, psychiatric and health-related problems as a result of neglect, abuse and exposure to unsafe living conditions and traumatic events. Other family members, including parents, husbands or sexual partners may also be HIV-infected or have mental health or substance abuse issues.
- Women and their families need a comprehensive continuum of HIV-related health care services, including HIV counseling and testing, HIV primary and specialty medical care, substance abuse and mental health treatment services, gynecologic care, pediatric care, case management and enabling support services.
- Women need greater access to HIV and AIDS medical research programs, including clinical drug trials. For years, pharmaceutical companies have excluded women from most drug trials out of fear of liability if a woman becomes pregnant and gives birth to a child who is harmed by the drug, or concern that women's hormonal levels could alter the research findings. As a result, women are being denied early access to new, alternative HIV treatments, and HIV medications that have primarily or exclusively been tested on men are being administered to women with potentially dangerous effects.
- Counselors and case managers need to help women become aware of available health care benefits and guide them through the health care system. Women also need ongoing support to remain engaged in health care and to adhere to HIV treatment regimens.
- While the number of infants born with HIV in New York State has declined dramatically over the past five years, an estimated 2,300 perinatally infected children under age 13 are living with HIV.³⁵ Families with HIV-infected children need access to health care services designed to meet the complex medical management and unique psychosocial and educational support needs of these children as they grow and develop while living with HIV.
- In some families, men have taken on the responsibilities of primary care taker for their infected and affected children. Greater efforts are needed to reach out to men, not previously engaged in care for themselves and/or their family members, to bring them into HIV testing and medical care, and to help them become involved in the care and treatment of family members.

Greater Access to Substance Abuse Treatment is Needed for Women and Women with Children

“Something we have realized through research and trial and error in substance abuse and addiction treatment is that women have very specific problems and needs that are very different from men.”

**Susan Plaza, Director
Family Center of Excellence, Odyssey House**

- Women face barriers to substance abuse treatment as a result of poverty, parenting responsibilities, histories of physical, sexual or emotional abuse and the predominance of

male-dominated treatment settings. Denial is a major barrier for some ethnic women because substance abuse is viewed as a loss of face or shame for the family.

- The New York State Office of Alcohol & Substance Abuse Services estimates that more than 500,000 New York women are in need of treatment for chemical abuse; 88,000 of these are adolescent females under the age of 18. During 2003, only 14 percent (71,400) of these adult and adolescent women were enrolled in licensed substance abuse treatment programs.³⁶
- There is an urgent need for family-focused residential substance abuse treatment programs that accept women with their children regardless of age, and that offer the full continuum of health, mental health and social support services needed by all family members. The availability of substance abuse treatment programs for women is inadequate to meet the need and programs are not available throughout the state. Most existing programs have limited capacity for children, particularly children over age five.³⁷
- Studies have shown that women are more open and amenable to entering substance abuse treatment when they are pregnant to protect the health of their unborn child. Yet, most residential drug treatment programs do not accept women who are pregnant or women with children.
- Concern about leaving their children is a major deterrent to women entering residential drug treatment. Many addicted women are single mothers who have no one to care for their children if they enter long-term substance abuse treatment.
- A parent-child treatment program not only gives the mother the peace of mind needed to concentrate on overcoming her addiction, it also provides an opportunity to address the emotional and developmental needs of the children and improve the mother's parenting skills.

Programs that Work

Odyssey House Family Center of Excellence

A National Prototype for Family-Centered Substance Abuse Services

“At Odyssey House we look at providing a continuum of recovery for women, from coming in our doors addicted, homeless, with strained relationships with their children, and hopefully leaving with a program of recovery, sober, learning and actively participating in parenting their children, and in a relationship that is healthy and nurturing, and being able to be self-sufficient and independent.”

Susan Plaza, Director

Family Center of Excellence, Odyssey House

The Odyssey House Family Centered Program provides the full continuum of medical, psychosocial and educational services needed by substance addicted women and their children. Many of the women suffer from long neglected health problems, including HIV infection and mental illness. Some women are pregnant. Their children frequently have behavioral and mental health issues, as well as developmental delays.

Building self-esteem and self-sufficiency: Helping drug addicted women gain self-esteem, belief in their self-worth, and confidence in their ability to turn their lives around is a key goal.

In addition to a full program of substance abuse treatment, Odyssey House offers parenting-skills workshops, educational and vocational counseling, job-training programs, abuse counseling and healthy-living seminars.

Structured programs for children: Children are cared for in day care or preschool programs by trained child care workers, certified teachers, physical and occupational therapists and nurses who work to address the youngsters' emotional, social, medical and cognitive developmental needs.

On-site medical care: Every woman and child receives an initial health assessment to determine the services they need. Medical care providers include specialists in prenatal care, pediatrics, obstetrics/gynecology, psychiatry, HIV/AIDS, well-baby and adult primary care.

Transitional housing: Supportive transitional housing allows women who have completed drug treatment to move into an apartment with their children before they are ready to seek independent living. This gives the women a chance to practice family management skills and taking care of their children.

Immigrant Women Need Culturally Competent Health Care Services

- Immigrant women need access to linguistically appropriate and culturally competent health care services based on an understanding of and respect for their cultural and religious customs, family structure, health care beliefs and preferences.
- Immigrant women who lack English language skills have great difficulty negotiating the American medical system. Traveling out of their ethnic neighborhoods to seek medical care can also be a major challenge and deterrent.
- Many immigrant women prefer to receive care from traditional providers who offer a holistic approach to medical care that integrates spiritual and herbal approaches. Unfortunately, many traditional providers have little knowledge of HIV or AIDS diagnosis or treatment, and avoid speaking about it to their patients.
- Western trained medical providers are frequently ill-equipped to provide immigrant sensitive medical services that take into account language differences, immigration status, cultural mores and customs, sexual practices and attitudes about health care. They may even cause women to drop out of care by expressing disapproval of women taking herbs or using alternative healing methods.

Rural Women Need Geographically Accessible HIV Care

- Women at risk for HIV living in rural areas of the state often do not have access to trained health care providers with experience in HIV diagnosis and therapy. This can result in late diagnosis, and limited access to clinical trials and the latest advances in HIV therapy.
- Major medical centers that provide comprehensive HIV and AIDS health care services for women and children are primarily located in urban areas with high rates of HIV seroprevalence. This requires some HIV-infected women and children, who are seriously ill, to travel hundreds of miles to reach medical providers that have the expertise to treat their complex medical conditions. In general, public transportation is not available outside of metropolitan areas.

Incarcerated Women Need Comprehensive Health Care Services

- Women who are incarcerated in State and local prisons need access to HIV prevention, counseling and testing; counseling and treatment for substance abuse and mental health problems; and access to appropriate health care services.
- HIV-infected women in prisons require HIV primary and specialty care that is consistent with current treatment standards and is provided by appropriately trained and experienced medical personnel.
- For incarcerated women with HIV, transitional planning must include a seamless transfer into community-based HIV medical and supportive services. Transitional planning is needed to ensure continuity of medical care for any woman scheduled to be transferred, discharged or released on parole.

- Prior to release women need Medicaid application assistance, linkages to medical care and services to address substance abuse, mental health, domestic violence and child custody issues. Assistance in finding housing is also a priority. Addressing these issues is paramount to helping women achieve successful re-entry to the community.

All Women Are Entitled to Non-Discriminatory Health Care

All women — no matter what their history, life-style, ethnicity, or risk factors for HIV — are entitled to respectful, non-judgmental, non-discriminatory medical care, mental health care and substance abuse treatment services.

Many women at risk for HIV infection may avoid the health care system due to fear of discrimination. These women may be:

- Drug users who fear their children may be taken away from them;
- Immigrants who fear the stigma associated with AIDS in their cultures;
- Lesbians and bisexuals who fear that health care providers may be judgmental about their sexual orientation; and
- Trans-women who are perceived by many care providers to have a pathological disorder.

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Appendices

AIDS Institute-Funded

HIV & AIDS Services for Women, Children and Adolescents

Since its creation in 1983, the AIDS Institute has worked to develop a comprehensive array of HIV and AIDS prevention and care services to meet the multiple needs of individuals and families affected by the epidemic. Total funding for HIV prevention, health care and support services now exceeds \$112 million, distributed to 234 community-based organizations and health care providers across the State and serving more than 349,000 individuals. The scope of services funded by the Institute continues to evolve to meet new and emerging service needs.

The escalating impact of HIV and AIDS on New York women, particularly women of color, prompted the creation of a continuum of comprehensive services for women at high risk for HIV infection and women living with HIV, and family-centered services for women with children, their partners, and family members. These special programs recognize the role of women as primary caregivers for children and other family members, and are designed to help overcome the unique barriers to HIV prevention and care that many women face.

The AIDS Institute initiatives described in Section I below focus on serving women and women with children and their families. Also described, in Section II, are initiatives that serve a significant number of women and address some of the needs described in this report.

I. AIDS Institute Initiatives Focused on Women and Their Families: Prevention Services For Women:

This initiative is targeted to women, particularly women of color, at high risk for HIV infection and women living with HIV, their partners and families. Community-based organizations, community health centers and hospitals are funded to:

- Provide HIV prevention interventions to sustain behavior change over time and reduce the risk of HIV transmission or acquisition;
- Provide interventions to increase the motivation of women to know their HIV status;
- Increase access to voluntary testing at community-based organizations and health care settings, utilizing the latest testing technologies; and
- Reduce perinatal HIV transmission by providing early access to primary prevention and HIV counseling and testing for pregnant women and women of childbearing age.

Key services include: HIV counseling and testing in clinical, community-based, and outreach settings; targeted and enhanced outreach to recruit and engage high risk and HIV-infected women who are not engaged in ongoing prevention, care and/or supportive services; multi-session individual and group prevention interventions provided to women at-risk and women living with HIV to minimize future transmission or acquisition of HIV; referrals, linkages and follow-up to needed services for at-risk and infected women.

Twenty-eight (28) agencies are supported by grants to provide these services.

Services for HIV Infected Women and Their Families:

This initiative strengthens linkages between HIV counseling and testing programs and community-based health and social services for women and their families. It represents a unique, jointly funded, public-private partnership for which the AIDS Institute provides programmatic oversight, and the United Way provides technical assistance and fiscal administration. Ten community-based organizations are funded to provide family-centered case management, community follow-up and support services to HIV-infected women and their families. In addition, a range of supportive services are provided to clients including: HIV prevention interventions for women at high-risk and HIV-infected women, child care, 24-hour crisis intervention, emergency financial assistance, housing placement assistance, transportation, individual and group counseling, peer support and HIV prevention education. All of the agencies provide permanency planning, legal and mental health services either on site, via consultants, or through linkage agreements.

This initiative is supported by State and federal funding as well as private funding from the United Way. Funds are currently distributed among ten programs providing services in the South Bronx, East New York, Central Brooklyn, North Brooklyn, Central Harlem, East Harlem, South Queens, and the Lower East Side of Manhattan.

Family-Centered Health Care Services:

This initiative promotes a holistic approach to family health, linking medical, psychosocial and concrete services to meet the needs of families, and encourages new community partnerships and greater involvement of families in planning their health care. Collaboration between families and professionals in making care decisions is an essential component of the family-centered approach.

Family-Centered HIV Health Care uses multicultural, multidisciplinary teams to integrate medical care, including HIV specialty and gynecologic care with mental health, substance use, case management and other HIV-related services in managing the complex medical and social issues faced by HIV-affected families. Programs foster strong working relationships between adult medicine, obstetric and pediatric programs for the care of mothers, fathers, children and adolescents who are exposed to, infected or affected by HIV. For women with HIV, gynecologic and reproductive health services, including family planning, are crucial components of care. Comprehensive care for pregnant women with HIV is also provided.

Eleven (11) health care facilities throughout the State are supported by grants to provide these services.

Maternal-Pediatric HIV Prevention and Care Program (MPHPCP):

This program is designed to reduce perinatal HIV transmission through education, technical assistance, and monitoring and regulatory action, when indicated. The goal of the program is to ensure that pregnant women have access to HIV counseling and testing and that those who test positive have access to antiretroviral (ARV) therapy for their own health and to prevent HIV transmission to their babies.

The major components of this program are set forth in the New York State Department of Health regulations which require that all women in prenatal care in regulated facilities receive HIV counseling with testing, presented as a clinical recommendation. The program also requires in accordance with the Newborn HIV Testing Law that all babies born in New York hospitals or birthing centers be routinely tested for HIV with the results reported to their mothers. In August 1999, as a result of medical and scientific advances in the prevention of perinatal HIV transmission, the MPHPCP was expanded to require expedited HIV testing of a woman presenting for delivery whose HIV status is unknown, or of her newborn. Informed consent is required for testing the mother. This program provides for counseling, testing and the initiation of antiretroviral (ARV) prophylaxis during labor and delivery, if possible, or to the newborn during the first hours of life, when ARV therapy is most effective.

By providing program oversight, and with the collective efforts of health facilities across the state, data from the New York State Department of Health indicates significant improvement in perinatal HIV testing rates and a marked decrease in mother-to-child HIV transmission rates. The prenatal HIV testing rate greatly improved from 64% when expedited testing in the delivery setting was implemented in August 1999, to 94% in January 2003. The perinatal transmission rate for HIV positive mothers dropped sharply – from 10.9% in 1997 to 2.4% in 2002 (preliminary data from NYSDOH).

Community Action for Prenatal Care (CAPC):

The Community-Action for Prenatal Care (CAPC) initiative supports the development of community coalitions dedicated to the reduction of perinatal HIV transmission through the recruitment of high risk pregnant women into prenatal care in targeted zip codes of the South Bronx, Central Brooklyn, Northern Manhattan, and Buffalo. Lead agencies are responsible for coordinating the activities of their local community coalitions, including implementation of a comprehensive model to reach high-risk pregnant women who are not in prenatal care. The basic elements of the comprehensive model are: local planning; recruitment/referrals (including a social marketing campaign; 24 hour a day/7day a week, confidential, free hotline; direct outreach by specially trained outreach workers; and referrals from agencies serving high-risk women); intake and transitional case management; user-friendly prenatal systems (including clinical consultations to providers); and case management/advocacy.

CAPC development and activities are guided by the New York Task Force for the Prevention of Perinatal HIV Transmission, a partnership that includes staff from the New York State Department of Health, the New York City Department of Health and Mental Hygiene and the New York State Office of Alcoholism and Substance Abuse Services.

Supportive and Legal Services for Families in Transition:

This initiative assists families affected by HIV and AIDS in planning for the future care and custody of children during the illness and after the death of a parent. Legal service contractors help parents address future care and custody options, including adoption, foster care, guardianship and standby guardianship. The latter enables HIV infected parents to designate a

guardian who, at the discretion of the parent, assumes care-giving responsibilities for children during periods of parental incapacitation or after the parent's death.

Social support programs are funded to assist families in coping with HIV illness and planning for the future care and custody of their children. Services include assistance to parents in disclosing their HIV infection to their children, counseling for family members to improve coping skills, education about the placement and custody plan options available to families, assistance in identifying an appropriate new caregiver, and activities to promote stabilization and build relationships between children and new caregivers.

Eighteen (18) agencies (non-profit legal service providers, community-based organizations, child welfare agencies, and a hospital) are supported by grants to provide these services.

Centers of Excellence in Pediatric HIV Care:

These Centers provide services to HIV infected children and HIV exposed infants. They are designed to meet the complex medical management and unique psychosocial and educational needs of these children as they grow and develop while living with HIV.

The Centers provide a continuum of medical care that includes pediatric primary care, prompt access to pediatric sub-specialists, home health care programs, and tertiary care centers with experience in treating children with HIV. The Centers also provide continuous support to family members in their caregiver roles.

Children with HIV infection may have significant mental health, neurological or developmental problems due to the impact of the disease on their development, as well as from environmental issues such as poverty and parental substance use. Mental health, nutritional, neurological and developmental assessments by qualified staff are integrated into the services provided on-site at Centers of Excellence. A Center's network of grant-funded services also includes family-centered case management, treatment and prevention education, and adherence support, as well as strong linkages with a variety of community-based organizations to support the child, parents, and other family members with psychosocial services.

There are 11 Centers of Excellence in Pediatric HIV Care across New York State.

II. Selected AIDS Institute Initiatives Serving Women, Youth and Families as Part of the Caseload:

Prevention Services for Adolescents and Young Adults:

The thirty-nine (39) service providers funded through this initiative are located across the State and serve a diverse cross-section of adolescents and young adults (ages 13 to 24) including heterosexual youth; young people who are lesbian, gay, bisexual or transgender; and young people from various socio-economic, racial and ethnic groups. The primary target population is youth who are at high risk for HIV infection, including young people who are homeless, out-of-school and incarcerated.

This initiative supports three primary HIV prevention program areas: community-based prevention; school-based prevention (from elementary through college); and a lesbian, gay, bisexual, transgender initiative. The prevention services are delivered through a variety of methods, including peer-delivered education and outreach interventions, the performing arts, adventure-based learning, parent education, positive youth asset development, social marketing and interactive educational activities.

Youth-Oriented Health Care Programs:

Eleven (11) Youth-Oriented Health Care Programs focus on prevention of HIV infection in at risk youth, early identification of HIV-infected young people, improved health care status and increased self-esteem. There are two service models:

Specialized Care Centers provide comprehensive health care and support services to adolescents and young adults who are infected or at high risk for HIV infection. In addition to primary and specialty health care, services include HIV prevention education, individual risk assessment, HIV counseling and testing, case management, advocacy, mental health and substance use assessment and referral to care, transportation, childcare, language interpretation and peer support. All services are designed to help youth increase self-esteem and build daily living and coping skills.

Youth Access Programs are designed to bring low-threshold health care and support services out into community settings where adolescents and young adults at risk or infected with HIV can be reached. These programs have community partners who can reach young people at highest risk, including lesbian/gay/bisexual/transgender youth, homeless or runaway youth, those in jail or detention centers, sex workers, teens who have been sexually or physically abused and those in social networks whose members engage in high risk behaviors. Services are provided by multi-disciplinary teams that set up part-time clinics in community-based settings (such as storefronts) or bring medically equipped vans into areas where high-risk youth congregate.

Community-Based HIV Prevention and Primary Care Services:

The goals of this initiative are to educate those at increased risk of HIV infection, promote the availability of HIV counseling and testing, and develop the capacity to deliver on-site HIV primary health care services. Forty (40) health care facilities are funded to provide street outreach, community outreach and education, patient education, HIV counseling and testing, partner notification assistance, peer support, HIV primary care, staff education, case management and referral to services unavailable on-site. Many agencies also offer mental health, substance abuse, dental, nutrition and specialty services. Special emphasis has recently been placed on the development of strategies to strengthen treatment adherence and on the integration of health behavior counseling and partner/spousal notification as critical service components.

Grant-funded programs are required to develop referral agreements with other HIV service providers, including: Designated AIDS Centers and other hospitals, community-based service organizations, drug treatment programs, county tuberculosis control programs, women's service agencies, parole offices, anonymous counseling and testing programs and agencies providing services to adolescents.

HIV-Uninsured Care Programs: ADAP, ADAP Plus, ADAP Plus Insurance Continuation, and HIV Home Care:

The mission of these HIV Uninsured Care Programs (AIDS Drug Assistance Program or ADAP, ADAP Plus, ADAP Plus Insurance Continuation and the HIV Home Care Program) is to provide access to primary medical services and medications for all New York State residents with HIV/AIDS, and home care for those who need those services. The programs' dual goals are: to empower uninsured and underinsured individuals to seek, access and receive medical care and prescription drugs without cost; and to supply a stable and timely funding stream to health care providers, enabling them to use the revenues to develop program capacity to meet the needs of the uninsured HIV population.

The programs serve HIV infected New York State residents who are uninsured or underinsured and meet established residency, financial and medical criteria. The programs serve as a transition to Medicaid by providing interim assistance to individuals eligible for, but not yet enrolled in Medicaid, or assistance in meeting spend-down requirements. Individuals with third-party insurance who cannot meet the deductibles or co-payments, or whose policies have waiting periods, may also enroll. Adolescents who do not have access to the financial or insurance resources of their parents/guardians are also eligible.

Mental Health Initiative:

This initiative supports a continuum of mental health services necessary to address a range of conditions among people living with HIV and AIDS. Service delivery models vary among the thirty (30) funded programs, depending upon the targeted population. The range of services supported through this initiative includes psychiatric assessment/evaluation, treatment planning, psychotherapy and care coordination; psychiatric consultation and medication management; and case management.

The thirteen (13) agencies funded most recently for the provision of mental health services emphasize the integration and co-location of mental health services with primary care and substance use treatment services.

Case Management – COBRA Community Follow-up Program:

This program provides family-centered, intensive case management services to targeted Medicaid populations: HIV-infected persons, and high-risk individuals, for a temporary period of time. The Community Follow-up Program (CFP) is designed for persons who have comprehensive service needs, require frequent contact with care providers and have had difficulty accessing medical care and supportive services either due to issues with follow-up or because of barriers to service. Program goals are to promote early intervention, provide access to services that foster independence and self-sufficiency, prevent or delay institutionalization, and increase universal access to HIV-related services. The CFP utilizes a team of case managers and paraprofessionals to provide more comprehensive and intensive case management. There are forty-nine (49) CFP providers across New York State.

Supported Housing Programs:

The overall goal of the Housing Initiative is to ensure a flexible continuum of services that empowers individuals and families to live as independently as possible and to avoid homelessness. This continuum, provided by thirty-one (31) contract agencies, includes the following components:

- Supported services in either congregate or scattered site housing settings, including such services as case management, counseling, peer support groups, crisis intervention, nutrition assistance, child care and transportation;
- Emergency stipends for rental and utility assistance;
- Housing placement and referral;
- HIV prevention education in NYC shelters; and
- Operational support to housing providers who receive Homeless Housing Assistance Program Funding.

Nutrition Initiative:

The Nutrition Initiative provides home-delivered and congregate meals, pantry bags (groceries), food vouchers and nutrition services to persons living with HIV and AIDS (PLWH/A) through fourteen (14) contractors across New York State.

Home delivered meals help to maintain or improve the health and well being of home restricted individuals with HIV and AIDS by providing high calorie, high protein, therapeutically tailored meals and snacks. For PLWH/A who lack the ability to shop for and prepare food, home-delivered meals fulfill a critical need, often allowing them to leave the hospital sooner and remain in the community longer.

Congregate meals are served in community locations, fostering sociability, access to health care, prevention and supportive services, and nutrition services while meeting the nutritional needs of PLWH/A. Many PLWH/A using the congregate meal programs are indigent, homeless, or in marginal housing which lack kitchen facilities and food preparation equipment.

Pantry bags (groceries) and food vouchers allow PLWH/A with limited financial resources access to nutritious food. In conjunction with nutrition services, PLWH/A are able to increase their levels of independence by preparing meals and making their own food choices.

Nutritional services, conducted by registered dietitians, include screenings, assessments and reassessments, counseling and workshops on HIV and AIDS nutrition related topics.

Transportation Services:

Many HIV positive individuals do not have the financial means to cover the cost of transportation to access critically needed services. The Transportation Initiative provides resources to support transportation services to assist individuals living with HIV and AIDS in accessing necessary health and supportive services. Transportation services include car, taxi, or bus service; subway token disbursement; ticket reimbursement; van or ambulette transport; and car mileage reimbursement.

Six (6) contract agencies provide these services on a dedicated basis, and many other community-based organization contracts include transportation assistance as a component of their service package.

Criminal Justice Initiative:

The goal of this Initiative is to provide a comprehensive continuum of high quality HIV prevention and supportive services to inmates and parolees to reduce HIV transmission and to improve the health and well being of HIV infected inmates and parolees.

In State Correctional Facilities, services provided to inmates include HIV prevention interventions, a hotline, peer educator training, anonymous HIV counseling and testing (with the option to convert to confidential), HIV supportive services and transitional planning for releasees. These services are provided to incarcerated youth in facilities operated by the New York State Office of Children and Family Services. Services are also available in some county jails and through community-based organizations.

HIV infected parolees, their partners, and family members are provided with HIV prevention and risk reduction interventions, HIV supportive services and time limited family-centered case management.

Lesbian, Gay, Bisexual and Transgender (LGBT) HIV Initiative:

This Initiative supports organizational capacity building within the lesbian, gay, bisexual, and transgender (LGBT) communities of New York State, and strengthens the ability of existing HIV service providers to improve access to and deliver effective HIV prevention interventions for gay men, men who have sex with men (MSM) who do not identify as gay, lesbians/women who have sex with women (WSW), bisexual and transgender individuals.

Eighteen (18) organizations are funded under the following three components of the initiative to provide a wide range of services: 1) outreach and prevention services to the targeted populations; 2) substance-use related services; and 3) innovative outreach strategies and prevention models to reach and effectively engage LGBT youth.

In addition to the programs funded under this initiative, the AIDS Institute contracts with various community-based HIV service organizations throughout New York State to provide a broad range of HIV prevention and supportive services to LGBT communities.

Community Service Programs (CSPs):

The fourteen (14) CSPs cover all regions of New York State and provide a wide range of community-based services designed to meet HIV prevention and client service needs of HIV infected and affected individuals. These services include: outreach, individual and group level prevention interventions using evidence-based risk reduction strategies, public information interventions that influence community norms in support of reducing risk behaviors, case management, individual counseling, peer group support, and referrals to services not provided on-site.

CSPs have a regional approach to service delivery through satellite service delivery sites, collaboration with local health units, local governments, businesses and other community-based organizations. They are designed to be accessible and responsive to the needs of the diverse populations most impacted by HIV and AIDS. CSPs facilitate early access to HIV prevention and the continuum of care and enabling support services for people infected and affected by HIV.

Multiple Service Agencies (MSAs):

The Multiple Service Agency (MSA) Initiative was established in recognition of the strong role that community-based agencies have in successfully reaching communities of color. MSA funding enables existing community-based organizations serving communities of color to expand their service capacity to provide HIV-related services. Funding assists contractors in developing agency infrastructure to support the delivery of HIV prevention and service programs including prevention and risk reduction education, peer programs and case management. Funding also assists community-based organizations in developing a coordinated community response to the HIV and AIDS-related needs of people of color.

MSAs were developed to target disproportionately affected communities with the highest rates of and risks for HIV infection. Currently, thirty-four (34) MSAs provide services to reach African Americans, Hispanics, Asians and Pacific Islanders, Native Americans, Caribbean women, high-risk youth, homeless men and women living on the street or in shelters, men who have sex with men, people who identify as transgender and other populations that might not readily access the traditional service delivery/care systems.

Services provided by MSAs include outreach, individual and group level interventions using evidence-based risk reduction strategies, health communication and public information interventions, and a range of client services such as case management, counseling, and peer support groups.

III. HIV/AIDS and Women Websites

AIDS Education Global Information System (AEGIS)

<http://www.aegis.com>

The American Foundation for AIDS Research (amfar)

<http://www.amfar.org/cgi-gin/iowa/index.html>

The Body: The Complete HIV/AIDS Resource

<http://www.thebody.com/Forums/AIDS/Women/index.html>

Center for AIDS Prevention Studies

Fact Sheets

<http://www.caps.ucsf.edu/womenrev.html>

<http://www.caps.ucsf.edu/youngwomen.html>

Centers for Disease Control and Prevention
National Center for HIV, STD and TB Prevention
<http://www.cdc.gov/nchstp/od/nchstp.html>

National Center for HIV, STD and TB Prevention
Divisions of HIV/AIDS Prevention
<http://www.cdc.gov/hiv/pubs/facts/women.htm>
<http://www.cdc.gov/hiv/dhap.htm>

National HIV Testing Resources
<http://www.hivtest.org>

National Prevention Information Network (NPIN)
<http://www.cdcpin.org/scripts/hiv/index.asp>

The CDC, HIV, STD, TB Prevention News Update
<http://www.cdcpin.org/scripts/News/NewsList.asp>

The Henry J. Kaiser Family Foundation
<http://www.kff.org/hivaids/index.cfm>

Daily HIV/AIDS Report
http://www.kaisernetwork.org/dialy_reports/rep_hiv.cfm

State Health Facts
<http://www.statehealthfacts.kff.org>

HIV Insite
University of California, San Francisco School of Medicine
<http://www.hivinsite.org/>

The Johns Hopkins AIDS Service
<http://hopkins-aids.edu>

National Institutes of Health
The National Library of Medicine
<http://www.nlm.nih.gov>

Fact Sheets
<http://www.niaid.nih.gov/factsheets/womenhiv.htm>

The New York Academy of Medicine Library
The HIV/AIDS Information Outreach Project
<http://www.aidsnyc.org>

The New York City Department of Health and Mental Hygiene
<http://www.nyc.gov/html/doh/html/ah/ahbasic.html>

The New York State Department of Health
<http://www.health.state.ny.us>

HIV/AIDS in New York State Surveillance Data
<http://www.ealth.state.ny.us/nysdoh/research/hiv aids.htm>

HIV Counseling and Testing Sites
<http://www.health.state.ny.us/nysdoh/aids/hivtesti.htm>

HIV/AIDS Information
<http://www.health.state.ny.us/nysdoh/hiv aids/aboutai/aboutai.htm>

The New York State Department of Health AIDS Institute
HIV Clinical Resource: Office of the Medical Director
<http://www.hivguidelines.org>

The U.S. Conference of Mayors HIV/AIDS Prevention
<http://usmayors.org/hivprevention/>

U.S. Department of Health and Human Services
AIDS info: HIV/AIDS Treatment, Prevention, and Research
<http://aidsinfo.nih.gov>

HRSA HIV/AIDS Bureau
<http://hab.hrsa.gov/about/contact.htm>

The Office on Women's Health
<http://www.4woman.gov/owh/hiv.htm>

U.S. Food and Drug Administration
<http://www.fda.gov/oashi/aids/hiv.html>



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