

**WOMEN AND HIV/AIDS IN NEW YORK CITY:
THE HIDDEN EPIDEMIC**



A Report Issued by the Office of the Public Advocate for the City of New York
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Table of Contents

I. Introduction.....	2
II. Trends in HIV/AIDS Infection Among Women.....	3
III. Issues of Specific Concern for Women Living with HIV/AIDS.....	12
IV. Available Ryan-White-Funded CARE Services and Recommendations.....	19
V. Conclusion.....	26

I. Introduction

Currently, many people with HIV/AIDS are living longer and healthier lives. Advances in treatment such as antiretroviral “cocktails” have kept the ravages of HIV/AIDS out of sight and out of mind for many New Yorkers. Although the issue of AIDS has almost vanished from public discourse, New York City remains the epicenter of an epidemic: as of September 2002, 79,966 New Yorkers live with HIV/AIDS.¹

While HIV/AIDS is generally perceived as an illness primarily affecting men, the fact is that the proportion of HIV cases among women to total cases in New York City, as well nationally, is rapidly growing. A recent Public Advocate Office report titled the *Battle to Succeed: Challenges and Obstacles Faced by New York City Women* found that in 2001, HIV/AIDS was the number one cause of death among New York City women ages 25 to 44. Despite this alarming statistic, few of the Ryan-White Title-I-funded programs providing services to HIV-positive New Yorkers address needs specific to women.

In hopes of bringing to light the plight of women living with HIV/AIDS in New York City, this report will discuss the following:

- trends in HIV/AIDS infection among women, including which groups and neighborhoods are most affected, and where and how the disease is transmitted
- issues of concern for women living with HIV/AIDS;
- available Ryan-White-funded care services specifically targeted to women and
- recommendations to improve the quality of life for women living with HIV/AIDS in New York City.

¹ New York City Department of Health and Mental Hygiene, “HIV Surveillance and Epidemiology Program 3rd Quarter Report,” July 2003. Vol. 1, No. 3

II. Trends in HIV/AIDS Infection Among Women

HIV/AIDS Among Women

National

The public generally perceives HIV/AIDS as an epidemic that primarily affects males. Women, however, account for a growing share of newly reported AIDS cases each year. An estimated 200,000 to 300,000 women live with HIV/AIDS nationally.² According to the Kaiser Family Foundation's analysis of Centers for Disease Control and Prevention (CDC) data, the proportion of new AIDS cases among women to total new cases has more than tripled since the mid-eighties, from 7 percent in 1986 to 23 percent in 1999.³

While the advent of various antiretroviral drug therapies and important prevention efforts have brought about a decline in the number of AIDS cases as well as deaths, the rate of decline for women has not paralleled that of men. Between 1993 and 1999, the number of new AIDS cases fell by 60 percent for men, compared to 36 percent for women nationally.⁴ Similarly, estimated AIDS deaths fell by 64 percent for men compared to 35 percent for women.⁵

New York City

Data for New York City indicates that local trends closely reflect national ones. According to the New York City Department of Health and Mental Hygiene (DOHMH), since case reporting began in 1985, a cumulative 136,064 New Yorkers have been diagnosed with AIDS.⁶ As of September 2002, 79,966 New Yorkers have been diagnosed, and are known to be living with HIV/AIDS.⁸ Women and adolescent girls account for 30.4 percent (24,277) of this total.⁹

² Henry J. Kaiser Family Foundation, "Fact Sheet: Women and HIV/AIDS," May 2001.

³ Ibid.

⁴ Centers for Disease Control and Prevention, HIV/AIDS Surveillance Reports, Year End Editions, 1993-1999.

⁵ Ibid.

⁶ New York City Department of Health and Mental Hygiene, "HIV Surveillance and Epidemiology Program 3rd Quarter Report," July 2003. Vol. 1, No. 3

⁸ Ibid.

⁹ Ibid.

The DOHMH's most recent Semi Annual Report, issued in June 2002, found that among all diagnosed AIDS cases, the proportion of adult or adolescent women had grown from 23 percent in 1992 to 32 percent in 2001.¹⁰ At the same time, the proportion of men had fallen from 76.8 percent in 1992 to 67.8 percent in 2001.¹¹ Furthermore, of the 6,779 new HIV cases diagnosed in 2001, 35 percent were women.¹² The rising number of HIV-infected women helps explain the fact that HIV/AIDS was the number one cause of death among women 25 to 44 years old in 2001.¹³

Characteristics of New York City Women with HIV/AIDS

¹⁰ New York City Department of Health and Mental Hygiene, "HIV/AIDS Semi-Annual Report: Surveillance Update, including Persons Living with AIDS in New York City," June 2002. Semi Annual Reports offer a look at HIV/AIDS data over a longer period, compared to the quarterly reports.

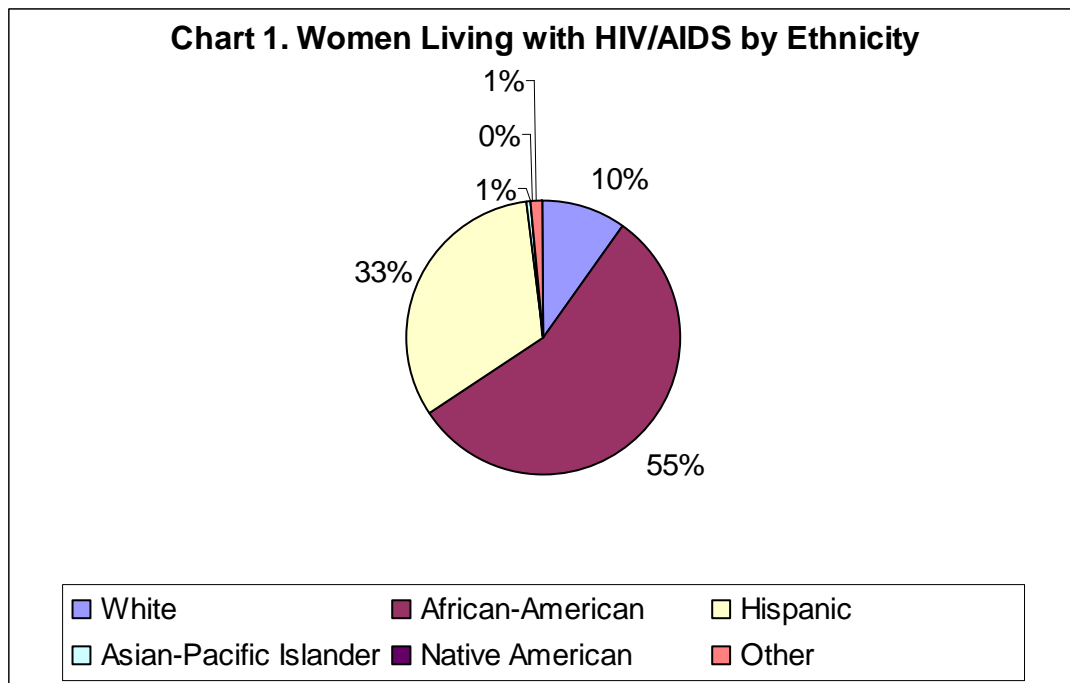
¹¹ Ibid.

¹² Press Release from NYC DOHMH on May 13, 2003. Available at <http://www.nyc.gov/html/doh/html/public/press03/pr050-0513.html>

¹³ NYC DOHMH, Summary of Vital Statistics 2000. Available at <http://www.nyc.gov/html/doh/pdf/vs/2001sum.pdf>

Race and Ethnicity

Since the mid-eighties, HIV/AIDS has disproportionately affected minority women. For instance, among the 23,059 adult or adolescent women living with HIV/AIDS in 2001, 88.6 percent were women of color.¹⁴ The incidence of HIV/AIDS is almost five times higher among African-American women and three times higher among Latina/Hispanic women than the incidence among Caucasian women. That is, African American women account for 55 percent of all HIV/AIDS cases among women living with HIV/AIDS in New York City. Latinas account for 33 percent of all living HIV/AIDS cases among women, while Caucasian women make up 13 percent.¹⁵ Although Asian, Pacific Islander, and Native American women with HIV/AIDS constitute less than one percent of the total female infected population, the raw numbers (123 cases) are troubling in their own right.

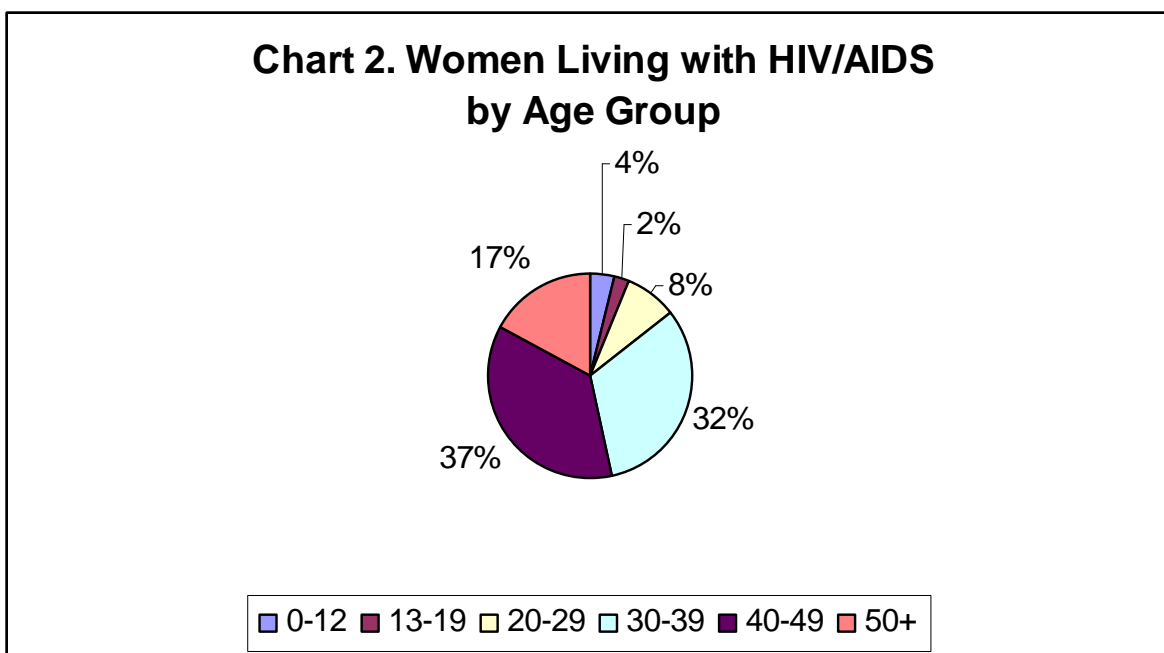


Age

¹⁴ New York City Department of Health and Mental Hygiene, “HIV Surveillance and Epidemiology Program 3rd Quarter Report,” July 2003. Vol. 1, No. 3. More recent data is available for the total number of women living with HIV/AIDS as of 9/30/2002, however, this data is not broken down by racial categories.

¹⁵ Ibid.

In New York City, HIV/AIDS is most prevalent among women between the ages of 40 and 49, who account for 37 percent of all living cases among women.¹⁶ The second highest occurrence can be found in the 30-39 age group, which accounts for 32.3 percent of all living HIV/AIDS cases among women. The over-50 group ranks third, accounting for 17 percent of all living cases among women. It is followed by the over 20-29 age group, which makes up eight percent, the under-12 group, which makes up four percent, and the 13-19 group, which makes up two percent of all living HIV/AIDS cases among women.

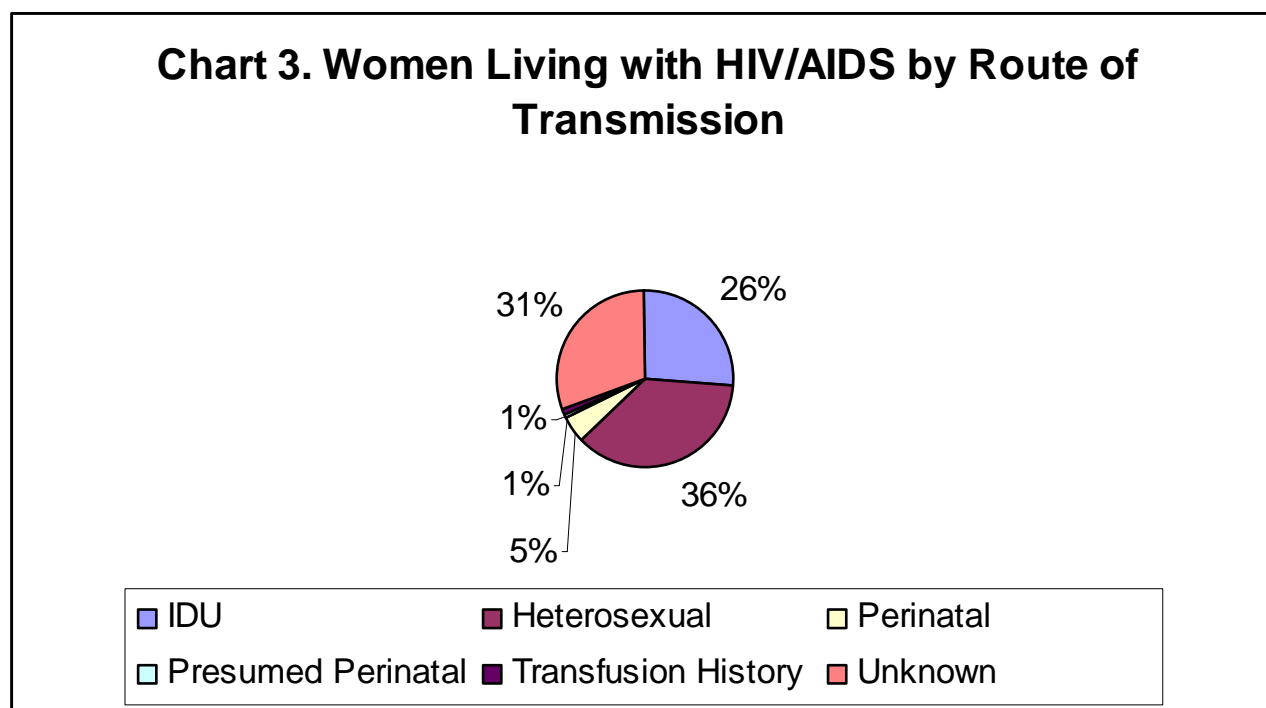


Source: New York City Department of Health

Modes of Transmission

¹⁶ New York City Department of Health and Mental Hygiene, “HIV Surveillance and Epidemiology Program 3rd Quarter Report,” July 2003. Vol. 1, No. 3.

Historically, injection drug use (IDU) has been the most common mode of HIV/AIDS transmission for women in New York City, accounting for 47.6 percent of all transmission among women.¹⁷ Since 1999, however, heterosexual contact has become the number one route of transmission for women, accounting for 36.1 percent of all cases in 2001.¹⁸ These trends are generally consistent across most racial and ethnic groups. It must be noted that in 31 percent of the cases, the route of transmission is still under investigation. Cases still under investigation will continue to be classified as such, until the investigations are resolved.



Source: New York City Department of Health

For younger women, ages 13-19, the most common route of transmission for HIV/AIDS is heterosexual contact (26.4 percent).¹⁹ The same holds true for women over 50 (33.9 percent). In contrast, injection drug use is the most common route of transmission for women between the ages of 30 and 49, with 52.5 percent of the 30-to-39-year-olds and 51.8 percent of the 40-to-49-year-olds

¹⁷ NYC Department of Health and Mental Hygiene, “HIV/AIDS Semi-Annual Report: Surveillance Update, including Persons Living with AIDS in New York City,” June 2002. Semi Annual Reports offer a look at HIV/AIDS data over a longer period, compared to the quarterly reports. Hence, the older data from the semi-annual report was used.

¹⁸ New York City Department of Health and Mental Hygiene, “HIV Surveillance and Epidemiology Program 3rd Quarter Report,” July 2003. Vol. 1, No. 3.

¹⁹ NYC Department of Health and Mental Hygiene, “HIV/AIDS Semi-Annual Report: Surveillance Update, including Persons Living with AIDS in New York City,” June 2002. More recent data is available, however, they do not provide a age by transmission breakdown.

infected by this means. IDU and heterosexual contact both seem to be major modes of transmission for women between the ages of 20 and 29, with IDU accounting for 40.2 percent and heterosexual contact 38.2 percent of all HIV/AIDS infection among women in this age group.

Impacted Areas by Borough

As of 2001, adult and adolescent women in Brooklyn have been most severely affected by the AIDS epidemic, accounting for 31.7 percent of all AIDS cases among women.²⁰ The cumulative case figure of 9,407 women infected with HIV/AIDS is the highest among all boroughs and is nearly twice, or 90 percent, higher than the city average of 4,948 cases.

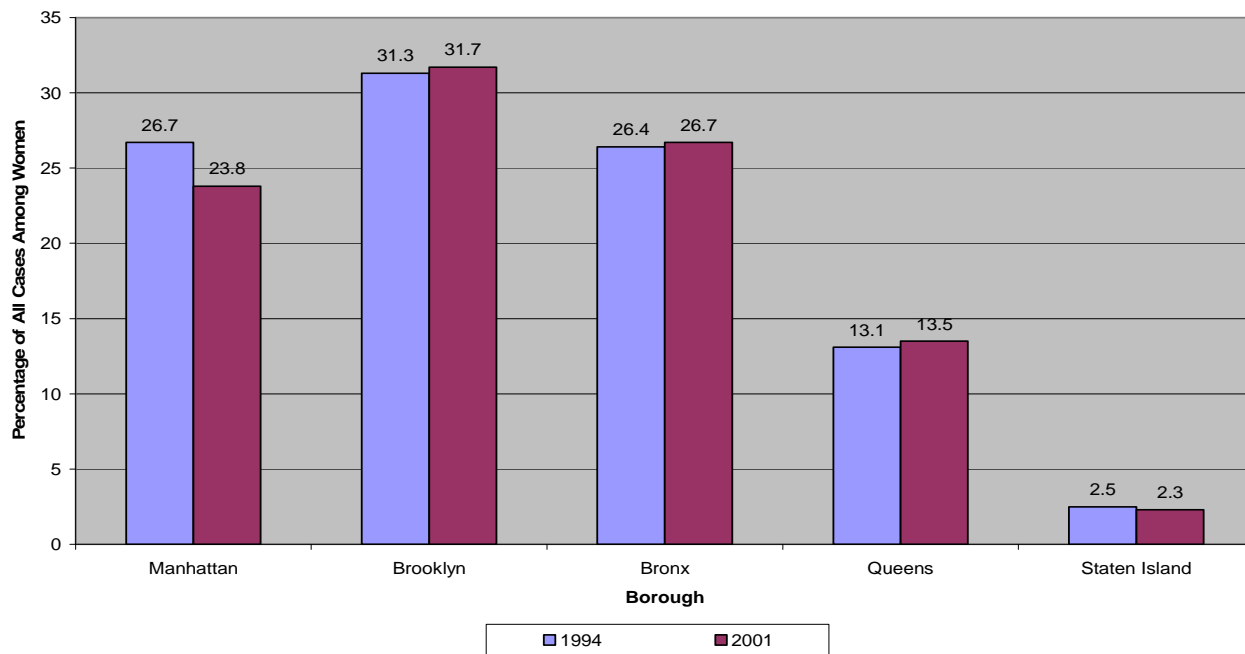
The Bronx has also been seriously affected by the AIDS epidemic, reporting 26.7 percent of all AIDS cases among women. The cumulative case figure of 7,917 is second highest among all boroughs and is 60 percent higher than the city average.

Manhattan accounts for 23.8 percent of all AIDS cases among women and, with a cumulative case figure of 7,053 women, ranks third citywide. Queens ranks fourth among the boroughs, with a cumulative figure of 4,010 women, accounting for 13.5 percent of all cases among women. Staten Island, with 681 cumulative cases, has reported the fewest AIDS cases among women, accounting for 2.3 percent of all cases among women.

²⁰ Ibid. More recent data is available, however, the semi-annual report was used to show trend over time.

According to Chart (4), the borough-wide distribution of AIDS cases among women has been consistent over time, with Brooklyn and the Bronx affected the most citywide, and Manhattan a close third.²¹

**Chart 4. AIDS Cases Among Women by Borough of Residence:
1994 vs. 2001**



Source: New York City Department of Health

²¹ Ibid.

Impacted Areas by Neighborhood

The following table (Table 1) ranks New York City neighborhoods by the total number of AIDS cases among women. This ranking is based on data from the New York City DOHMH’s neighborhood figures in 1999, the latest year for which neighborhood data is available.

Table 1. AIDS Cases Among Women in New York City Neighborhoods²²

Citywide Ranking	Borough	New York City Neighborhoods	Total AIDS Cases Among Women
1	Brooklyn	Bedford-Stuyvesant	1965
2	Bronx	Highbridge	1520
3	Manhattan	Central Harlem Morningside	1448
4	Bronx	Crotona Tremont	1416
5	Brooklyn	Williamsburg	1181
6	Brooklyn	East Flatbush	1089
7	Manhattan	East Harlem	1058
8	Bronx	Fordham Bronx Park	1028
9	Bronx	Pelham	1005
10	Bronx	Hunts Point	978
11	Manhattan	Union Square	843
12	Brooklyn	East New York	833
13	Queens	Jamaica	821
14	Brooklyn	Downtown Heights	816
15	Manhattan	Washington Heights	734
16	Queens	West Queens	631
17	Manhattan	Upper West Side	604
18	Manhattan	Chelsea Clinton	461
19	Bronx	North East Bronx	413
20	Brooklyn	Coney Island	393
21	Queens	South West Queens	325
22	Brooklyn	Borough park	318
23	Queens	South East Queens	308
24	Queens	Rockaway	296
25	Queens	Long Island City/ Astoria	290
26	Brooklyn	Greenpoint	279
27	Staten Island	Stapleton	278
28	Brooklyn	Canarsie Flatlands	259
29	Brooklyn	Sunset Park	235
30	Manhattan	Gramercy Park	217

²² New York City Department of Health and Mental Hygiene, “AIDS in Boroughs & Neighborhoods of New York City,” Volume 3, 1999.

31	Queens	Ridgewood	214
32	Queens	Flushing	162
33	Manhattan	Upper East Side	160
34	Staten Island	Port Richmond	147
35	Bronx	Kingsbridge	111
36	Manhattan	Greenwich Village	92
37	Staten Island	South Beach	92
38	Manhattan	Lower Manhattan	83
39	Queens	Fresh Meadows	69
40	Staten Island	Willowbrook	44
41	Queens	Bayside/Little Neck	36

According to Table 1, Bedford Stuyvesant in the borough of Brooklyn has the highest number of all AIDS cases among women in the city, 1,965.²³ Highbridge in the Bronx was found to have the second highest number of all AIDS cases among women in the City, 1,520. The Manhattan neighborhood of Central Harlem Morningside has the third highest number of all AIDS cases among women in the city, 1,448.

²³ Ibid.

III. Issues of Specific Concern for Women Living With HIV/AIDS

Issue I: Symptoms, Diagnosis, and Treatment

Although HIV/AIDS has a devastating impact on both men and women, there are certain instances in which its effect on women differs from its effect on men. The differences in the clinical manifestation of HIV/AIDS in men and women are well documented. For example, women are more vulnerable to HIV infection and face higher risks of contracting HIV during unprotected intercourse.²⁴ Research has shown that the risk is two to four times higher for women.²⁵ HIV-positive women also progress to AIDS at lower viral load levels and higher CD4 counts than men do.²⁶

In addition, there are many symptoms of HIV/AIDS that are specific to women. Many of these symptoms, however, went unnoticed by healthcare providers for a long period. It was not until 1993, ten years into the epidemic, that the CDC expanded its case definition to include female-specific symptoms.

The first symptoms of illness in women with HIV are usually gynecological in nature, commonly appearing as gynecological infections and disorders.²⁷ As the immune system deteriorates, vaginal yeast infections, human papillomavirus infections, and pelvic inflammatory diseases appear to occur commonly and aggressively in HIV-infected women.

Therefore, it is imperative that women with HIV/AIDS receive good gynecological care from physicians who have experience treating women and with whom patients are comfortable. Yet many women do not receive adequate gynecological care, resulting in delays in diagnosis and treatment.²⁸ Compounding this problem is the fact that many women rarely bring up HIV/AIDS when visiting their

²⁴ UNAIDS, "Women & AIDS," October 1997.

²⁵ Ibid.

²⁶ The CD-4 count measures the number of CD-4 cells, or T-helper white blood cells that organize the immune system's response to some microorganisms. The viral load is used to describe the amount of HIV in an individual's blood.

²⁷ SFAF Foundation, "AIDS 10: Women with HIV/AIDS"

²⁸ 2002 AIDS Community Research Initiative of America (ACRIA)

http://www.criany.org/treatment/treatment_edu_women.html

healthcare providers and, when they do, they often do not know the right questions to ask. In fact, a recent national survey by the Kaiser Family Foundation found that approximately half of women between the ages of 18 and 49 have never discussed HIV/AIDS or other Sexually Transmitted Diseases with their healthcare providers out of embarrassment or concerns about being judged.²⁹

Once an individual is infected, early diagnosis and treatment are crucial to the successful management of the infection. The longer a person with HIV goes without being tested and treated, the quicker the progression of disease.³⁰ Yet early detection in women is seriously hampered by the fact that women are not perceived as being at risk and tend to be overlooked even by healthcare providers.³¹

Furthermore, the Health Resources and Services Administration (HRSA) found that even after a diagnosis is made, 31 percent of women who test positive for HIV delay accessing healthcare for three months or longer out of fear, depression, and anxiety about their status.³²

A similar study in the Journal of The American Medical Association found that HIV-positive women are 12 percent less likely than men to have received the accepted standard for care, combination antiretroviral therapy.³³

Gender-specific social issues may hinder women's ability to access needed services. Even when HIV-positive women are able to access available services, the complex socio-economic circumstances they face may prevent them from adhering to the therapies. This is particularly troubling because adherence to treatment regimens is critical to the ability to live longer with HIV. Treatment Adherence is complex, especially when regimens include taking up to 20 pills a day, and some studies have found that women, African-Americans, Hispanics, younger adults, and patients with higher CD-4 counts reported lower adherence.³⁴

²⁹ Kaiser Family Foundation, "National Survey of Women on their Sexual Health," June 18, 2003.

³⁰ Nauren, Elinor, *The Body*, "Women and HIV: AIDS: A Women's Disease"

³¹ Ibid.

³² Source: HRSA

³³ Shapiro, et al., "Variations in the Care of HIV Infected Adults in the United States," *JAMA*, Vol.281. No.24, 1999.

³⁴ Wenger N, Gifford A, Liu H, et al. "Patient characteristics and attitudes associated with antiretroviral (AR) adherence," Program and Abstracts of the 6th Conference on Retroviruses and Opportunistic Infections, Chicago, Abstract 98, 1999.

Issue II: Clinical Trials

Clinical trials are research studies that find out how investigative procedures, tests, and medicine work. They also determine how different factors impact the efficacy of investigational treatments. Seventeen antiretroviral drugs have been approved and are currently being used for treating HIV infection.³⁵ These advances in medicine have been largely due to clinical trials that have been conducted over the years.

Because men and women have different body chemistries, they react differently to medication. Therefore, medication may have side effects that only occur in women. Despite these recognized physiological differences, there have been very few women participating in clinical trials for HIV/AIDS medication. In fact, women comprise only 9 to 20 percent of all clinical trial participants.³⁶

Many hypothesize that this lack is due to the unwillingness of pharmaceutical companies to run the risk of women getting pregnant during the study period. Past studies have found that participation by women in clinical trials is also affected by factors such as location, gender of study investigator, availability of childcare, and transportation. Many clinical trials units in New York City are not conveniently located for women in the outer boroughs.³⁷

Issue III: Pregnancy

With HIV infection rising among women of childbearing age, pregnancy is a complex issue that an HIV-positive woman may face. Decision-making regarding pregnancy is difficult for any woman, let alone for a woman simultaneously dealing with the medical symptoms and stigma attached to being HIV-positive. Invariably, the choice to keep the child or terminate will be one of many pressures that a HIV positive pregnant woman faces. HIV-positive women are often told that they should not have children or that they should take antiretroviral therapy to prevent infection to the child.³⁸ Pregnant HIV-positive women must have accurate knowledge in order to understand their treatment options as well as its impact on their bodies and their child's.

³⁵ Jackson-Figueroa, Haley, Cornell Clinical Trials Unit, "Women and Clinical Trials"

³⁶ Ibid.

³⁷ Ibid.

³⁸ de Bruyn, Marta., "Reproductive Choice and Women Living with HIV/AIDS," December 2002.

Issue IV: Child Care

Women are most often the primary caregivers for their children and families. In fact, according to a study published in the American Journal of Public Health, 60 percent of women being treated for HIV/AIDS have children younger than 18.³⁹ Many lack the social networks that help in caring for children.⁴⁰ In order to leave the home to receive medical care, seek substance abuse treatment, or participate in clinical trials, HIV-positive women must be able to make child care arrangements. Lacking the resources to do this may seriously alter a women's ability to adhere to treatment or counseling plans.

Issue V: Child Welfare

Mothers infected with HIV face many serious challenges including whether to disclose their positive status to their children and other members of their families. With progression of the illness, the mother will face one of the hardest decisions a parent can make: planning for the placement of her children after her death. This is often called "permanency planning" and involves the mother selecting a caregiver who will take care of her children when she is gone.

In many instances, extended family members assume responsibility for the children as legal guardians. New York State allows parents, without giving up legal rights, to designate a standby legal guardian who will step in to care for the children in the case of the mother's illness or subsequent death. This is known as "standby guardianship."⁴¹ In 2001, New York State passed the Families in Transition Act, a bill enabling social services agencies to aid parents and guardians in setting up stand-by guardians for their children in the event of a serious illness or death. This bill helps stand-by guardians become certified foster parents, allowing for easy transition, and allowing the child to retain public assistance even after the death of the parent or guardian.⁴²

³⁹ Schuster, M.A., Kanouse, D.S., et al., "HIV-infected parents and their children in the United States," American Journal of Public Health 90 (7) pp. 1074-1081

⁴⁰ Ibid

⁴¹ Havens, et al., "Families" Available on the <http://www.thebody.com/encyclo/families.html>

⁴² Long Island Association for AIDS care, Inc. <http://www.liaac.org/policy.html>

Sometimes, when a mother has no family or friends with whom to leave the children, they are placed in the child welfare system. Once they place their children in the child welfare system, mothers often find it very difficult to get them back, or even gain visitation rights, upon recovery. Extensive postponements in family court delay the process further.⁴³

Issue VI: Substance Abuse

Until as recently as 1999, intravenous drug usage has been the most common mode of HIV transmission for women in New York City, constituting 47.6 percent of all transmitted cases among women.⁴⁴ Despite the fact that substance abuse is very common among women with HIV/AIDS, many care services are based on models that treat men. Hence, there are very few treatment plans and care sites that address the personal, social, and familial needs of women.

There are very few residential programs for pregnant women with addiction issues and very few places where HIV-positive women can stay with their children and get treatment. Furthermore, many substance-abusing HIV-positive women with children are afraid to access treatment services because they fear their children will be taken away from them. As a result, women face a choice between treating their addiction and keeping their children.

Issue VII: Domestic Violence

In New York City, the issue of domestic violence cuts across all racial and ethnic lines. The New York City Domestic Violence Hotline received an estimated 140,769 calls in 2001.⁴⁵

While no local data on the prevalence of domestic violence against women with HIV/AIDS could be identified, an intergenerational HIV study by the National Institute of Health found that nearly 50

⁴³ Shapiro, Laura, Duke Journal of Gender Law and Policy, "An HIV Advocate's View of Family Court: Lessons From A Broken System," 5 pg 133 <http://www.law.duke.edu/journals/djglp/articles/gen5p133.htm>

⁴⁴ Source: NYC DOHMH

⁴⁵ Source: Mayor's Office to Combat Domestic Violence

percent of the HIV-positive women surveyed reported a history of sexual abuse and 60 percent were victims of domestic violence.⁴⁶

Partners or spouses of HIV-positive women often become enraged at their medical condition and use it as an excuse to batter them.

Issue VIII: Poverty

Women are disproportionately represented among the poor. In fact, most women who are HIV-positive live in poverty and were already poor when they learned of their HIV status.⁴⁷ Many of these women struggle for survival. Concern for their children and family takes precedence over their own health.

According to the HRSA, a study of HIV positive women from four urban areas in the Northeast indicates that 72 percent have incomes of less than \$1,000 per month. Taking care of their own health needs is less of a priority for these women than meeting basic needs like food, housing, and employment. Hence, socioeconomic status can be a barrier to healthcare access.

With the average monthly rent for a one-bedroom apartment at \$907, it is difficult for many New Yorkers to afford a place to live.⁴⁸ This is an added burden for many HIV-positive women who already face an uphill battle.

Group homes often fail to provide safe haven for HIV-positive women with children because many are single room occupancies and do not allow a child older than twelve to live with his/her mother. Federal Section 8 vouchers are expedited for victims of domestic violence yet still take an average of a year to get. Even when housing opportunities are available, they are often substandard and lack safe and decent environments for children. HIV-positive mothers on public assistance face the loss of

⁴⁶ Source: HRSA

⁴⁷ Source: HRSA

⁴⁸ Source: National Low-Income Housing Coalition. Available at <http://www.nlihc.org/cgi-bin/oor2002.pl?getmsa=on&msa=newyork&state=NY>

housing subsidies if they seek employment, keeping them dependent on public benefits. There is very little recourse for women who want to retain their jobs and not rely on public assistance programs.

IV. Available Ryan-White-Funded CARE Services and Recommendations

This section explores current HIV/AIDS care services for women in the New York City Ryan White Title I Comprehensive AIDS Resource Emergency (CARE) relief grant program⁴⁹. A number of the issues above—including clinical trials for women, job training, and domestic violence—are not addressed by currently available Ryan-White-funded services.

It is important to note that a host of government and philanthropic entities fund HIV/AIDS care services in New York City, but a recent study by the Center for an Urban Future found that the system of available HIV/AIDS services in New York City are “fundamentally fragmented.”⁵⁰ The study failed to find any analysis of how services funded by different streams overlap. In addition, the study found that no one single agency or official was responsible for monitoring the City’s response to the AIDS epidemic.

The Mayor’s Office of AIDS Policy Coordination (MOAPC) oversees the coordination work of the HIV Health and Human Services Planning Council, a community body established under the Ryan White CARE Act. The Council decides what services are most needed, as well as how much Title I money should be used for each of these services, and develops a written plan to provide these services.⁵¹ Mayor Bloomberg has recently incorporated MOAPC into the DOHMH.

Since 1990, the New York City CARE program has been funded under Title I of the federal Ryan White CARE Act. In 1998, additional federal funds were allocated to target racial and ethnic minority communities under the Minority AIDS Initiative (MAI) and included with Title I grant awards to hard-hit metropolitan areas like New York City. Of the 318 Ryan-White-Title-I-funded HIV/AIDS care services currently available for New Yorkers, only 17 specifically target women.

⁴⁹ The DOHMH contracts with the Medical and Health Research Association of New York City (MHRA) to administer Title I funds. Under the direction of DOHMH, MHRA contracts with various providers to deliver the services.

⁵⁰ Hantman, Julie. Center for an Urban Future, “Epidemic Neglect: How Weak Infrastructure and Lax Planning Hinder New York’s Response to AIDS,” February 24, 2003

⁵¹ HIV Health and Human Services Planning Council of New York, available at <http://nyhivplanningcouncil.org/council.html>

RYAN WHITE-FUNDED SERVICES

Service I: Outpatient Medical Care

Of the twenty-three Ryan-White-funded HIV/AIDS outpatient medical care programs in the City, only two specifically target women. Both these programs, Albert Einstein College of Medicine of Yeshiva University and New York Presbyterian Hospital, offer clinical case management and treatment education for women.

They provide women and their families assistance in accessing medical care, accessing substance abuse services, crisis interventions, and referrals in conjunction with care given at the clinic.

Recommendation I: Improve Access to and Efficacy of Medical Services

Women face HIV/AIDS symptoms that are specific to them and need medical care that can address these symptoms. There are presently two programs specifically targeting women in the city, but this is not enough to deal with the growing number of women infected with HIV/AIDS. The Health and Hospitals Corporation (HHC) is the primary provider of care to more than 70 percent of New York City residents living with HIV/AIDS. HHC already provides outpatient programs for HIV/AIDS infected individuals; however, they should develop programs that specifically target women.

Many providers do not know how to effectively communicate with HIV-positive women or how to develop sensitivity to their needs. Nor do they know how important communication and sensitivity are to the health of HIV-positive women. One way this deficiency can be addressed is by implementing mandatory training programs that teach medical students at HHC residency programs how best to interact with women.

Although existing HIV/AIDS services provide women with vital support, they are not always adequate for their specific health needs. For women to have adequate access to health care, services must be located in the communities in which women living with HIV/AIDS live. The issues of stigma and HIV/AIDS confidentiality are critical. Therefore, services should be made available in the community

in a way that makes access and respect for privacy paramount. Enabling services like free transportation to medical facilities and onsite childcare are also central to breaking barriers to healthcare.

Service II: Supportive Counseling

Of the six Ryan-White-Title-I-funded supportive counseling programs for HIV-infected individuals in the City, only two run programs specifically targeted to women: Gay Men’s Health Crisis and Women’s Prison Association. They provide educational and emotional support to HIV-infected women with a focus on pregnancy, parenting, relationships, and responses to the complexities of living with HIV/AIDS.

Recommendation II: Incorporate Uniform Treatment Education into Counseling Programs

There should be uniform incorporation of HIV treatment options, including the prevention of perinatal transmission, into supportive counseling programs and all Ryan-White-funded settings that engage women.

Service III: Custody Planning

Although there are ten custody-planning programs for individuals with HIV/AIDS in the city, Iris House is the only program that specifically assists HIV-positive women and their family members in developing custody plans with the help of individual and family counseling services.

Recommendation III: Increase Assistance in Navigating the Child Welfare System

New York City’s child welfare system is a complex one for healthy mothers. It is that much more complex for mothers living with HIV/AIDS. The number of custody planning programs that assist HIV-positive mothers in navigating the child welfare system must be increased.

State agencies like the Office of Children and Family Services and New York City’s Administration for Children’s Services must improve efforts to inform all terminally ill parents of existing standby

guardianship laws and the Families in Transition Act. This can be accomplished by conducting orientation sessions in court or by passing out handbooks that fully explain the rights and responsibilities of terminally ill parents.

Service IV: Harm Reduction Services

There are twenty-eight harm reduction programs throughout the city, five that specifically target women. One of these programs, run by the Center for Community Alternatives, is targeted to HIV-positive women involved in the criminal justice system. It offers education, support, and counseling groups, individual alcohol and drug counseling, case management, and acupuncture for its clients.

Other programs, like Exponents, Inc., provide harm reduction services for women through bilingual peer support interventions that include stress management, medications, and complimentary therapies. Harm reduction programs differ from many traditional services because they seek to remedy the primary need of the individual client on a first-need-first basis. These programs are based on a behavioral change model and offer an array of services that run the gamut from needle exchange programs to case management to accessing health care to providing clothing, shelter, and food. The nature of the harm reduction service depends on the organization providing it.

Recommendations IV: Develop Women-Focused Substance Abuse Services

Because most substance abuse treatment facilities have been developed to meet the needs of men, they are often ill-equipped to respond to the special needs of women. The Ryan White CARE program should continue to support a range of approaches to women specific drug treatment and prevention programs such as harm reduction, including residential and outpatient drug treatment programs.

Because women are primary caregivers and custodial parents, Ryan White CARE programs must develop residential and outpatient drug treatment programs for addicted HIV-positive mothers with children.

Service V: Transitional Housing Assistance

Although New York City's HIV/AIDS Services Administration (HASA) provides several types of housing assistance, Ryan White Title I only funds transitional housing and housing placement programs.⁵² Of the six Ryan-White-Title-I-funded transitional housing programs in the city, only one—run by Housing Works—specifically targets women. This program consists of 20 scatter-site apartments, where parolees and individuals transitioning out of the criminal justice system can seek a stable environment with a full range of medical, clinical, psychosocial, and case management services.

Of the four Ryan-White-funded housing placement assistance programs in New York City, only one—run by the Women's Prison Association and Home—specifically targets women.

Recommendation V: Improve Housing Availability for Women with HIV/AIDS

To meet the housing needs of women living with HIV/AIDS, the City needs to develop Ryan-White-funded permanent housing, as well as transitional housing, for individual women and for women with children. The housing should include support services for women.

Mayor Bloomberg's proposed \$3 billion housing plan to construct and rehabilitate 65,000 housing units within the next five years should include housing for women living with HIV/AIDS. Rules and regulations at shelters and group homes must be re-evaluated to accommodate mothers with children and to help keep families together. Section 8 vouchers should be expedited for HIV-positive women.

SERVICES NOT AVAILABLE THROUGH RYAN-WHITE-FUNDED-PROGRAMS

Clinical Trials

There are no available Ryan-White-funded enabling services to assist HIV-infected women participate in clinical trials.

⁵² HASA provides emergency housing, transitional placements, congregate settings, permanent scatter-site apartments, and rental assistance for those in private market or public housing.

Recommendation: Increase Participation of Women in Clinical Trials

Clinical trials conducted in New York City must do a better job of recruiting HIV-positive women. To accomplish this, clinical trials appropriate to women should be held in areas accessible to women of all ages. Enabling services such as childcare and transportation should be incorporated into these clinical trials.

Childcare Services

There are no Ryan-White-funded programs that specifically provide childcare services, but mothers living with HIV/AIDS can access childcare through one home care program provided by the Visiting Nurse Service of New York. This program provides childcare services for women with HIV/AIDS during appointments and hospitalizations. In addition, the program provides homemaking and respite care, and substance abuse, mental health, and nutrition counseling.

Recommendation: Provide Childcare Services for Mothers Living with HIV/AIDS

The lack of childcare for mothers with HIV/AIDS has a major impact on their ability to access healthcare services, participate in clinical trials, and seek employment. According to our analysis of available services, the need for childcare services is great.

There are five home care programs in the city in addition to Visiting Nurse Service of New York. DOHMH should work with these service providers to enable them to offer childcare provisions. In addition to working with already existing homecare services, more Ryan White Title I funding should be allocated to provide childcare services. For example, mothers with HIV/AIDS could be given vouchers to be used at any childcare center.

Domestic Violence

There are no Ryan-White-funded services to help HIV-infected women deal with domestic violence.

Recommendation: Develop Domestic Violence Protocols and Strong Referral Mechanisms at All Ryan White CARE Service Programs

It is important that all Ryan-White-funded service providers contracting with the City consider the impact of abuse and violence on a women's health. All Ryan-White-funded providers must establish tools to assess the occurrence of domestic violence in their client's homes and develop strong referral mechanisms to enable these women to seek help.

Job Training Opportunities

There are no Ryan-White-funded job training programs for women living with HIV/AIDS.

Recommendations: Develop Job Training Opportunities for Women with HIV/AIDS

The sporadic nature of HIV/AIDS symptoms makes the job training needs of HIV-positive women unique. A pilot program analyzing the specific job training and placement needs of women living with HIV/AIDS would enable New York City to help facilitate their economic independence.

The New York City Department of Small Business Services and the Human Resources Administration should collaborate on a pilot job training and placement program for women living with HIV/AIDS.

V. Conclusion

Although women with HIV/AIDS can access and receive services from any one of the 318 Ryan-White-Title-I-funded programs available throughout the city, it is important for them to be able to access gender-specific programs in which providers can take into account their different physiology and socio-economic circumstances. With only 17, or 5.3 percent, of New York City's Ryan-White-Title-I-funded programs specifically targeting women, there is a critical need for women-specific HIV/AIDS services.

New York City's looming financial crisis and the recent loss of \$14 million in Ryan White funding poses a tough challenge for the City and service providers alike to provide effective and essential services for women living with HIV/AIDS. While the impact on women of the consolidation of the Mayor's Office of HIV/AIDS Policy Coordination with DOHMH is yet to be seen, the City must make a concerted effort to tackle the growing issue of women with HIV/AIDS, or it will continue to be a hidden epidemic, wreaking tragic consequences for women and families in the City.