

Women Living With HIV and AIDS in NYC

A MAPPING PROJECT AND LITERATURE REVIEW



Women Living With HIV and AIDS in New York City:

A Mapping Project and Literature Review was developed by the Women's HIV Collaborative of New York with assistance from individuals working on the front lines of the epidemic providing women-specific HIV/AIDS services and programs throughout New York City.

Executive Summary



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EXECUTIVE SUMMARY

Of the 30,000 women and girls¹ living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) in New York City (NYC), a disproportionate number (90 percent) are black or Hispanic and over the age of 40 (68 percent); more than a third were infected through heterosexual activity (41 percent). Statistics like these are distressingly familiar: the epidemic's distribution among women in the United States has looked like this for decades.

What this report does, for the first time, is to identify the problem and some of the factors that contribute to it in one place and in an easily understandable visual format. It then suggests concrete solutions based on these data. Throughout the report, maps appear that identify “hot spots” by ZIP code within the five boroughs and the city as a whole—specific areas with the highest concentration of HIV-positive women. This first set of maps is overlaid with another set that shows the various intersecting types of social and economic distress within these hot spots that heighten women's risk for contracting HIV.

Together, these maps reveal that more than half of the HIV-positive women in NYC (60 percent) live in the same geographic areas—specifically, eastern Brooklyn, the Bronx, and northern Manhattan. These are also the areas in the five boroughs with the highest concentrations of poverty and prison admissions and the lowest rates of adults with high school diplomas.

By combining these data, this report provides both a road map of the geographic areas of greatest need and an outline of the services necessary to curb the epidemic and heal neighborhoods and communities. Its suggestions for action, which appear at the end of this brief summary, involve many stakeholders, from advocates and service providers to politicians, and prescribe changes on the level of infrastructure. Moreover, these suggestions take into account the unique needs of women when compared with their male counterparts—many of whom live in these same areas as well as throughout mid- and southern Manhattan.

A primary contributor towards lowering women's risk for HIV is the provision of adequate health care, including reproductive health care and comprehensive sexuality education that lowers the rate of sexually transmitted infections (STIs) and unintended pregnancies. Currently, these services are scarce in the hot spots where most women living with HIV/AIDS reside, which means that they also do not exist as an early preventative method for women

¹ For the purposes of this report, we will use the word “women” going forward to include all females living with HIV.

at risk for HIV. And while detailed maps show a fair number of service providers for women once they become HIV positive, multiple stressors in women's lives still serve as barriers to service utilization and inhibit access to care.

As the literature review included at the end of this report documents, the majority of HIV-positive women report histories of intimate partner and family violence and substance use. Rates of homelessness and mental health problems run high; concerns about family and children take precedence. Simply put, women bear the brunt and show the cost of poverty and violence in this culture, and they continue to provide most of its caretaking, unpaid and around the clock. If a woman living with HIV/AIDS is struggling to protect her children from an abusive partner, or scrambling to keep some kind of roof over their heads, or wrestling with her own addiction or depression, or even choosing between keeping her doctor's appointment or taking her children to theirs, her HIV status is to likely to be the last item on her list of priorities. Once women contract HIV, they become sicker faster and die sooner than men.

Community-based services can play a crucial role in reducing the harms that can arise in these environments. Lowering women's risk for contracting HIV requires a variety of services that are currently scarce in NYC's hot spots: for example, adequate health care, including reproductive health care and comprehensive sexuality education to lower the rate of sexually transmitted infections (STIs) and unintended pregnancies. For HIV-positive women, support groups, case management, housing support, and gender-specific programming all help to improve access to social services and health care and reduce mental health problems. Therefore, it is important to place services in locations that are readily accessible to HIV-positive women as well as women at high risk for HIV.

This report is meant to serve as a resource, a road map, and a tool kit. It can inform program design as well as further communications between advocates and elected officials about what is needed and what can be done in NYC's boroughs and neighborhoods. In addition to demonstrating the need for a heightened response to the intersecting social and economic issues affecting the lives of women living with HIV/AIDS, this report makes the following recommendations for action.

RECOMMENDED NEW YORK CITY-LEVEL ACTIONS

- **The Chair of the New York City Council General Welfare Committee (Council Member Bill de Blasio) should ensure adequate housing for all HIV-positive New Yorkers: his next step towards this goal should be to secure a hearing date for the HASA for ALL Act.** Current policies make HIV-positive New Yorkers ineligible for subsidized housing until they become symptomatic for AIDS rather than providing them with the housing that could prevent or postpone them from becoming seriously ill. Per our colleagues at Housing Works: "More and more scientific studies are showing that in order to stave off further cell degradation and slow down disease progression, doctors should



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offer patients AIDS meds well before the disease progresses to AIDS. The HASA for ALL Act simply follows the science: early access to medication, early access to housing, and early access to life-stabilizing support services keep people living with HIV living longer and healthier." The passage of the HASA for ALL Act would expand eligibility and reverse that trend by moving an estimated 7,000 asymptomatic, low-income HIV-positive New Yorkers into medically appropriate emergency and permanent housing. The Act also seeks rent subsidy increases, and calls for an increase in individual public assistance, which includes nutrition and transportation allowances. As our colleagues at Gay Men's Health Crisis (GMHC) note, "For many with HIV/AIDS, permanent housing is the difference in having access to medication, to stability, and, ultimately, re-entry into the labor market. Pure and simple: Housing equals healthcare and health for People Living with HIV/AIDS."

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- **Mayor Michael Bloomberg and the Chancellor for New York City schools Joel I. Klein should mandate comprehensive sexuality education programs in New York Public schools and provide proper oversight of the program's implementation.**

- **The New York City Human Resources Administration's Back to Work programs should adopt the following measures to help participants more successfully gain and maintain meaningful employment:**

- **Increase** focus on pre-employment services that help to make individuals work-ready in the areas of housing, substance use treatment, domestic violence, etc.

- **Improve** retention in Back to Work program by providing more substantial transitional benefits that allow participants to remain employed, yet still have the support they need once they begin working—for example, the continuation of subsidized childcare and housing. Currently many participants who enter the Back to Work program drop out between 30 to 60 days because they cannot afford the resulting loss of benefits.

- **Take advantage** of some increased flexibility for example, around education and training, and be creative in implementing the federal regulations that govern welfare programs.

• **The Chair of the New York City Council Civil Rights Committee (Council Member Larry Seabrook) should advance and adopt pending Int. 731, the legislation proposed by the New York Human Rights Initiative (NYCHRI) titled the Human Rights in Government Operations Audit Law (GOAL)**, currently sponsored by Council Member Helen Foster and co-sponsored by Council Member Darlene Mealy. This proposed legislation expands on the current law and will help to promote equality by enabling NYC to stop discrimination before it happens; moreover, it gives residents a greater say in solving the problems facing their communities. Int. 731 incorporates human rights standards and law found in the International Convention on the Elimination of all forms of Racial Discrimination (CERD). The definition of discrimination under CERD is much broader than the one found in Federal law in that it takes into account both the intent and the effects of discrimination.

Per the United Nations CERD Committee Observations CERD/C/USA/CO/6...February 2008 the United States and all its territories has an affirmative obligation to implement CERD in theory and in practice.

“The Committee recommends that the State party consider the establishment of an independent national human rights institution in accordance with the Paris Principles (General Assembly resolution 48/134 of 20 December 1993, annex).”

The US human rights activists and the Obama administration are already taking steps to establish human rights bodies at the federal level per recommendations found in the **Human Rights at Home: A Domestic Blueprint for the new Administration**, by the American Constitutional Society. NYC should be a model of human rights and take steps to enact Int. 731.

Int. 731 allows us to address the indisputable link between discrimination and persistent poverty and aligns us with international human rights norms. Per our allies at the Human Rights Project at the Urban Justice Center, “Those persons living in extreme poverty in the US are those that have historically suffered discrimination on the grounds of race. Persistent poverty has continued to aggravate racial and social discrimination for this population. Indicators of social mobility such as higher education, employment, and low rates of imprisonment show how racial minorities continue to suffer the impact of racial discrimination.” Council Member Seabrook should also ensure the human rights of the members of NYC’s most vulnerable communities by securing a hearing that addresses racial discrimination under CERD and the UN’s concluding observations.



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RECOMMENDED NEW YORK STATE-LEVEL ACTIONS:

- **Good prison health care is good public health policy to such a great extent that there are three primary recommendations along these lines.**

- **First**, the Chairperson of the New York State Senate Health Committee (Senator Tom Duane) should sponsor the Department of Health Oversight Bill (A 903), which would require the New York State Department of Health to oversee and monitor HIV and Hepatitis C care in prison. Once the bill has been introduced, the Senate should support it. More than 27,500 people were released from the Department of Correction's custody in 2007, and many are poor people of color who returned to their communities—often the very same communities identified in this report as hot spots. People living with HIV and the Hepatitis C Virus (HCV) who receive quality health services in prison are more likely to seek care and continue treatment after release, and are less likely to pass on illnesses to loved ones and other community members.

- **Secondly**, and for many of the same reasons, we recommend that the Health Committee introduce a bill that would require the Department of Correctional Services to provide timely, evidence-based drug dependence treatment to all prisoners in need of such services, including medication-assisted therapy such as methadone and buprenorphine for prisoners dependent on opiates.

- **Finally**, the bill sponsored by Senator Duane (S 1792) promoting programs for prevention of HIV and other sexually transmitted diseases, including making prophylactic devices available, should be referred out of committee and passed by the Senate in order to protect the health of prisoners and the communities to which they return.

- **The New York State Education Department should issue a state mandate to teach comprehensive sexuality education in schools, while the State Senate should pass legislation introduced by Senator Velmanette Montgomery (S1295) and the Healthy Teens Act proposed by the Family Planning Advocates of NY.**

The latter establishes a grant program for schools and communities to teach sexuality education. The grant program, which will be administered by the New York State Department of Health, should favor communities like the ones designated hot spots in this report, which experience high rates of teen pregnancy and sexually transmitted infections.

RECOMMENDED FEDERAL-LEVEL ACTIONS:

- **We, The Women’s HIV Collaborative of New York (WHCNY), along with our colleagues at The National Women and AIDS Collective (NWAC), urge Kevin Fenton, M.D., the director of the National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention at the Centers for Disease Control (CDC), to permanently adopt the incorporation of the “Female Presumed Heterosexual” category to obtain better surveillance outcomes for women—30-60% of whom fall into a “no identified risk” category.** Additionally, we urge the CDC to encourage local planning groups to incorporate a model such as the Dynamic Prioritization Model (DPM) developed by the Intervention, Behavioral Science, and Evaluation (IBSE) Committee of New York City’s Prevention Planning Group. The DPM takes into account the local epidemiology and the social determinants that put individuals at risk for acquiring HIV/AIDS such as homelessness, mental distress, etc. The combination of these two things would result in more accurate surveillance data which in turn would result in better funding for prevention efforts targeting women.

A **Geographic Analysis** of Women with HIV/AIDS in New York City



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A Geographic Analysis of Women with HIV/AIDS in New York City



INTRODUCTION

New York City is home to over 30,000 women living with HIV, 60 percent of who have experienced enough serious health complications that qualify for an AIDS diagnosis. Ten percent of the women with HIV in the United States live in NYC, making it the city with the largest population of women with HIV in the country. If all of these HIV-positive women were to come together and walk down Fifth Avenue, the crowd would approximate the swell of runners in the New York City Marathon. They could sell out Radio City Music Hall five times over and occupy over half the seats in Yankee Stadium. Women are dispersed across the city's five boroughs to such an extent that they are often invisible to policy makers and community members. The goal of the report is to call attention to and illustrate, visually and statistically, the unique geographic distribution of women and girls living with HIV/AIDS and other important intersecting socioeconomic conditions, such as poverty, household income, and incarceration.

Young women of color, ages 13 to 24, are also disproportionately impacted by HIV. According to the Centers for Disease Control and Prevention, black and Hispanic women make up less than one-fourth of women in the United States but represent more than three-fourths of reported AIDS cases. Black and Hispanic women account for 79 percent of all reported HIV infections among women ages 13 to 19 and 75 percent of HIV infections among women ages 20 to 24 in the U.S., although together they represent only about 26 percent of U.S. women in this age group. Additionally, an estimated one-half of all new HIV infections occur among people under the age of 25. As of June 2000, young black and Hispanic women, ages 13 to 24, account for 75 percent of new HIV infections among women in NYC.

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Young women affected by the epidemic are prey to the same socioeconomic factors as women 25 and older: factors for increased risk are poverty, domestic violence, and homelessness. The Youth Risk Behavior Survey (YRBS) data, a national survey conducted every two years by the CDC that assists educators and health professionals in determining the prevalence of health-risk behaviors as self-reported by New York City youths, reveals that the same neighborhoods that have high rates of sexually transmitted infections (STIs) and

unplanned pregnancies are the same neighborhoods that have high rates of HIV/AIDS. This implies that more bridging is necessary between agencies that provide reproductive health information and those that provide services around STIs and HIV/AIDS.

At-risk and infected women and girls continue to suffer the consequences of built-in structural deficiencies in our current, inadequately integrated systems of care. Typically, sexual and reproductive health services and HIV/AIDS prevention and health care, are organized and delivered through separate systems of care, by different sets of providers who are often not only disconnected from one another but are also unconnected or at best poorly connected to the mainstream health care system and to other systems of care that serve the same women.

Ten percent
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The characteristics of lower risk young women include having two parents at home with whom they can talk openly about sex, attending a good school, feeling hopeful about the future, being involved in extra-curricular activities and having high self-esteem. The fact that there are always going to be many young women who do not live in low-risk situations reinforces the need for comprehensive sex education in schools as well as after-school programs that will provide constructive activities for young people. (Young Women of Color HIV/AIDS Coalition, forthcoming report 2009).

The first section of this report provides a statistical overview of HIV/AIDS in NYC. The maps in the second section provide a city-wide geographical view of the issue and larger-scale context and understanding. The third section explains the methodology used to identify hot spots in NYC as a whole and in each of the four most populated boroughs (Manhattan, the Bronx, Brooklyn, and Queens). It describes how these hot spots were selected and how the definition of a hot spot varies by geographic location. The fourth section provides a detailed data overview of all of the hot spots, both on a citywide scale and separately within each borough. This section offers detailed and powerful information about each of the hot spots that can be used to plan, locate or improve services, apply for grant funding, and better understand the multiple components that make up the realities of women living with HIV/AIDS.

SECTION 1: OVERVIEW OF HIV/AIDS IN NYC

Table 1 (next page) gives a summary of 2006 HIV/AIDS statistics from the New York City Department of Health and Mental Hygiene. In that year, 3,745 people in NYC were diagnosed with HIV and 3,672 were diagnosed with AIDS. At the end of 2006, nearly 100,000 people in NYC were living with HIV or AIDS. Thirty percent were women, 77 percent were black and Hispanic, 31 percent lived in Manhattan, 72 percent were over 40 years old, and 62 percent had AIDS.



A Geographic Analysis of Women with HIV/AIDS in New York City

Table 1: REPORTED HIV/AIDS DIAGNOSES AND REPORTED PERSONS LIVING WITH HIV/AIDS (PLWHA) AS OF 12/31/2006, NYC (ALL PEOPLE)

Data Source: A (SEE PAGE 25)

	HIV Diagnoses, 2006		AIDS Diagnoses, 2006		PLWHA, 12/31/06*	
	Count	%	Count	%	Count	%
TOTAL	3,745	100	3,672	100	98,861	100
SEX						
Male	2,729	72.9	2,551	69.5	68,858	69.7
Female	1,016	27.1	1,121	30.5	30,003	30.3
RACE/ETHNICITY						
Black	1,899	50.7	1,801	49	44,703	45.2
Hispanic	1,148	30.7	1,141	31.1	31,369	31.7
White	611	16.3	649	17.7	20,622	20.9
Asian/Pacific Islander	74	2	56	1.5	1,251	1.3
Native American	9	0.2	8	0.2	97	0.1
Other/unknown	4	0.1	17	0.5	819	0.8
AGE GROUP (YEARS)						
0-12	13	0.3	2	0.1	814	0.8
13-19	168	4.5	64	1.7	1,556	1.6
20-29	899	24	400	10.9	6,177	6.2
30-39	1,091	29.1	937	25.5	19,341	19.6
40-49	973	26	1,323	36	38,719	39.2
50-59	449	12	687	18.7	24,200	24.5
60+	152	4.1	259	7.1	8,054	8.1
BOROUGH OF RESIDENCE						
Manhattan	1,078	28.8	1,093	29.8	30,167	30.5
Brooklyn	975	26	995	27.1	24,482	24.8
Bronx	829	22.1	856	23.3	21,502	21.7
Queens	578	15.4	450	12.3	13,577	13.7
Staten Island	66	1.8	63	1.7	1,750	1.8
Unknown/outside NYC	219	5.8	215	5.9	7,383	7.5
TRANSMISSION RISK						
Men who have sex with men	1,449	38.7	1,085	29.5	29,532	29.9
Injection drug use history	248	6.6	522	14.2	20,915	21.2
Heterosexual	848	22.6	787	21.4	17,206	17.4
Perinatal	12	0.3	45	1.2	2,451	2.5
Other	1	0	4	0.1	378	0.4
Unknown	1,187	31.7	1,229	33.5	28,379	28.7
CLINICAL STATUS						
HIV (non-AIDS)	N/A	N/A	N/A	N/A	37,272	37.7
AIDS	N/A	N/A	N/A	N/A	61,589	62.3

* = people living with HIV or AIDS

Table 2 (below) provides NYC's HIV/AIDS data by gender. This analysis provides valuable insight into the differences between men and women with HIV/AIDS. One of the most striking differences (see highlighted cells in the table) is the fact that, compared with men, a greater percentage of women are black and living in Brooklyn or the Bronx. Although the majority of HIV-positive men are also black and living in Brooklyn or the Bronx, there is more racial and geographic variation with a larger portion of the male population described as white and living in Manhattan. Routes of transmission vary by gender: the highest risk category among women is heterosexual sex, while men who have sex with men comprise largest risk category for men.

Table 2: REPORTED PEOPLE LIVING WITH HIV/AIDS AS OF 12/31/2006, NYC (FEMALE DATA COMPARED TO MALE DATA)

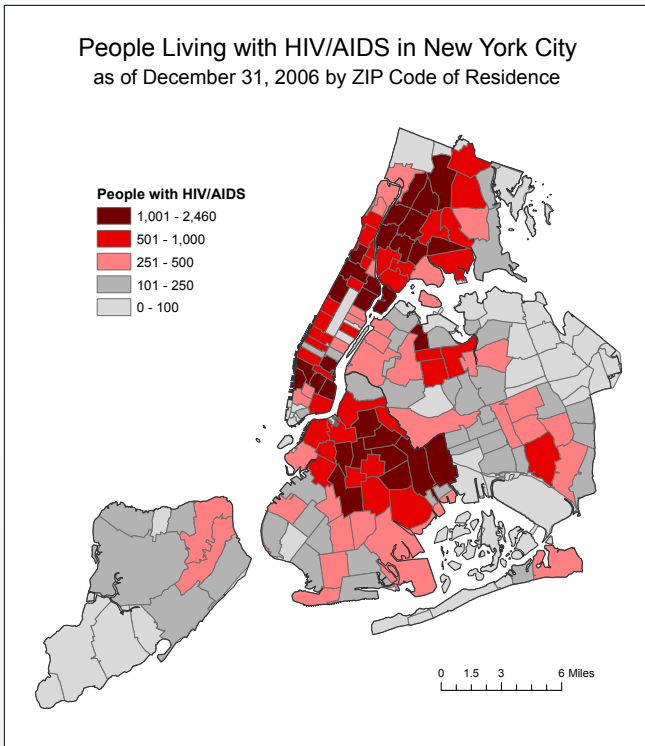
Data Source: A (SEE PAGE 25)

	Females LWHA*, 12/31/06		Males LWHA*, 12/31/06	
	Count	%	Count	%
TOTAL	30,003	100	68,858	100
RACE/ETHNICITY				
Black	17,526	58.4	27,177	39.5
Hispanic	9,427	31.4	21,942	31.9
White	2,564	8.5	18,058	26.2
Asian/Pacific Islander	244	0.8	1,007	1.5
Native American	26	0.1	71	0.1
Other/unknown	216	0.7	603	0.9
AGE GROUP (YEARS)				
0-12	438	1.5	376	0.5
13-19	744	2.5	812	1.2
20-29	2,179	7.3	3,998	5.8
30-39	6,368	21.2	12,973	18.8
40-49	11,837	39.5	26,882	39
50-59	6,494	21.6	17,706	25.7
60+	1,943	6.5	6,111	8.9
BOROUGH OF RESIDENCE				
Manhattan	6,001	20	24,166	35.1
Brooklyn	9,250	30.8	15,232	22.1
Bronx	8,721	29.1	12,781	18.6
Queens	4,078	13.6	9,499	13.8
Staten Island	661	2.2	1,089	1.6
Unknown/outside NYC	1,292	4.3	6,091	8.8
TRANSMISSION RISK				
Men who have sex with men	N/A	N/A	29,532	42.9
Injection drug use history	6,040	20.1	14,875	21.6
Heterosexual	12,141	40.5	5,065	7.4
Perinatal	1,255	4.2	1,196	1.7
Other	178	0.6	200	0.3
Unknown	10,389	34.6	17,990	26.1
CLINICAL STATUS				
HIV (non-AIDS)	12,049	40.2	25,223	36.6
AIDS	17,954	59.8	43,635	63.4

* = living with HIV or AIDS

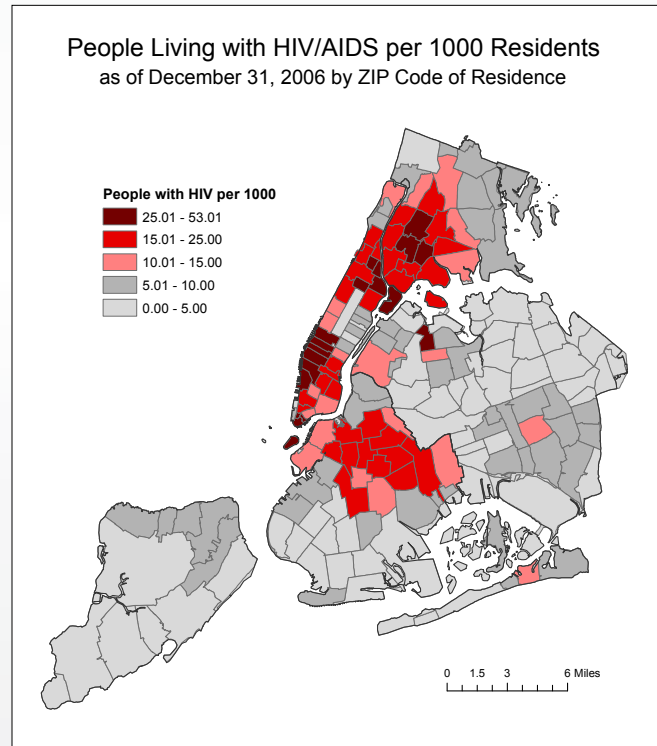
SECTION 2: GEOGRAPHIC ANALYSIS OF HIV/AIDS IN NEW YORK CITY

Map 1 and **Map 2** (below) show the geographic distribution of HIV/AIDS cases in NYC by ZIP code. **Map 1** is a "count" map that shows the total number, or count, of cases per ZIP code. **Map 2** is a "per capita" map that shows the "per 1000" rate of cases in each ZIP code. Count maps are very important for understanding where in the city most people with HIV reside. However, count maps offer a somewhat distorted comparison of different areas of the city because ZIP codes with larger populations are likely to have more HIV/AIDS cases. Per capita maps are more useful in understanding the impact of the disease in proportion to the total population (in short they show the percentage of people living with HIV in a given area). In creating the per capita map, data for each ZIP code is divided by the population of that ZIP code. For example, if a ZIP code has 600 HIV/AIDS cases and a population of 30,000 people, the rate would be 600 divided by 30,000 or 0.02 HIV/AIDS cases per person. To make the numbers easier to understand, this number is multiplied by 1,000 to get the rate per 1,000 people as shown in **Map 2**.



Map 1: ALL PEOPLE LIVING WITH HIV/AIDS (COUNT)

Data Source: B (SEE PAGE 25)



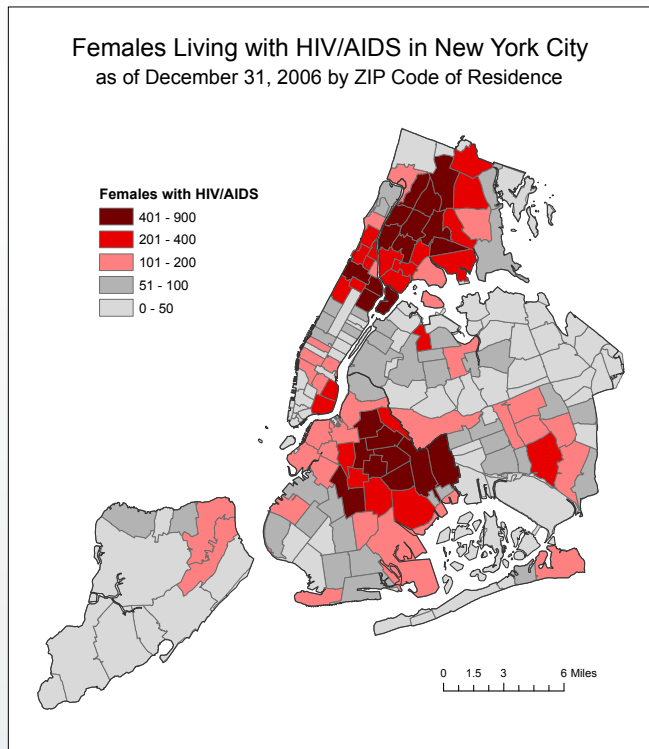
Map 2: ALL PEOPLE LIVING WITH HIV/AIDS (PER 1000)

Data Source: B (SEE PAGE 25)

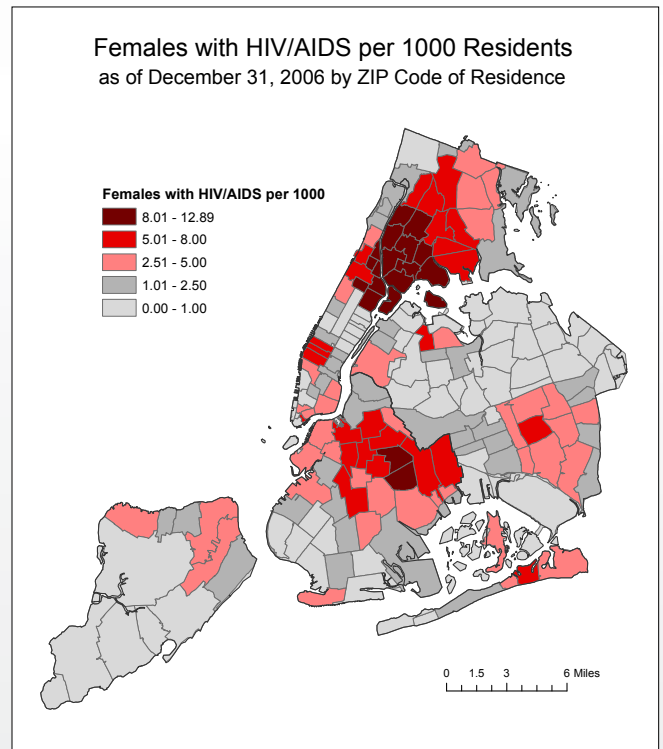
...areas with high concentrations of HIV-positive women also tend to be non-white, high poverty areas with high concentrations of people being sent to prison and adults without high school diplomas.

Map 1 also illustrates that the highest numbers of people living with HIV/AIDS in NYC are clustered in four regions: central and east Brooklyn, lower Manhattan, northern Manhattan and the central Bronx. These are the places we would expect to have the highest numbers because they are also the places with the highest residential population concentrations.

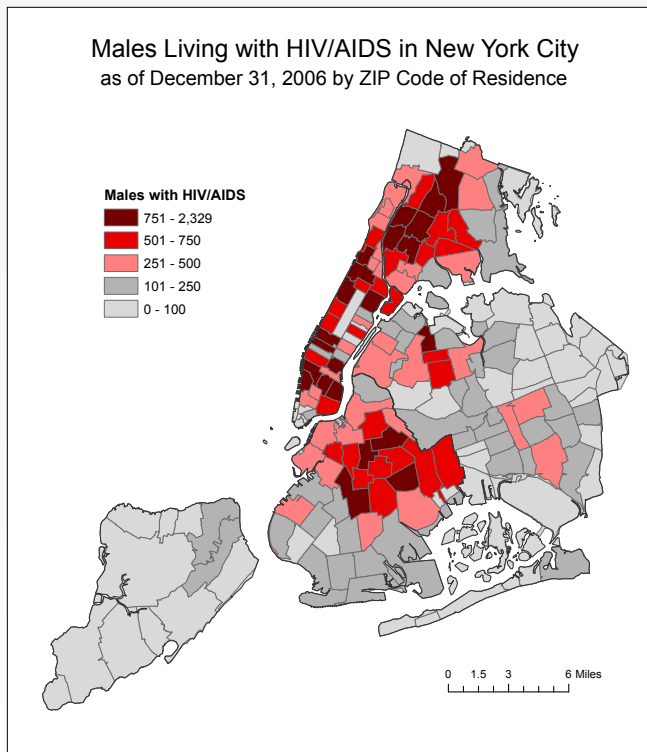
As discussed previously, it's easier to understand where people living with HIV/AIDS are disproportionately over represented, **Map 2** which shows what ZIP codes contain the highest rates per 1000 adult residents. Most of the same areas still emerge, but within those areas we find smaller, well-defined pockets where both high volume and high rates prevail: those are the hot spots.



Map 3: FEMALES WITH HIV/AIDS (COUNT)
Data Source: B (SEE PAGE 25)

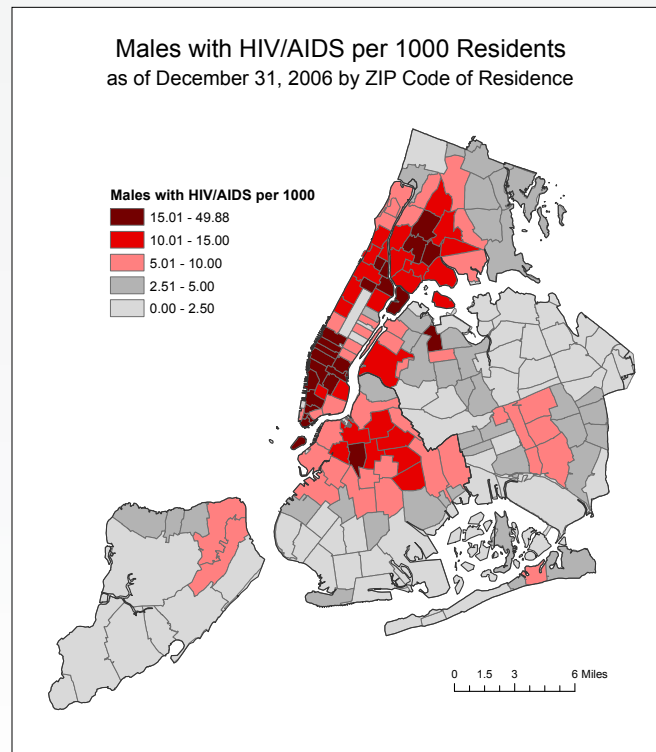


Map 4: FEMALES WITH HIV/AIDS (PER 1000)
Data Source: B (SEE PAGE 25)



Map 5: MALES WITH HIV/AIDS (COUNT)

Data Source: B (SEE PAGE 25)



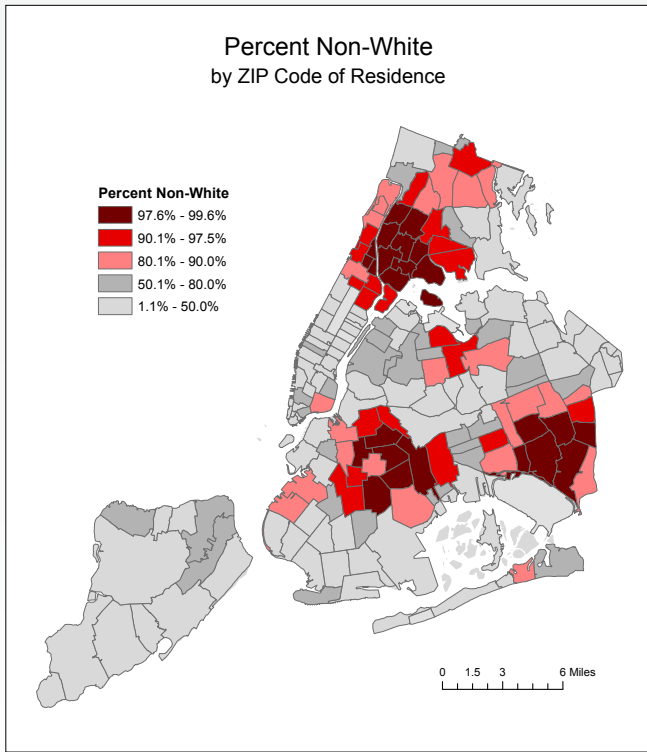
Map 6: MALES WITH HIV/AIDS (PER 1000)

Data Source: B (SEE PAGE 25)

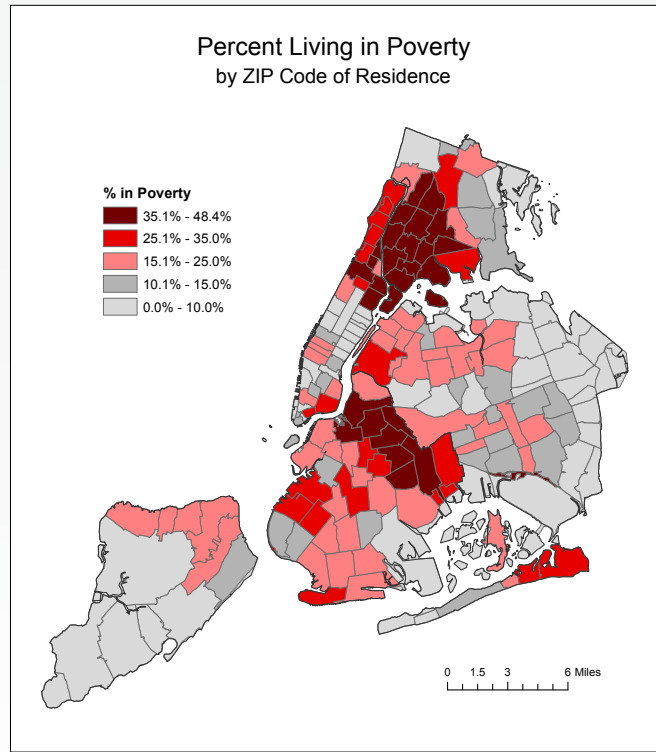
Maps 3 and **4** provide the geographic distribution of females with HIV/AIDS, while **Maps 5** and **6** show the distribution of males with HIV/AIDS. These maps, especially the per capita maps, illustrate that males are much more concentrated in lower Manhattan than females, while females have high concentrations in central Brooklyn and the Bronx. Queens and Staten Island have relatively few HIV/AIDS cases when compared with the other three boroughs.

Maps 7 through **10** show the distribution of a variety of different socio-economic indicators across the city. Comparing **Maps 3** and **4** with **Maps 7** through **10** reveals that areas with high concentrations of HIV-positive women also tend to be non-white, high poverty areas with high concentrations of people being sent to prison and adults without high school diplomas. **Map 8** (Percent living in Poverty) and **Map 3** (Females Living with HIV/AIDS) are nearly identical. While there are similarities between **Maps 5** and **6** (Males Living with HIV/AIDS) and the socio-economic maps, particularly

Poor women of color are disproportionately infected with HIV.



Map 7: PERCENT NON-WHITE
Data Source: B (SEE PAGE 25)



Map 8: PERCENT LIVING IN POVERTY
Data Source: B (SEE PAGE 25)

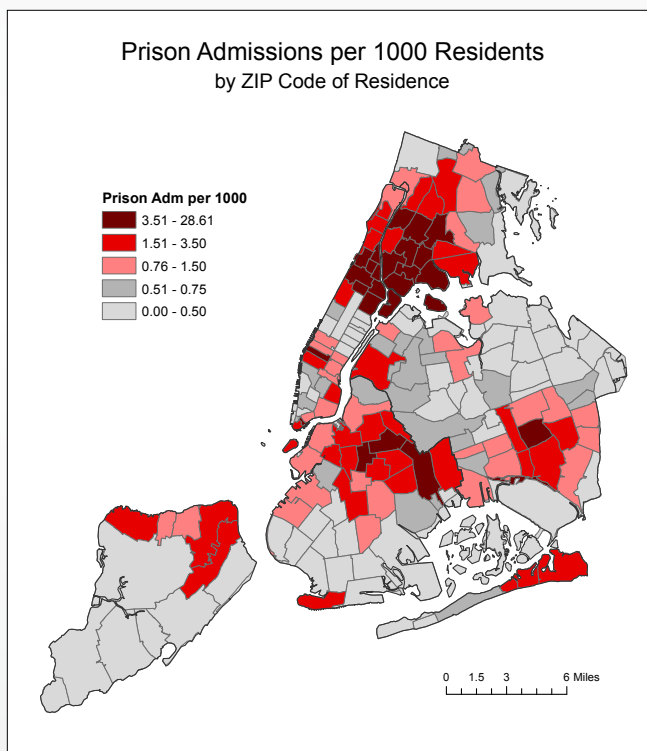
in the Bronx, there is also considerable variation between these geographic distributions. These maps highlight the fact that while both HIV-positive men and women in NYC live in low-resource communities, women reside almost exclusively in these environments while men are also significantly represented in the more affluent neighborhoods of Manhattan.

Indeed, the HIV burden among women in the US and in NYC is not distributed equally across age, race, or socio-economic class. Poor women of color are disproportionately infected with HIV: in 2005, over 66 percent of the women diagnosed with HIV in the U.S. were black, and fully 64 percent of the women living with HIV had annual incomes below \$10,000 (Centers for Disease Control and Prevention, 2007; Kaiser Family Foundation, 2008). In NYC 58 percent of HIV-positive women are black and 31 percent are Hispanic (New York City Department of Health and Mental Hygiene, 2007).

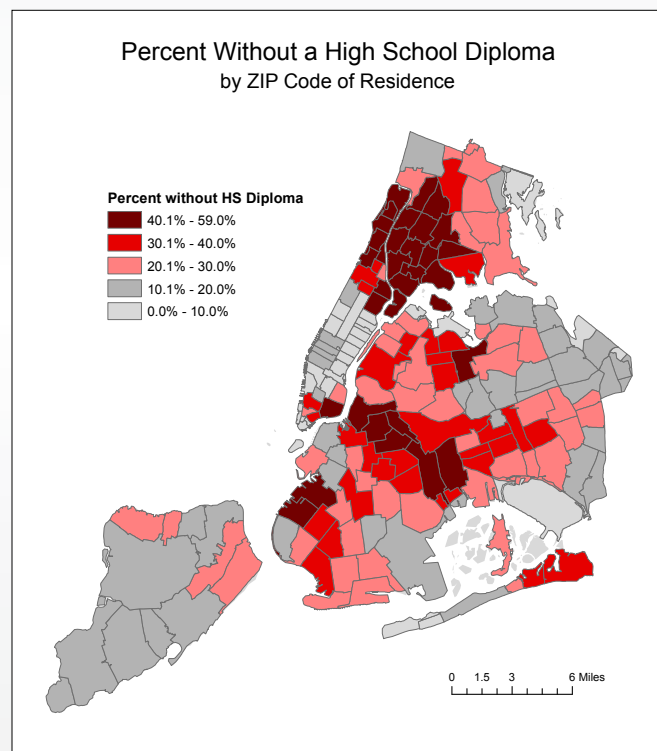
HIV-positive women in NYC report experiencing high rates of interpersonal violence as children and adults (Simoni & Cooperman, 2000), illicit drug use (Sharpe, Lee, Nakashima, Elam-Evans, & Fleming, 2004), homelessness (Aidala et al., 2006) and depression (Morrison et al., 2002). Given the overlap between the geographic distribution of women with HIV and

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negative socio-economic indicators, these facts come with little surprise. While violence, drug use, homelessness and depression are certainly not inevitable in the stressful, low-resource communities where these women live, women with HIV are particularly vulnerable to these negative occurrences because of the multiple oppressions, including the stigma of living with HIV, which they experience. Community based services can play a crucial role in reducing the harms that can arise in these environments. Support groups, case management, housing support, and gender-specific programming help HIV-positive women to reduce their mental health problems and improve access to social services and health care (Kenagy et al., 2003; Schrimshaw, 2002; Sikkema, Hansen, Meade, Kochman, & Lee, 2005; Simoni et al., 2005). Therefore, it is important to locate services in locations that are readily accessible to HIV-positive women. Section 3 describes how the maps were used to further hone in on the hot spots where women with HIV/AIDS are most concentrated and Section 4 illustrates where support services are located in relationship to these hot spots.



Map 9: PRISON ADMISSIONS PER 1000 RESIDENTS
Data Source: B (SEE PAGE 25)



Map 10: PERCENT WITHOUT A HIGH SCHOOL DIPLOMA
Data Source: B (SEE PAGE 25)

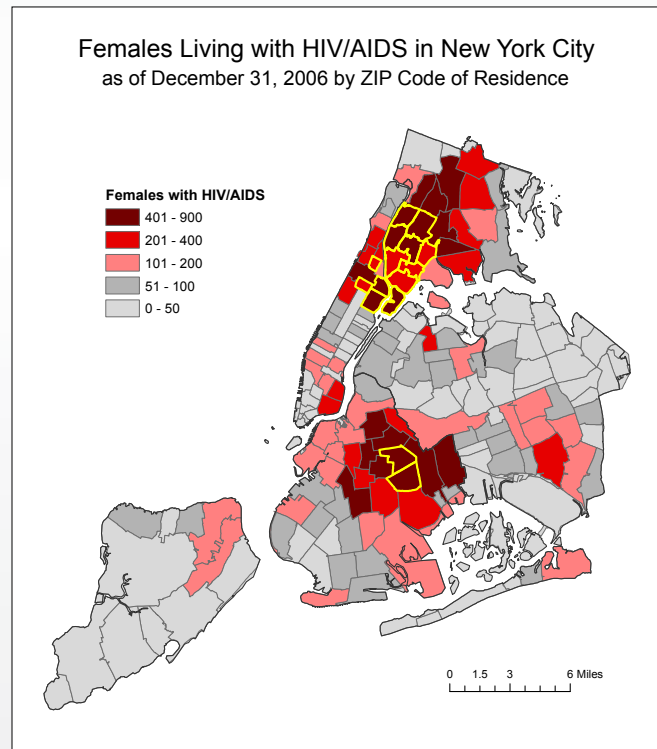
SECTION 3: WOMEN WITH HIV/AIDS: HOT SPOT SELECTION CRITERIA

Section 3 of this report profiles the hot spots, or areas with the highest concentration of women with HIV/AIDS, in NYC as a whole and each of the boroughs. This section describes how these hot spots were chosen and why these areas in particular merit detailed analysis.

As described earlier, there is a significant difference between maps showing the number (count) of HIV/AIDS cases in each ZIP code and maps showing the per capita rates of HIV/AIDS. Even though each of these approaches has limitations, each can also be extremely valuable. The nature of the question being asked determines which type of map is preferable. "Count maps" show where most people in the city with HIV reside, but offer a somewhat distorted comparison of different areas of the city because ZIP codes with larger populations are likely to have more HIV/AIDS cases. "Per capita" maps are more

Table 3: SELECTED NEW YORK CITY ZIP CODES
Data Source: A (SEE PAGE 25)

ZIP	Borough	Count	Per 1000
10456	Bronx	900	11.71
10457	Bronx	745	10.76
11226	Brooklyn	720	6.77
11212	Brooklyn	705	8.27
10452	Bronx	669	9.32
11207	Brooklyn	665	7.72
10453	Bronx	633	8.23
10029	Manhattan	615	8.10
11221	Brooklyn	557	7.40
10458	Bronx	545	7.01
11233	Brooklyn	531	8.49
11206	Brooklyn	510	7.35
10467	Bronx	476	5.04
10472	Bronx	446	6.94
11208	Brooklyn	445	5.08
10468	Bronx	433	5.50
10460	Bronx	421	7.87
11213	Brooklyn	418	6.40
10027	Manhattan	416	7.50
10035	Manhattan	413	12.89
11216	Brooklyn	406	7.17
10462	Bronx	386	5.35
11203	Brooklyn	382	4.55
10459	Bronx	367	9.37
10025	Manhattan	345	3.55
10451	Bronx	344	8.39
10030	Manhattan	336	12.81
10026	Manhattan	334	10.86
10031	Manhattan	331	5.49
11236	Brooklyn	331	3.44
10454	Bronx	328	9.37
10455	Bronx	317	8.46
11225	Brooklyn	311	4.87
11238	Brooklyn	309	6.29
10473	Bronx	303	5.40
10466	Bronx	300	4.37



Map 11: SELECTED NYC ZIP CODES
Data Source: B (SEE PAGE 25)



A Geographic Analysis of Women with HIV/AIDS in New York City

useful in understanding the impact of the disease in proportion to the total population (in short, they show the percentage of people living with HIV in a given area). However, the math used to create these per capita maps can result in areas with very few people but incredibly high rates of infection. Consequently, a combination of both count and per capita criteria were used to select these hot spots of women with HIV/AIDS in NYC and in each of the boroughs.

Since each area is unique, different hot spot selection criteria were used for each location. In creating the per capita map, data for each zip code are divided by the population of that ZIP code. For example, if a ZIP code has 600 HIV/AIDS cases and a population of 30,000 people, the rate would be 600 divided by 30,000 or 0.02 HIV/AIDS cases per person. To make the numbers easier to understand, this number can be multiplied by 1,000 to get the rate per 1,000 people. The city-wide criteria include: count greater than 300 and per 1000 rate greater than 8.0. All the ZIP codes that met these criteria are shaded gray in Table 3 (left) and highlighted in yellow on **Map 11**. These areas will be profiled in detail in the next section of this report.

DATA SOURCES FOR MAPS

(A) New York City and Borough HIV/AIDS Statistics

New York City HIV/AIDS Annual Surveillance Statistics, 2006. New York: New York City Department of Health and Mental Hygiene, 2007. Updated November 27, 2007. Accessed July, 2008 at <http://www.nyc.gov/html/doh/html/ah/hivtables.shtml>.

(B) New York City ZIP Code HIV/AIDS Statistics

New York City HIV/AIDS Annual Surveillance Statistics, 2006. New York: New York City Department of Health and Mental Hygiene, 2007. Updated November 27, 2007. Specific ZIP Code level data was generously provided by the Department of Health and Mental Hygiene for this research project.

(C) Census Data

Census of Population and Households Summary File 3, 2000. U.S. Census Bureau. Washington, DC. <http://www.census.gov/main/www/cen2000.html>.

(D) Prison Admissions Data

New York State Prison Admissions, 2003. New York State Division of Criminal Justice Services (DCJS).

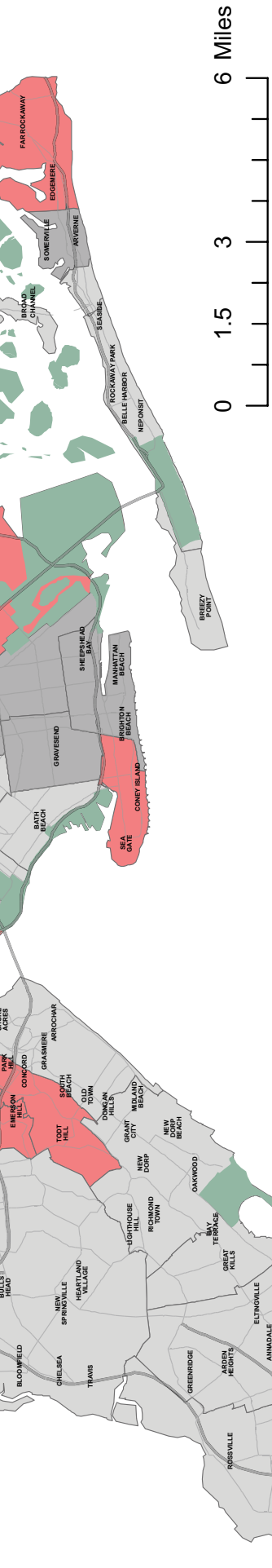


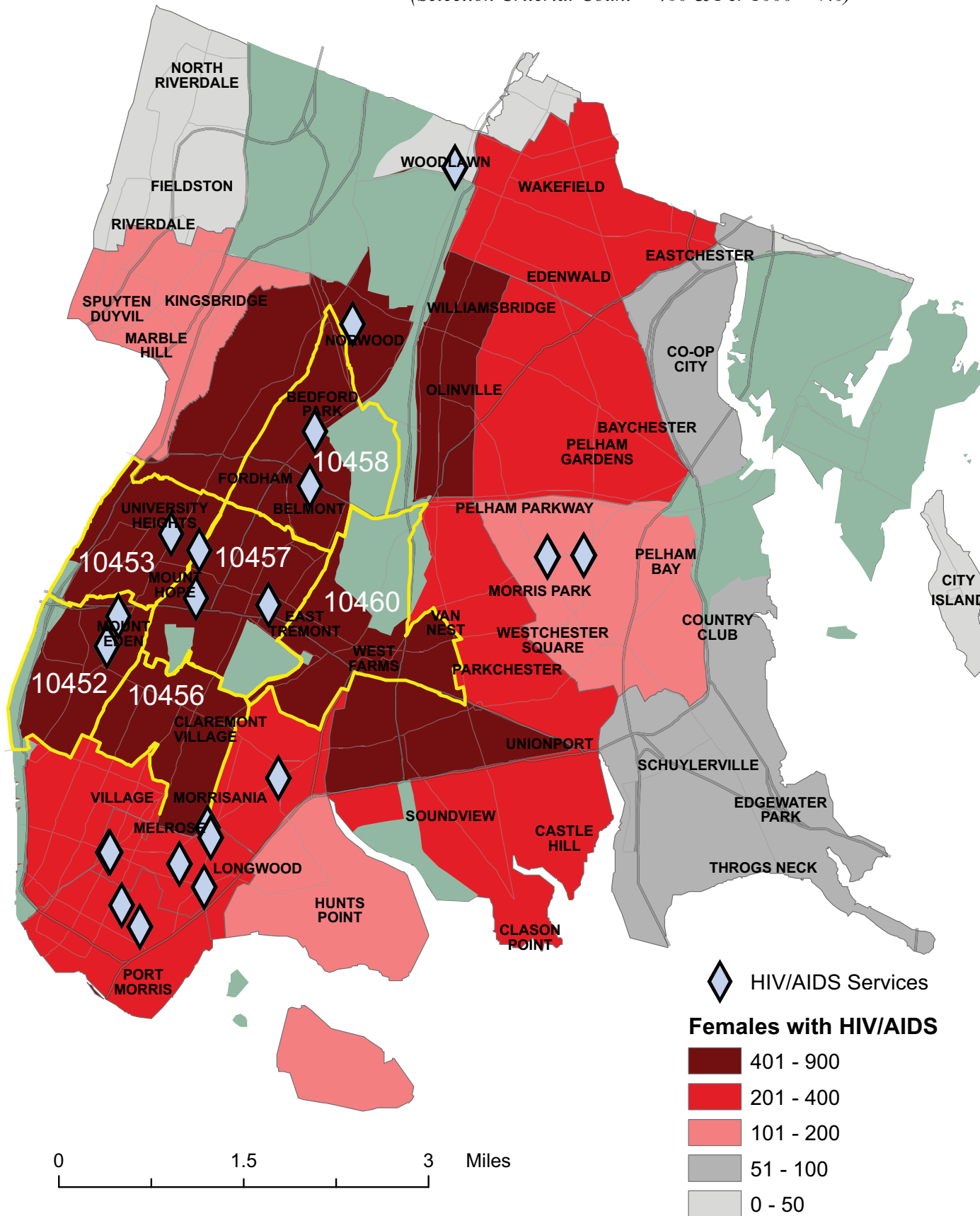
Table 4: Detailed data for Hot Spots of Females with HIV/AIDS by New York City ZIP Codes

	10456	10457	11212	10452	10453	10029	11233	10035	10459	10451	10030	10026	10454	10455
Females with HIV/AIDS 2006	900	745	705	669	633	615	531	413	367	344	336	334	328	317
.....per 1000	11.71	10.76	8.27	9.32	8.23	8.10	8.49	12.89	9.37	8.39	12.81	10.86	9.37	8.46
Black	569	361	598	376	353	297	456	282	170	160	277	280	127	120
Hispanic	309	350	85	280	264	287	56	116	183	178	46	44	193	183
White	20	31	16	9	14	27	12	12	11	6	10	9	1	11
Age 0 to 12	21	17	12	18	14	8	8	8	1	1	7	1	12	1
Age 13 to 29	112	69	66	49	72	63	58	30	25	42	45	30	39	28
Age 30 to 45	412	357	302	336	289	264	247	199	199	140	140	155	143	156
Age 46 to 59	295	260	283	227	230	238	194	158	122	129	122	117	110	114
Age 60+	60	42	42	39	48	42	24	18	16	29	22	27	24	14
Females L WHA 2001	777	666	584	564	510	550	466	369	320	311	295	292	308	273
.....% Change '01 to '06	15.83	11.86	20.72	18.62	24.12	11.82	13.95	11.92	14.69	10.61	13.90	14.38	6.49	16.12
Males with HIV/AIDS	1171	1134	854	982	769	1094	666	744	652	525	489	596	479	478
.....per 1000	15.23	16.37	10.02	13.68	10.00	14.41	10.84	23.21	16.64	12.80	18.64	19.38	13.68	12.75
Population 2000	76,868	69,259	85,232	71,802	76,928	75,919	62,568	32,052	39,174	41,021	26,239	30,760	35,012	37,482
% Male	45.70	46.61	43.85	46.64	46.02	46.35	42.82	50.01	46.22	44.88	46.00	46.69	47.08	46.40
% Female	54.30	53.39	56.15	53.36	53.98	53.65	57.18	49.99	53.78	55.12	54.00	53.31	52.92	53.60
Median Household Income	\$16,664	\$19,233	\$20,839	\$20,606	\$21,109	\$22,232	\$22,754	\$14,896	\$17,498	\$20,307	\$17,970	\$22,491	\$14,271	\$19,389
Per Capita Income	\$9,641	\$10,113	\$10,666	\$9,033	\$10,047	\$14,558	\$11,862	\$10,457	\$9,667	\$11,268	\$12,725	\$13,924	\$8,831	\$9,403
% Black	51.11	36.80	84.78	34.92	41.44	34.56	87.00	49.89	31.24	45.75	82.34	74.20	29.61	27.86
% Hispanic	50.44	61.63	14.03	65.33	59.84	57.49	12.63	48.66	71.69	54.59	16.63	21.44	73.93	74.16
% Living in Poverty	44.93	42.55	38.28	41.34	40.04	35.88	37.14	43.71	44.76	38.49	39.74	34.65	48.41	40.68
% Non-White or Hispanic	99.13	98.35	99.51	98.58	98.59	92.81	99.17	95.73	98.94	97.93	98.73	96.08	99.36	97.95
% No High School Diploma	50.41	49.78	39.89	49.04	46.35	44.29	34.46	50.03	53.51	44.82	35.71	35.19	59.02	56.04
Prison Admissions 2003	364	304	243	207	286	392	210	300	214	156	203	252	174	149
.....per 1000	4.74	4.39	2.85	2.88	3.72	5.16	3.36	9.36	5.46	3.80	7.74	8.19	4.97	3.98

Data Sources: B, C (see page 25)

Map 13: Hot Spots of Females with HIV/AIDS by Bronx ZIP Codes

(Selection Criteria: Count > 400 & Per 1000 > 7.0)



Data Sources: A, B, C (see page 25)

Table 5: Detailed data for Hot Spots of Females with HIV/AIDS by Bronx ZIP Codes

	ZIP Code	10456	10457	10452	10453	10458	10460
HIV/AIDS Data	Females with HIV/AIDS 2006	900	745	669	633	545	421
per 1000	11.71	10.76	9.32	8.23	7.01	7.87
	Black	569	361	376	353	244	190
	Hispanic	309	350	280	264	280	216
	White	20	31	9	14	18	11
	Age 0 to 12	21	17	18	14	9	6
	Age 13 to 29	112	69	49	72	48	46
	Age 30 to 45	412	357	336	269	277	214
	Age 46 to 59	295	260	227	230	182	121
	Age 60+	60	42	39	48	29	34
	Females LWHA 2001	777	666	564	510	439	367
% Change '01 to '06	15.83	11.86	18.62	24.12	24.15	14.71
	Males with HIV/AIDS	1171	1134	982	769	828	546
per 1000	15.23	16.37	13.68	10.00	10.66	10.20
Census and Prison Data	Population 2000	76,868	69,259	71,802	76,928	77,699	53,505
	% Male	45.70	46.61	46.64	46.02	46.92	46.14
	% Female	54.30	53.39	53.36	53.98	53.08	53.86
	Median Household Income	\$16,664	\$19,233	\$20,606	\$21,109	\$22,072	\$19,517
	Per Capita Income	\$9,641	\$10,113	\$9,033	\$10,047	\$10,415	\$9,772
	% Black	51.11	36.80	34.92	41.44	22.49	34.91
	% Hispanic	50.44	61.63	65.33	59.84	59.58	64.52
	% Living in Poverty	44.93	42.55	41.34	40.04	39.42	39.75
	% Non-White or Hispanic	99.13	98.35	98.58	98.59	86.21	96.89
	% No High School Diploma	50.41	49.78	49.04	46.35	44.39	46.08
	Prison Admissions 2003	364	304	207	286	221	193
per 1000	4.74	4.39	2.88	3.72	2.84	3.61

Table 6: Female HIV/AIDS Diagnoses and Females Living with HIV/AIDS (FLWHA) as of 12/31/2006, The Bronx

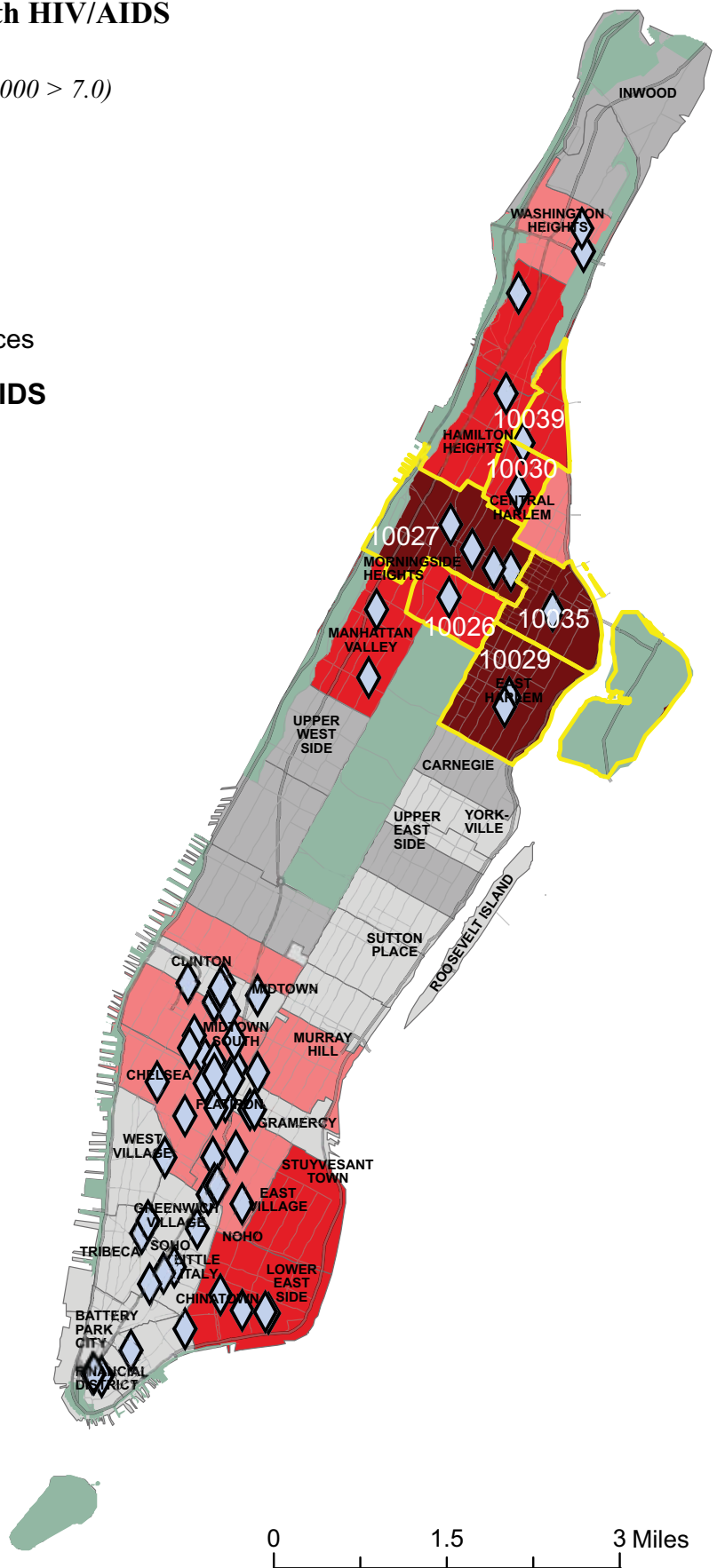
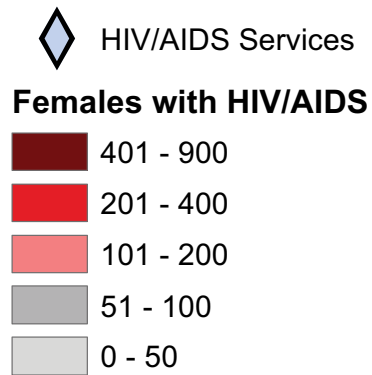
	HIV Diagnoses, 2006		AIDS Diagnoses, 2006		FLWHA*, 12/31/06	
	Count	%	Count	%	Count	%
TOTAL	310	100	346	100	8,721	100
RACE/ETHNICITY						
Black	166	53.5	173	50	4,406	50.5
Hispanic	136	43.9	157	45.4	3,913	44.9
White	6	1.9	13	3.8	335	3.8
Asian/Pacific Islander	*	*	*	*	24	0.3
Native American	*	*	*	*	8	0.1
Other/unknown	0	0	0	0	35	0.4
AGE GROUP (YEARS)						
0-12	*	*	0	0	158	1.8
13-19	21	6.8	9	2.6	222	2.5
20-29	70	22.6	37	10.7	677	7.8
30-39	85	27.4	106	30.6	1,935	22.2
40-49	78	25.2	126	36.4	3,463	39.7
50-59	40	12.9	47	13.6	1,723	19.8
60+	14	4.5	21	6.1	543	6.2
TRANSMISSION RISK						
Injection drug use history	14	4.5	43	12.4	1,746	20
Heterosexual	190	61.3	151	43.6	3,252	37.3
Perinatal	*	*	6	1.7	397	4.6
Other	0	0	0	0	40	0.5
Unknown	104	33.5	146	42.2	3,286	37.7
CLINICAL STATUS						
HIV (non-AIDS)	N/A	N/A	N/A	N/A	3,703	42.5
AIDS	N/A	N/A	N/A	N/A	5,018	57.5

* = females living with HIV or AIDS

Cells representing 1-5 person(s) are marked with an asterisk (*).

Map 14: Hot Spots of Females with HIV/AIDS by Manhattan ZIP Codes

(Selection Criteria: Count > 200 & Per 1000 > 7.0)



Data Sources: A, B, C (see page 25)

Table 7: Detailed data for Hot Spots of Females with HIV/AIDS by Manhattan ZIP Codes

	ZIP Code	10029	10027	10035	10030	10026	10039
HIV/AIDS Data	Females with HIV/AIDS 2006	615	416	413	336	334	220
per 1000	8.10	7.50	12.89	12.81	10.86	10.10
	Black	297	322	282	277	280	185
	Hispanic	287	78	116	46	44	29
	White	27	13	12	10	9	1
	Age 0 to 12	8	1	8	7	1	1
	Age 13 to 29	63	35	30	45	30	26
	Age 30 to 45	264	188	199	140	155	100
	Age 46 to 59	238	158	158	122	117	73
	Age 60+	42	30	18	22	27	17
Females LWHA 2001	550	384	369	295	292	191	
.....% Change '01 to '06	11.82	8.33	11.92	13.90	14.38	15.18	
Males with HIV/AIDS	1094	806	744	489	596	306	
.....per 1000	14.41	14.54	23.21	18.64	19.38	14.04	
Census and Prison Data	Population 2000	75,919	55,449	32,052	26,239	30,760	21,792
	% Male	46.35	47.60	50.01	46.00	46.69	43.66
	% Female	53.65	52.40	49.99	54.00	53.31	56.34
	Median Household Income	\$22,232	\$23,150	\$14,896	\$17,970	\$22,491	\$17,370
	Per Capita Income	\$14,558	\$16,769	\$10,457	\$12,725	\$13,924	\$11,298
	% Black	34.56	52.91	49.89	82.34	74.20	79.31
	% Hispanic	57.49	23.51	48.66	16.63	21.44	19.57
	% Living in Poverty	35.88	35.49	43.71	39.74	34.65	39.66
	% Non-White or Hispanic	92.81	82.03	95.73	98.73	96.08	98.81
	% No High School Diploma	44.29	30.48	50.03	35.71	35.19	40.13
Prison Admissions 2003	392	306	300	203	252	162	
.....per 1000	5.16	5.52	9.36	7.74	8.19	7.43	

Table 8: Female HIV/AIDS Diagnoses and Females Living with HIV/AIDS (FLWHA) as of 12/31/2006, Manhattan

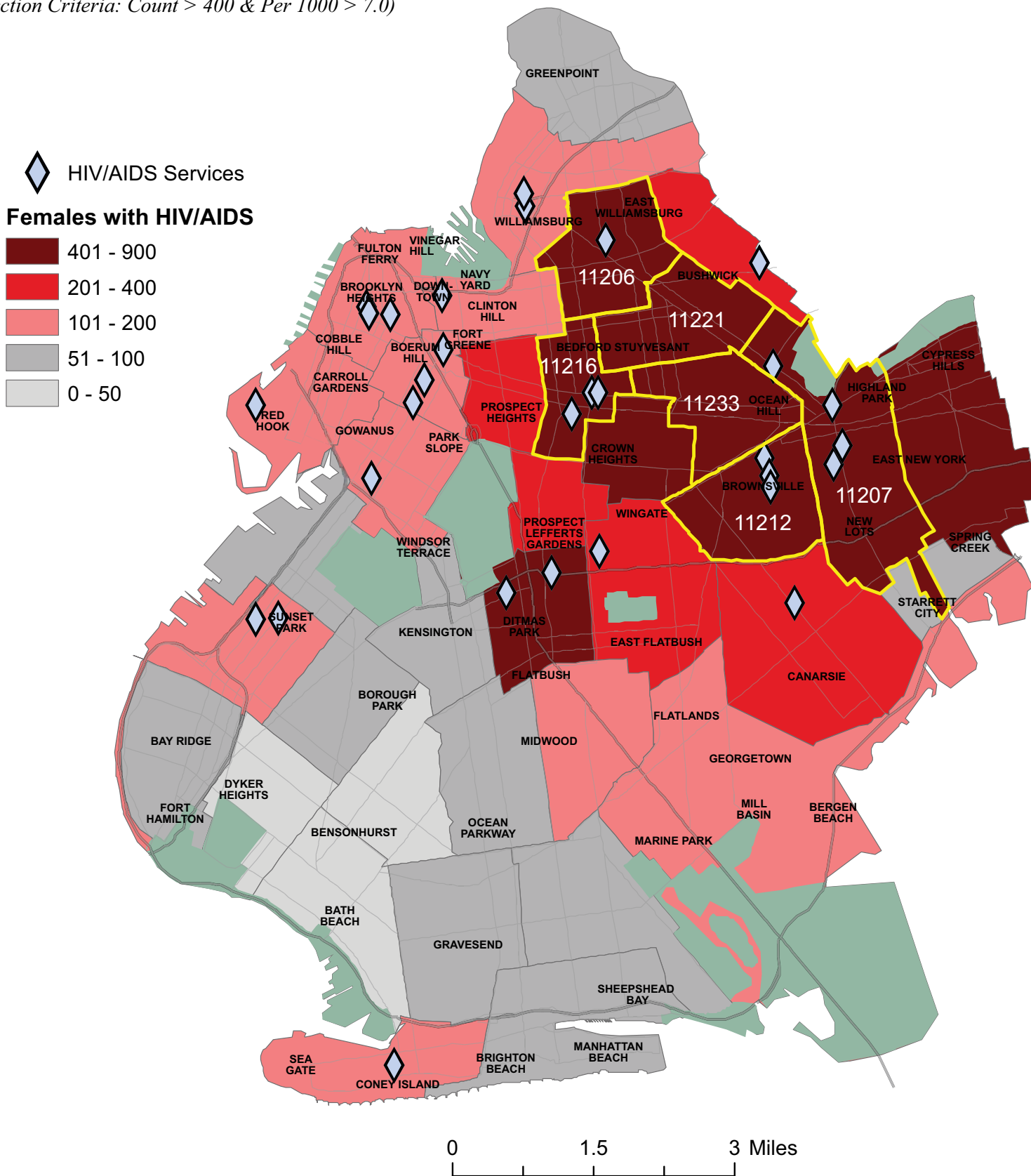
	HIV Diagnoses, 2006		AIDS Diagnoses, 2006		FLWHA*, 12/31/06	
	Count	%	Count	%	Count	%
TOTAL	181	100	236	100	6,001	100
RACE/ETHNICITY						
Black	111	61.3	129	54.7	3,385	56.4
Hispanic	53	29.3	78	33.1	1,854	30.9
White	16	8.8	26	11	647	10.8
Asian/Pacific Islander	0	0	*	*	47	0.8
Native American	0	0	0	0	*	*
Other/unknown	*	*	*	*	64	1.1
AGE GROUP (YEARS)						
0-12	*	*	0	0	73	1.2
13-19	10	5.5	*	*	149	2.5
20-29	41	22.7	23	9.7	357	5.9
30-39	52	28.7	51	21.6	1,203	20
40-49	51	28.2	93	39.4	2,426	40.4
50-59	18	9.9	49	20.8	1,371	22.8
60+	7	3.9	17	7.2	422	7
TRANSMISSION RISK						
Injection drug use history	6	3.3	28	11.9	1,486	24.8
Heterosexual	113	62.4	124	52.5	2,282	38
Perinatal	*	*	*	*	231	3.8
Other	0	0	*	*	32	0.5
Unknown	60	33.1	79	33.5	1,970	32.8
CLINICAL STATUS						
HIV (non-AIDS) N/A	N/A	N/A	N/A	N/A	2,298	38.3
AIDS N/A	N/A	N/A	N/A	N/A	3,703	61.7

* = females living with HIV or AIDS

Cells representing 1-5 person(s) are marked with an asterisk (*).

Map 15: Hot Spots of Females with HIV/AIDS by Brooklyn ZIP Codes

(Selection Criteria: Count > 400 & Per 1000 > 7.0)



Data Sources: A, B, C (see page 25)

Table 9: Detailed data for Hot Spots of Females with HIV/AIDS by Brooklyn ZIP Codes

	ZIP Code	11212	11207	11221	11233	11206	11216
HIV/AIDS Data	Females with HIV/AIDS 2006	705	665	557	531	510	406
per 1000	8.27	7.72	7.40	8.49	7.35	7.17
	Black	598	482	425	456	297	360
	Hispanic	85	165	121	56	199	33
	White	16	16	9	12	10	7
	Age 0 to 12	12	13	8	8	1	1
	Age 13 to 29	66	73	49	58	48	47
	Age 30 to 45	302	325	263	247	208	173
	Age 46 to 59	283	219	194	194	215	159
	Age 60+	42	35	43	24	35	23
	Females LWHA 2001	584	571	491	466	476	326
% Change '01 to '06	20.72	16.46	13.44	13.95	7.14	24.54
	Males with HIV/AIDS	854	717	893	666	705	767
per 1000	10.02	8.32	11.86	10.64	10.16	13.54
Census and Prison Data	Population 2000	85,232	86,194	75,309	62,568	69,385	56,635
	% Male	43.85	44.65	46.23	42.82	46.19	45.01
	% Female	56.15	55.35	53.77	57.18	53.81	54.99
	Median Household Income	\$20,839	\$24,163	\$22,305	\$22,754	\$18,661	\$25,135
	Per Capita Income	\$10,666	\$11,008	\$10,890	\$11,862	\$10,073	\$14,620
	% Black	84.78	65.99	64.64	87.00	34.90	87.77
	% Hispanic	14.03	34.28	34.61	12.63	54.34	8.03
	% Living in Poverty	38.28	36.19	36.37	37.14	40.82	28.96
	% Non-White or Hispanic	99.51	98.63	99.07	99.17	92.26	99.03
	% No High School Diploma	39.89	41.24	42.14	34.46	53.73	32.98
	Prison Admissions 2003	243	312	276	210	240	224
.....per 1000	2.85	3.62	3.66	3.36	3.46	3.96	

Table 10: Female HIV/AIDS Diagnoses and Females Living with HIV/AIDS (FLWHA) as of 12/31/2006, Brooklyn

	HIV Diagnoses, 2006		AIDS Diagnoses, 2006		FLWHA*, 12/31/06	
	Count	%	Count	%	Count	%
TOTAL	322	100	346	100	9,250	100
RACE/ETHNICITY						
Black	251	78	257	74.3	6,436	69.6
Hispanic	56	17.4	71	20.5	2,088	22.6
White	13	4	16	4.6	603	6.5
Asian/Pacific Islander	*	*	*	*	55	0.6
Native American	0	0	0	0	6	0.1
Other/unknown	0	0	0	0	62	0.7
AGE GROUP (YEARS)						
0-12	0	0	0	0	123	1.3
13-19	10	3.1	10	2.9	222	2.4
20-29	68	21.1	36	10.4	730	7.9
30-39	87	27	82	23.7	1,954	21.1
40-49	90	28	110	31.8	3,576	38.7
50-59	49	15.2	75	21.7	2,039	22
60+	18	5.6	33	9.5	606	6.6
TRANSMISSION RISK						
Injection drug use history	18	5.6	43	12.4	1,680	18.2
Heterosexual	223	69.3	184	53.2	3,876	41.9
Perinatal	0	0	6	1.7	365	3.9
Other	0	0	0	0	57	0.6
Unknown	81	25.2	113	32.7	3,272	35.4
CLINICAL STATUS						
HIV (non-AIDS)	N/A	N/A	N/A	N/A	3,689	39.9
AIDS	N/A	N/A	N/A	N/A	5,561	60.1

* = females living with HIV or AIDS

Cells representing 1-5 person(s) are marked with an asterisk (*).

Map 16: Hot Spots of Females with HIV/AIDS by Queens ZIP Codes

(Selection Criteria: Count > 100 & Per 1000 > 3.0)

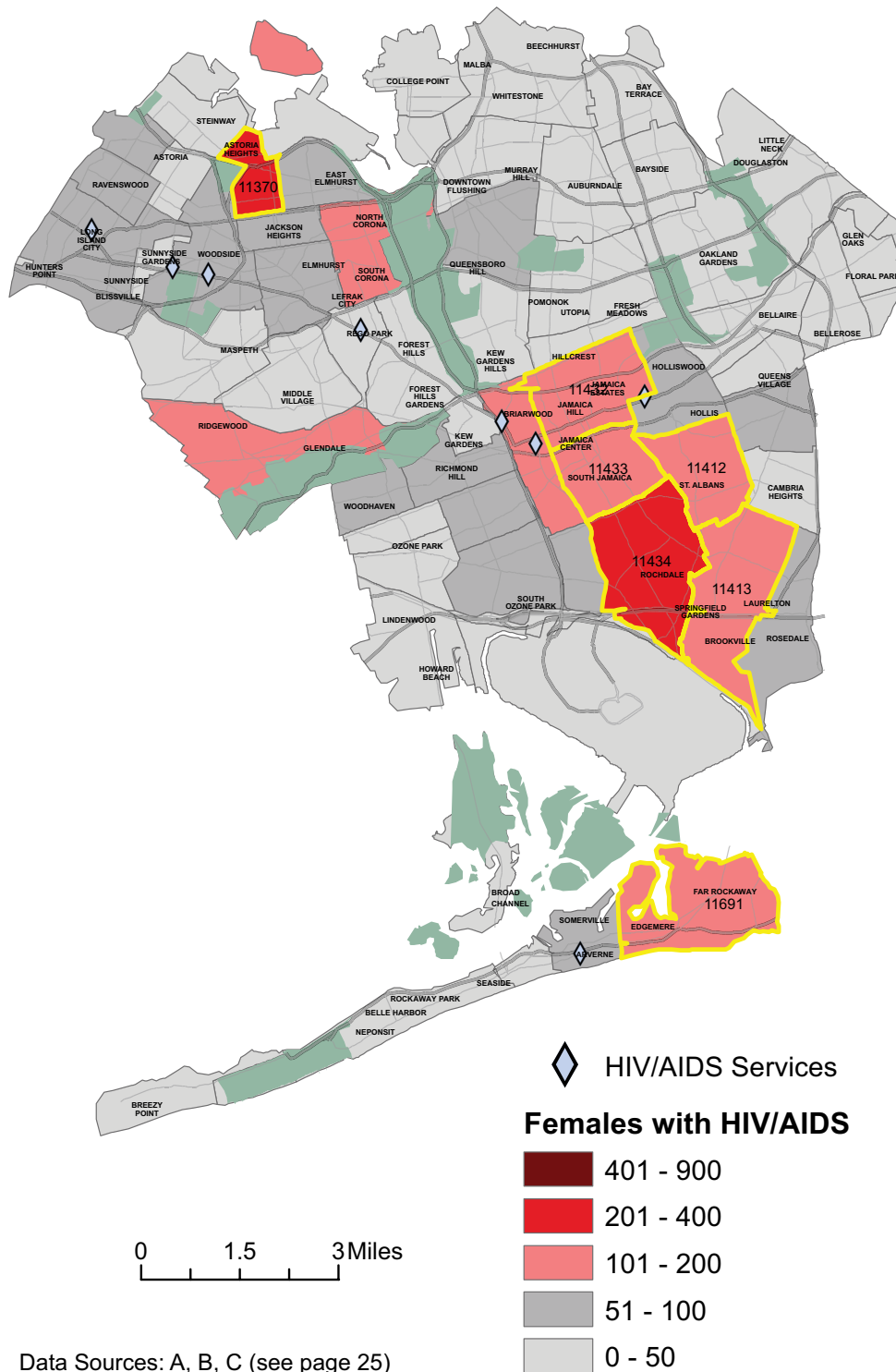


Table 11: Detailed data for Hot Spots of Females with HIV/AIDS by Queens ZIP Codes

	ZIP Code	11370	11434	11691	11432	11433	11412	11413
HIV/AIDS Data	Females with HIV/AIDS 2006	288	257	199	171	156	145	122
per 1000	6.79	4.33	3.55	3.02	5.45	3.84	3.01
	Black	161	235	147	126	132	131	103
	Hispanic	94	12	39	30	19	10	12
	White	29	7	9	10	1	1	1
	Age 0 to 12	0	1	1	1	1	1	1
	Age 13 to 29	21	24	19	19	11	15	13
	Age 30 to 45	175	112	80	61	68	55	48
	Age 46 to 59	81	95	81	76	55	66	47
	Age 60+	11	22	14	12	18	6	11
	Females LWHA 2001	252	215	169	136	132	123	86
% Change '01 to '06	14.29	19.53	17.75	25.74	18.18	17.89	41.86
	Males with HIV/AIDS	851	330	236	312	169	187	147
.....per 1000	20.05	5.56	4.21	5.52	5.90	4.95	3.62	
Census and Prison Data	Population 2000	42,443	59,350	56,020	56,551	28,628	37,759	40,553
	% Male	60.84	43.69	45.46	48.14	44.61	44.73	46.21
	% Female	39.16	56.31	54.54	51.86	55.39	55.27	53.79
	Median Household Income	\$44,429	\$43,133	\$27,820	\$42,414	\$31,869	\$48,536	\$56,726
	Per Capita Income	\$15,910	\$17,923	\$12,654	\$18,391	\$13,249	\$18,686	\$20,835
	% Black	18.98	90.65	51.29	22.68	86.58	93.94	89.63
	% Hispanic	37.01	4.86	22.70	24.89	8.13	3.38	5.17
	% Living in Poverty	13.14	13.87	26.36	14.98	24.49	11.74	6.85
	% Non-White or Hispanic	73.09	98.67	77.84	82.00	99.39	98.76	97.75
	% No High School Diploma	35.61	23.55	33.64	27.64	31.02	22.16	19.33
	Prison Admissions 2003	22	96	120	57	107	67	36
per 1000	0.52	1.62	2.14	1.01	3.74	1.77	0.89

Table 12: Female HIV/AIDS Diagnoses and Females Living with HIV/AIDS (FLWHA) as of 12/31/2006, Queens

	HIV Diagnoses, 2006		AIDS Diagnoses, 2006		FLWHA*, 12/31/06	
	Count	%	Count	%	Count	%
TOTAL	142	100	127	100	4,078	100
RACE/ETHNICITY						
Black	87	61.3	75	59.1	2,387	58.5
Hispanic	39	27.5	30	23.6	1,053	25.8
White	9	6.3	16	12.6	499	12.2
Asian/Pacific Islander	7	4.9	*	*	99	2.4
Native American	0	0	0	0	*	*
Other/unknown	0	0	*	*	36	0.9
AGE GROUP (YEARS)						
0-12	0	0	*	*	52	1.3
13-19	6	4.2	*	*	104	2.6
20-29	32	22.5	10	7.9	282	6.9
30-39	25	17.6	27	21.3	882	21.6
40-49	51	35.9	54	42.5	1,581	38.8
50-59	26	18.3	26	20.5	914	22.4
60+	*	*	7	5.5	263	6.4
TRANSMISSION RISK						
Injection drug use history	9	6.3	18	14.2	743	18.2
Heterosexual	88	62	75	59.1	1,890	46.3
Perinatal	0	0	*	*	166	4.1
Other	0	0	0	0	33	0.8
Unknown	45	31.7	32	25.2	1,246	30.6
CLINICAL STATUS						
HIV (non-AIDS)	N/A	N/A	N/A	N/A	1,566	38.4
AIDS	N/A	N/A	N/A	N/A	2,512	61.6

* = females living with HIV or AIDS

Cells representing 1-5 person(s) are marked with an asterisk (*).

**Map 17: Hot Spots of Females with HIV/AIDS
by Staten Island ZIP Codes**
(Selection Criteria: Count > 50 & Per 1000 > 2.0)

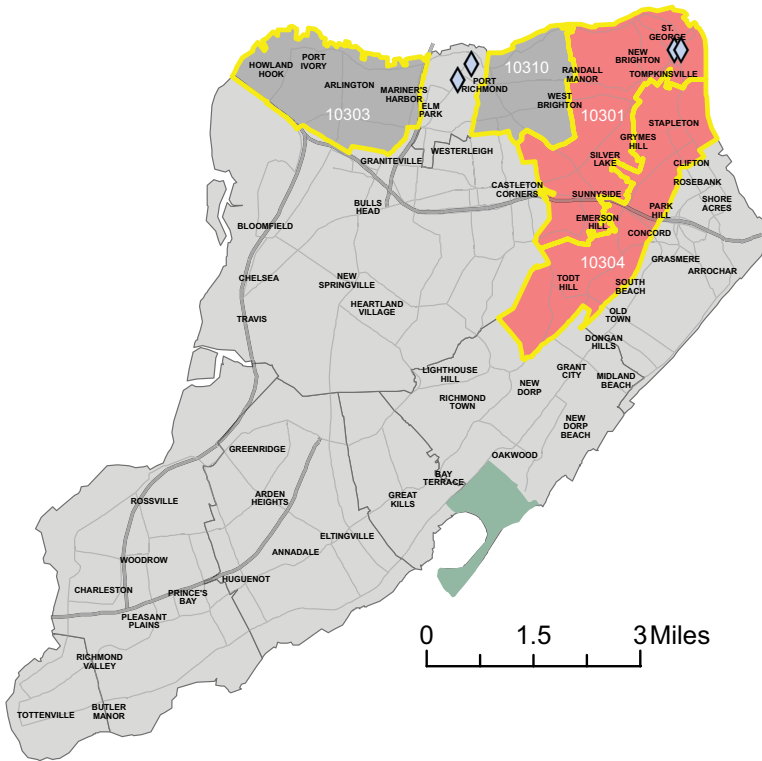


Table 13: Detailed data for Hot Spots of Females with HIV/AIDS by Staten Island ZIP Codes

	ZIP Code	10304	10301	10303	10310
HIV/AIDS Data	Females with HIV/AIDS 2006	142	110	66	51
per 1000	3.63	2.84	2.81	2.26
	Black	86	64	47	24
	Hispanic	31	21	13	16
	White	24	22	6	10
	Age 0 to 12	1	1	1	1
	Age 13 to 29	16	6	8	1
	Age 30 to 45	65	50	24	25
	Age 46 to 59	53	47	29	17
	Age 60+	6	1	1	1
Census and Prison Data	Females LWHA 2001	114	93	55	43
% Change '01 to '06	24.56	18.28	20.00	18.60
	Males with HIV/AIDS	208	205	78	86
per 1000	5.32	5.29	3.32	3.82
	Population 2000	39,079	38,762	23,521	22,524
	% Male	47.68	48.49	47.60	47.35
	% Female	52.32	51.51	52.40	52.65
	Median Household Income	\$41,041	\$45,620	\$42,463	\$46,198
	Per Capita Income	\$21,828	\$23,174	\$16,722	\$20,226
	% Black	29.71	24.30	34.04	21.33
	% Hispanic	18.01	18.88	28.00	19.07
	% Living in Poverty	20.98	15.25	17.37	15.36
% Non-White or Hispanic	55.10	50.76	68.02	45.72	
% No High School Diploma	23.41	18.77	23.36	19.08	
Prison Admissions 2003	65	63	45	26	
.....per 1000	1.66	1.63	1.91	1.15	

Geographic Information Systems (GIS) & HIV Literature Review



Women Living With **HIV** and **AIDS** in **NYC**

A MAPPING PROJECT
AND LITERATURE
REVIEW



Geographic Information Systems (GIS) & HIV Literature Review



Geographic Information Systems (GIS) allow many different types of data to be geographically viewed, organized and analyzed. This information can be used to make decisions about the allocation of health care and prevention interventions (Rushton, 2003). In the fight against HIV and AIDS, GIS technology has been used in several different ways, including for spatial epidemiology, locating high-risk populations and prevention services, and understanding barriers and access to care among people with HIV and AIDS.

SPATIAL EPIDEMIOLOGY

Spatial epidemiology involves using GIS to locate and track the progression of disease in order to identify epidemiological trends (Rushton, 2003). For example, military doctors at the Walter Reed Army Institute of Research used GIS to map the location of HIV-positive applicants for military service (Bautista, Sateren, Sanchez, Singer, & Scott, 2008). About 4,000 of the 5.7 million people who applied for US military service between 1985 and 2003 tested positive for HIV. The analysis found “significant regional differences in HIV among white and African American applicants;” white HIV-positive applicants came from urban areas in the southern parts of FL, TX and CA, and African American HIV-positive applicants were concentrated in the New York City metro area and parts of the south (Bautista, Sateren, Sanchez, Singer, & Scott, 2008, p. 613). This data reflected the increasing prevalence of HIV in the south and the impact of the disease on African Americans, who comprised 66% of the positive applicants. Scribner et al. (2008) used GIS to map HIV cases in New Orleans by risk category, including men who have sex with men (MSM), intravenous drug users (IDU), and high risk heterosexuals (HRH). The maps revealed the location of a core group, or “bull’s eye,” for each of these three high risk populations (Scribner et al., 2008, p. 204). Law et al (2004) created similar maps that identified core areas of sexually transmitted disease in North Carolina. In addition to these spatial methods, Scribner et al. (2008) used standard statistical analysis to test if these individuals’ common location could be explained by socio-demographic characteristics. They found that the spatial location of the IDUs and HRHs with HIV

The HIV Prevention Services [GIS] Database can be used to inform decisions about prevention services and their spatial relationships to each other and to high risk communities.

was explained largely by other variables or “shared social structures,” but location was significant for the MSMs, even after controlling for these other factors (Scribner et al., 2008, p. 212). These results suggest that for MSM in New Orleans, place, in and of itself, can elevate HIV risk.

PREVENTION: LOCATING HIGH RISK POPULATIONS

GIS has also been used to locate individuals who are at risk for HIV in order to make decisions about prevention services. For example, information collected from sex workers in Kenya was used to create GIS maps that identified truck stops with high volume of transactional sex (Ferguson & Morris, 2007). In Chicago, GIS was used to map the location of young black MSM and *HIV prevention services* tailored to MSM (Pierce, Miller, Morales, & Forney, 2007). These Chicago maps identified parts of the city where young black MSM were underserved. Researchers in Vancouver interviewed street-based sex workers about where they lived and worked, where they accessed syringes and health services and which areas they avoided because of concerns about personal safety and police harassment (Shannon et al., 2008). In answering these questions, the participants were asked to identify specific street sections or corners. GIS spatial analysis of this data found “significant geographic correlation between the health service and syringe availability core...and physical settings avoided due to violence and policing” (Shannon et al., 2008, p.143). Further statistical analysis found that this relationship between the service availability core and areas of avoidance was strongest for Aboriginal women, young women, and heavy drug users. This study suggests the need to provide more prevention services via mobile units in the perimeter areas where women work to decrease their risk of violence and harassment (Shannon et al., 2008).

Between 2001 and 2006, a multi-site US study about high-risk youth used “GIS-produced maps to determine a neighborhood and population of focus, recruit appropriate community partners...examine geographic and neighborhood characteristics that may contribute to HIV infection rates, and garner community support for the project’s objectives” (Geanuracos et al., 2007, p.1974). Each of the 15 sites mapped the rates of STDs (including HIV) among people aged 12 to 24 (by gender, race and year), homicide, and socio-economic census data (e.g. people living below the poverty line, female-headed households, high school graduates). Some maps reflected a single variable, while others overlaid more than one risk factor. This information was used to reach community consensus about this population’s most pressing service needs and design and target interventions accordingly (Geanuracos et al., 2007; Ziff et al., 2006).



ACCESS TO HIV/AIDS CARE

Finally, GIS has been used to map the number of HIV services in a given area in order to understand access to prevention and health care (McLafferty, 2003). The US Centers for Disease Control and Prevention (CDC) led a major initiative between 2000 and 2002 to map all the community-based organizations providing CDC-funded prevention services (Hanchette, Gibbs, Gilliam, Fogarty, & Bruhn, 2005). The CDC collected data about the location of these programs and their geographic service area(s). The resulting *HIV Prevention Services [GIS] Database* can be used to inform decisions about prevention services by describing their spatial relationships to each other and to high risk communities (Hanchette, Gibbs, Gilliam, Fogarty, & Bruhn, 2005). A similar GIS project was undertaken in Toronto, Canada (Fulcher & Kaukinen, 2005). The researchers mapped five categories of HIV service providers and found that emergency and prevention services were clustered together in one part of the city while medical and end-of-life services were more evenly distributed. The distance from the center of each census tract to the nearest HIV related service was also calculated in order to identify underserved areas of the city.

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Literature Review

on Issues Related to
Women with HIV/AIDS in
New York City



Women Living With **HIV** and **AIDS** in **NYC**

A MAPPING PROJECT
AND LITERATURE
REVIEW



Literature Review on Issues Related to **Women** with **HIV/AIDS** in **New York City**



INTRODUCTION

Half of the 34 million people living with HIV/AIDS worldwide are women (UNAIDS, 2007). In contrast, women in the United States are less likely to be infected than men: women comprise about 25% of the 1.2 million domestic cases of HIV (Kaiser Family Foundation, 2008). For many years the number of newly diagnosed cases of HIV hit a plateau at approximately 40,000 each year in the US and, in 2005, 27% of these cases were among women (Centers for Disease Control and Prevention, 2007). Employing new technology able to more accurately track new cases of HIV, the CDC issued revised numbers in 2008. The results were significantly higher, with approximately 53,600 adolescents and adults having been newly infected (Hall, Song, Rhodes; et al, 2008). The HIV burden among women in the US is not distributed equally across age, race, or socio-economic class. Young, African American and poor women are disproportionately infected with HIV: in 2005, over half of the women diagnosed with HIV in the U.S. were between the ages of 15-39, 66% were African American, and 64% of the women living with HIV have annual incomes below \$10,000 (Centers for Disease Control and Prevention, 2007; Kaiser Family Foundation, 2008). Most women with AIDS (73%) acquired HIV through high-risk heterosexual contact, the remainder were primarily infected through IV drug use (24%) (Kaiser Family Foundation, 2008).

New York State has the largest population of people with AIDS in the United States (Kaiser Family Foundation, 2008). The state also has the country's largest population of women, Blacks and Hispanics living with AIDS (Kaiser Family Foundation, 2008). The rates of HIV/AIDS among women in New York City approximate national averages but vary in terms of demographic distribution. In 2007, 30% of the 100,642 people known to be living with HIV/AIDS in New York City were women (New York City Department of Health and Mental Hygiene, 2008). While the percent of women with HIV in New York City who are African American reflects national figures (58% in 2006), there is a far larger representation of Hispanics: 31% of the New York City women living with the virus are Hispanic, versus 14% nationwide (Centers for Disease Control and Prevention, 2007; New York City Department of Health and Mental Hygiene, 2007). The female population of women with HIV/AIDS in New York is also much older than the national average: 83% were between 39 and 59 years old in 2006 (New York City Department of Health and Mental Hygiene, 2007). Still, AIDS was the leading cause of death among women in New York City aged 25-44 between 2000 and 2002 (Kerker, Kim, Mostashari, Thorpe, & Frieden, 2005). In terms of transmission categories, 39% of HIV-positive women report acquiring the disease through high-risk heterosexual contact and 21% attribute the infection to injection drug use (New York City Department of Health and Mental Hygiene, 2007). The remaining women report their transmission route as "unknown" (36%) and perinatal (4%) (New York City Department of Health and Mental Hygiene, 2007).

What challenges do women with HIV in New York City face? What are the needs of this population and what interventions have been successful in meeting these needs? In an effort

to answer these questions, this literature review summarizes the current research on women living with HIV in New York City and other major urban areas in the United States. Specifically, the review includes research that focuses exclusively on women or includes analysis based on gender. Academic databases were searched using the terms “woman/women” and “HIV” and “United States.” Because this summary focuses on women living with HIV, articles about prevention among high-risk women were not included unless they contain information about secondary prevention among women who are already infected (“prevention for positives”). Research was identified about the psychosocial issues (mental health, substance use, violence, abuse, spirituality, sexuality, stigma, family and children), medical concerns (co-morbidities, access to care, reproductive services) and structural factors (criminal justice systems, housing) to form a holistic picture of the issues that shape the lives of women and girls with HIV in New York City and beyond.

PSYCHOSOCIAL ISSUES

Mental Health

The literature reports high rates of mental health problems, ranging from distress to suicidal ideation, among women living with HIV/AIDS in the United States. For example, studies have found that rates of depression among women with HIV are four times higher than uninfected women (Morrison et al., 2002) and the general population (Simoni, Bu, Goodry, & Montoya, 2005). A 2005 study of HIV-positive women in New York City found that 26% had attempted suicide at least once since being diagnosed with HIV (Cooperman & Simoni, 2005). Studies have found that 50% of HIV-positive women experience some kind of psychiatric disorder (Dodds et al., 2004). Depression is experienced by about 15%, anxiety by 11%, and post-traumatic stress disorder (PTSD) by as much as 35% of all women with HIV (Dodds et al., 2004). Women’s identities as caregivers (versus people who receive care) and hesitation to disclose their HIV status are two gender specific barriers to mental health treatment (Schrimshaw, 2002).

Untreated, these mental health issues can interfere with women’s capacity to adhere to HIV treatment (Anaston et al., 2005; Cook et

Women in New
York City ...believe
[when] social
support is available
to them and/
or receive social
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friends and family
are less likely to be
depressed.



Literature Review on Issues Related to **Women with HIV/AIDS in New York City**

al., 2004) and access social support services (Catz, Gore-Felton, & McClure, 2002). However, interventions have been developed to help reduce mental health problems in this population. Surveys conducted with HIV-positive women in New York City found that women who feel a strong sense of belonging to a social network, have high levels of self-esteem, feel in control over their lives, experience low levels of social conflict, and believe social support is available to them and/or receive social support from friends and family are less likely to be depressed (Schrimshaw, 2002; Simoni et al., 2005). From this, support groups and efforts by AIDS service organizations to accommodate women have been effective in reducing mental health problems among HIV-positive women (Schrimshaw, 2002; Sikkema, Hansen, Meade, Kochman, & Lee, 2005; Simoni et al., 2005; Simoni & Cooperman, 2000). The high prevalence of mental health problems in this population suggests the need to more fully integrate psychiatric services into primary HIV care for women. The University of Miami reports on a successful project that locates mental health clinicians, including social workers and psychiatrists, directly inside the Obstetrics/Gynecology office that delivers care to women with HIV in order to facilitate client access to these services (Dodds et al., 2004).

While HIV-related medical problems and the unique bereavement, stigma, stress and anxiety issues among HIV-positive women certainly contribute to mental health problems in this population (amfAR, 2008; Cooperman & Simoni, 2005; Feist-Price & Wright, 2003; Sikkema et al., 2005; Simoni et al., 2005), many of their mental health problems relate to experiences of poverty, physical/sexual abuse, violence and substance use that are related, but distinct, from their HIV status. As Catz et al. (2002) explain, "The emotional effects of being HIV seropositive are compounded in these women, who may already be prone to high levels of anxiety and depression as a consequence of their low SES [socio-economic status]" (p. 58). Similarly, when researchers compared the psychological health of women in New York City before and after the advent of HAART they found was that the two groups of women had the same rates of mental health problems even though the women who had access to HAART had improved physical health outcomes (Siegel, Karus, & Dean, 2004). The authors explained the lack of difference in this way:

...a national study of HIV-positive women found that 66% had experienced some form of domestic violence in their lifetime and 31% had been sexually abused as children.

[W]omen in both samples, most of whom were socioeconomically disadvantaged, faced numerous other life stressors independently associated with depression (e.g. drug or alcohol addiction, violence,

poverty, being the sole caregiver of 1 or more dependent children), some of which posed a more imminent threat to their psychological and physical well-being than did HIV. Indeed many women who are at risk of contracting HIV or who are already infected do not view the disease as the most challenging stressor they confront (p. 1131).

Violence & Abuse

In fact, a national study of HIV-positive women found that 66% had experienced some form of domestic violence in their lifetime and 31% had been sexually abused as children (Cohen et al., 2000). A survey administered to HIV-positive women in New York City found even higher rates of interpersonal violence: 50% reported childhood abuse, 68% reported abuse during adulthood, 7% had been physically assaulted or raped in the last 90 days (Simoni & Cooperman, 2000). One national study found that some incidents of violence are related to HIV status: half of the women who reported domestic violence since their diagnosis indicated that this post-diagnosis violence was caused by their HIV status (Zierler et al., 2000). While HIV-positive men also report abuse and violence, rates of abuse are higher among HIV-positive women (Henny, Kidder, Stall, & Wolitski, 2007; Zierler et al., 2000).

Interventions to help women with HIV cope with histories of abuse and reduce the violence in their lives are important to improving their mental health, increasing their access to antiretrovirals (Pence et al., 2007) and building their ability to negotiate safer sex practices, including condom use (Lang, Salazar, Wingood, DiClemente, & Mikhail, 2007). While the literature has documented high rates of violence and articulated the need for systems of care “to address the HIV epidemic’s shift into poor, minority, and female populations” (Pence et al., 2007, p. 1114), there are few programs that specifically address this intersection of HIV status and histories of violence and abuse (Pence et al., 2007; Sikkema et al., 2004; Simoni & Ng, 2000; Zierler et al., 2000). In one such intervention, HIV-positive women participating in group therapy for survivors of childhood sexual abuse in New York City experienced significant improvement in trauma symptomology (Sikkema et al., 2004). The researchers credited this improvement to the skills for coping with stress that were taught to the group and the social support that the group members conveyed to each other.

Substance Use

Similarly, there is a need for substance abuse treatment programs that specifically target HIV-positive women (Von Unger & Collins, 2005). Women with HIV report high rates of substance use. Nationally and in New York City, 20% of the women living with HIV were infected through injection drug use (Centers for Disease Control and Prevention, 2007; New York City Department of Health and Mental Hygiene, 2007). Interviews with HIV-positive women living in urban areas between 1997 and 2000 found that in the preceding five years, 23% had used crack, 42% had used other drugs and 35% had never used drugs (Sharpe, Lee, Nakashima, Elam-Evans, & Fleming, 2004). An HIV diagnosis has different impacts on female drug users. For



Literature Review on Issues Related to **Women with HIV/AIDS in New York City**

some, the diagnosis can motivate them to stop using, for others, an HIV diagnosis will increase use, while others are too “caught up” in drug use to care about their HIV status (Von Unger & Collins, 2005). Medical professionals may be reluctant to prescribe antiretroviral medication to women who are actively using drugs because of concerns about adherence (Parsons, Rosof, Punzalan, & Di Maria, 2005; Sharpe et al., 2004). Research has found that HIV-positive women with histories of substance use are more likely to adhere to antiretroviral regimes when they are involved in drug treatment programs, irrespective of modality (Kapadia et al., 2008). From this, it is essential help HIV-positive women access drug treatment programs (Kapadia et al., 2008; Sharpe et al., 2004; Thorpe et al., 2004; Von Unger & Collins, 2005).

Research has found that HIV-positive women with histories of substance use are more likely to adhere to antiretroviral regimes when they are involved in drug treatment...

Family & Children

Family can be a strong source of psychosocial support for women living with HIV (Latham, Sowell, Phillips, & Murdaugh, 2001). A study of HIV-positive women in a Midwestern city found that while friends were more supportive on a day to day basis, the women’s perceptions of family support – the extent to which they felt family support existed, even when family did not live nearby and did not provide actual assistance – was correlated more strongly with the women’s mental health (anxiety, stress, depression, loneliness) than the friend’s support (Serovich, Kimberly, Mosack, & Lewis, 2001). For HIV-positive women, disclosing their HIV status is the first step towards gaining family support. Studies have found that while women approach disclosure with high levels of trepidation, most experience little or no regret after disclosure (Serovich, McDowell, & Grafsky, 2008). Women are mostly likely to disclose to female relatives, especially mothers and sisters, who they see regularly, live close to and with whom they experience high levels of relationship satisfaction (Serovich, Craft, & Hae-Jin, 2007). Women who feel devalued and discriminated against are less likely to disclose (Letteney & LaPorte, 2004). Disclosure to children can be particularly difficult but is critical to their planning and care (Letteney & LaPorte, 2004; Simoni & Davis, 2000). HIV-positive women are more likely to have children than HIV-positive men (60% vs. 18%) and are more likely to live with their children (76% vs. 34%) (Schuster et al., 2000).

In addition to hesitations about disclosure, there are other factors that inhibit HIV-positive women from accessing support from family. Many of their families face multiple stressors, including

interpersonal violence and drug use, which limit their ability to provide support (Latham et al., 2001). In addition, a national study found that “multiple HIV infections are remarkably common in families of HIV-positive women:” 35% of the HIV-positive participants had family members with HIV, most often a sibling or a husband (Fiore et al., 2001, p. 213). Creative programming is needed to assist women before, during and after disclosure and bolster the families of HIV-positive women, given the multiple stressors that they face, so that they might be a source of support to these women (Fiore et al., 2001; Latham et al., 2001; Serovich et al., 2007).

Sexuality/Prevention for Positives

Relationships with sexual partners are another key psychosocial issue for HIV-positive women: “The sexual and relational aspirations of HIV-positive women appear to mirror those of women generally and many women living with HIV continue to pursue these despite additional challenges” (Keegan, Lambert, & Petrak, 2005, p. 654). An eight year study of 389 HIV-positive women in New York City documented how the participants’ sexuality changed over time, alternating between periods of safe and unsafe sex, different types of sexual partnering, and shifting sexual orientations (Aidala, 2006). While the majority of HIV-positive women report being sexually active, they also report a range of sexual and relationship issues including lowered libido, reduced intimacy, fears of infecting partners and being re-infected by partners, relationship avoidance (which translates into more casual partners) and difficulties in sustaining condom use in long-term relationships (Keegan, Lambert, & Petrak, 2005).

As with family, disclosure is a major issue in sexual relationships. A study of 180 Black HIV-positive women in New York City found that “only half of the women and half of their network members discussed and disclosed an HIV status” (Miller, Korves, & Fernandez, 2007, p. 862). In other words, most of the women in this study did not disclose their HIV status to their partners, nor were they aware of their partners’ status. Similarly, research has found that women are often unaware of their male partners’ sexual histories: a national study found that while 13-34% of men who have sex with men reported also having sex with women, but only 6-14% of women reported having a bisexual partner (Montgomery, Mokotoff, Gentry, & Blair, 2003). These findings may explain why 36% HIV-positive women in New York City do not know the source of their HIV infection (New York City Department of Health and Mental Hygiene, 2007).

Especially in an environment where HIV-positive women may not be aware of their sexual partners’ HIV status or sexual history, it is important for them to practice safer sex in order to avoid transmitting the virus to others and reduce their own risk of re-infection. However, several studies, many of them conducted in New York City, have found low rates of condom use among HIV-positive women, with between 23% - 50% of participants reporting unprotected sex (Demmer, 2002; Kanouse, Collins, Miu, & Berry, 2005; Massad, Evans, Wilson et al., 2007; McGowan et al., 2004; Wilson et al., 2004; Wilson et al., 2006). Women who have been sterilized (Massad, Evans, Wilson et al., 2007), use oral contraceptives (Kanouse et al., 2005) or exchange sex for money or drugs (McGowan et al., 2004) are less



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likely to use condoms. Unstably housed women and women who use drugs are more likely to report exchanging sex for money (Aidala, Gunjeong, Garbers, & Chiasson, 2006). Condom use has declined as access to HAART has increased because women believe the medication reduces their risk of transmitting the virus (Demmer, 2002; Wilson et al., 2004). This research identifies the need to create culturally appropriate, on-going risk reduction counseling programs for HIV-positive women and their partners that take into account the impact of HAART, sterilization, housing instability, drug use and poverty on condom use.

Wingood et al. (2004) created a randomized controlled trial to test the impact of risk reduction group counseling on the sexual behavior of a predominately Black sample of HIV-positive women living in mid-size cities in Alabama and Georgia. The women's sexual behavior was measured six and twelve months after they participated in the four session intervention. The researchers found that the participants were less likely to report unprotected sex and experienced fewer bacterial STDs than a comparable group of women that had not received the intervention. The success of the program was attributed to the information transferred, the social support created among the group, and efforts to address gender-specific barriers to participation, including child care and transportation (Wingood et al., 2004). This example illustrates that interventions can help HIV-positive women reduce their sexual risk, especially when they are specifically tailored to meet women's circumstances and needs.

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MEDICAL CARE

Access to Care & Adherence

In addition to the psychosocial challenges of living with HIV, positive women obviously face a range of medical issues. The advent of antiretroviral (HAART) medication has reduced HIV symptoms and delayed the onset of AIDS, but access to medical care and these medications varies, with gender being a significant variable. "US women are less likely than men to have access to appropriate health care and to utilize services, including the latest antiretroviral drug therapies" (Burke, 2003, p. 452). A study of unstably housed people with HIV in New York City found that women were more likely to be hospitalized and identify an emergency department clinic as their usual location of care than men (Cunningham, Sohler, McCoy, Heller, &

Selwyn, 2005). A Chicago study found that HIV-positive men were more likely to use HIV medication than HIV-positive women (Kenagy et al., 2003). Many factors contribute to this inferior access including dissatisfaction with care (Burke, 2003), untreated drug use (Sharpe et al., 2004) and difficulties securing housing support and transportation (Kenagy et al., 2003). This research echoes the findings from the psychosocial research: providers must design systems of care that meet women's unique needs in order to fully engage them in services.

Co-morbidities

Women with HIV also experience a unique set of co-morbidities, or other non-HIV illnesses, when compared to HIV-positive men and HIV-negative women. The Women's Interagency HIV Study (WIHS) enrolled 2,628 women, 2,059 of whom were HIV-positive, between 1994 and 1995 and interviews them on a semiannual basis (Women's Interagency HIV Study, n/d). The WIHS study sites include New York City (two sites), Washington DC, Chicago, Los Angeles and San Francisco. The inclusion of high-risk non-infected women allows researchers to compare the health outcomes of HIV-positive and HIV-negative women. Analysis of this data has found that HIV-positive women were more likely to get a hysterectomy (Massad, Evans, Weber et al., 2007), and be diagnosed with anemia (Levine & Berhane, 2001) and cancer (Hessol et al., 2004) than HIV-negative participants. HIV-positive and HIV-negative women were equally likely to be overweight or obese (Mulligan et al., 2005). HIV-positive women had better dental health than their uninfected counterparts because of their access to dental services through HIV-specific funding (Shiboski et al., 2005). Other studies that have compared HIV-positive and HIV-negative women have found that positive women experience higher rates of pneumonia (Kohli et al., 2006) and syphilis (Chesson, Heffelfinger, Voigt, & Collins, 2005).

Pregnancy & Perinatal Transmission

Since the beginning of the epidemic, nearly 8,500 children in the United States have been infected perinatally: the virus was transmitted to them from their mother during pregnancy, childbirth or breastfeeding (Centers for Disease Control and Prevention, 2007). The number of babies infected perinatally each year has been reduced dramatically by prenatal protocols, including antiretroviral medications during pregnancy and cesarean delivery, which can reduce the vertical transmission rates to 2% or less (Centers for Disease Control and Prevention, 2007; "Cesarean delivery for HIV-positive women," 2000; Dominguez et al., 2003). Still, 67 cases of perinatal transmission were reported in 2005 (Centers for Disease Control and Prevention, 2007). Many states, including New York, developed mandatory prenatal HIV testing policies to identify HIV-positive women in need of prenatal care and reduce the number of HIV-positive infants ("Prenatal HIV testing and antiretroviral prophylaxis at an urban hospital in Atlanta, Georgia, 1997-2000," 2004; Sarnquist, Cunningham, Sullivan, & Maldonado, 2007; Webber et al., 2003). Concerns have been raised, however, about the lack of drug adherence among pregnant and post-natal HIV-positive women that can lead to drug resistance. In a



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study of 53 HIV-positive pregnant women residing in urban areas, including Brooklyn, NY, Ickovics et al. (2002) found that adherence was extremely low, especially postpartum. Adherence problems, during pregnancy and throughout the lifespan, may erode the ability of women to benefit from antiretroviral medications. For example, researchers in New York City recorded much higher rates of drug resistance (34% vs. 15%) among HIV-positive pregnant women between 1999-2001, compared to pregnant women with HIV between 1991-1994 (Welles, Bauer, Larussa, Colgrove, & Pitt, 2007).

Healthy pregnancies
are a very real option
for HIV-positive
women today

In spite of these resistance issues, healthy pregnancies are a very real option for HIV-positive women today. Pregnancy rates among women with HIV have steadily increased since 1997, especially among younger, healthier women who have access to HAART (Blair, Hanson, Jones, & Dworkin, 2004; Bryant et al., 2007; Craft, Delaney, Bautista, & Serovich, 2007). A multi-site study of over 2,000 HIV-positive pregnant women that began in 1989 found that 22% had at least one repeat pregnancy, and 23% of that subgroup had more than one repeat pregnancy (Bryant et al., 2007). Several studies have examined pregnancy decisions among HIV-positive women (Craft et al., 2007; Kirshenbaum et al., 2004; Siegel & Schrimshaw, 2001; Wilson et al., 2003). Craft et al. (2007) found that 26% of the 74 HIV-positive, urban, primarily African American, women who participated in their study had chosen to become pregnant since being diagnosed with HIV. These women weighed concerns about vertical transmission and their own personal health against their desire to have a child (Craft et al., 2007). Interestingly, “medical personnel were more influential upon the decision to terminate a pregnancy than the choice to become pregnant” (Craft et al., 2007, p. 933). Another similar study of HIV-positive, urban, primarily African American women found that perceived risk of vertical transmission and desire for motherhood factored heavily into the women’s pregnancy decisions (Kirshenbaum et al., 2004). Stigma, religious beliefs and attitudes of partners and health care providers also played a major role in pregnancy decision-making (Kirshenbaum et al., 2004).

Women’s concerns about vertical transmission in these studies suggest that they may not be adequately educated about the actual risks of pregnancy. Many factors could contribute to women’s misinformation on this issue including the possibility that reproductive “counseling may be complicated by health care provider opinions, expressed directly or indirectly, that may jeopardize a women’s ability to make independent and informed decisions” (Kirshenbaum et al., 2004, p. 112). More research is needed to understand opinions of medical professionals about pregnancy among HIV-positive women and how these are shaped by racism, classism and bias against drug users. Indeed, reproductive techniques that “safeguard the uninfected while providing effective, affordable care to the HIV-seropositive patient” are largely unavailable in the United States (one of the few programs that exists is at Columbia University Medical Center in New York City) suggesting some reluctance on the part of the medical profession, and/or society at large, to facilitate pregnancy among HIV-positive individuals (Sauer, 2003).

STRUCTURAL FACTORS

In addition to these psychosocial and medical issues, there are a range of structural factors that shape the lives of HIV-positive women including the criminal justice system, housing and social stigma. These external factors mediate women's quality of life and access to care and support systems. Research about these structural determinants of health suggests how social systems might be altered to improve health outcomes for HIV-positive women.

Criminal Justice Systems

National statistics. Since the 1980s, the number of women who are incarcerated has grown exponentially. There were 19,761 women incarcerated in State prisons in 1986 (Snell, 1994). By 1996, there were 74,730 women in State or Federal prison and by 2007 that number had grown to 115,308, or about 7% of the imprisoned population (Mumola & Beck, 1997; Sabol & Couture, 2008). Sixty percent (60%) of the women in State prison meet the criteria for drug dependence or abuse and 58% are serving time for non-violent drug, property or public order offenses (Bonczar, 2007; Mumola & Karberg, 2006). In 2006, 2.4% of the women (n=2,138) in state and federal prison were HIV-positive (Maruschak, 2008). There are nearly 100,000 women in jails on any given day (Sabol & Minton, 2008), over one million women on probation and nearly 96,000 women on parole. (Glaze & Bonczar, 2007). African American women are disproportionately impacted by the criminal justice system. Although African Americans comprise 13% of the U.S. population, 28% of female prisoners are Black (Sabol, Couture, & Harrison, 2007); Black women are incarcerated at a rate that is 3.7 times that of White women (Sabol & Couture, 2008).

New York statistics. In the state of New York, there are 2,821 women in prison, 23,700 women on probation and 3,100 women on parole (Correctional Association of New York, 2008). Eighty-four (84%) of the incarcerated women were convicted of non-violent offenses (Correctional Association of New York, 2008). The number of women who are incarcerated in New York State grew by more than 600% between 1973 and 2008, but these numbers have been on a decline and are down by about 25% since 1997 (Correctional Association of New York, 2008). Two-thirds of New York State inmates come from New York City (Correctional Association of New York, 2008).

New York State has the second largest population of female prisoners with HIV in the United States (Maruschak, 2008). In 2006, 350 female inmates in New York were known to be HIV positive, about 12% of the female inmate population (Maruschak, 2008). This rate of HIV infection among female prisoners is higher than among male prisoners of whom 6% are HIV-positive (Maruschak, 2008). HIV rates are higher in the New York City jail system: a 1999 study by the New York Department of Health found that 18% of the women entering the city's jails were HIV-positive; a lower rate, 7.3%, was found among men. (Correctional Association of New York, 2006)



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Research on HIV-positive women and incarceration explores programs and policies that will reduce the number of women who go to prison and tests interventions that promote continuity of care between the community and prisons. Freudenberg et al. (2007) studied a group of nearly 2,000 individuals that left New York City jails between 1997 and 2004. About one-third of the sample (n=704) were women and 10% of these women were HIV-positive. In general, these researchers found that female participants were more likely to be homeless, use drugs and have health problems than male participants. Women were also more likely to have been arrested for a drug related charge.

Their study of the re-entry outcomes highlights the gender, age and race differences among ex-prisoners and suggests that programs to meet these diverse needs must be tailored for each group. They concluded, “[M]any health and reentry programs for women in jail are still developed by men for a male model of needs, the problems women in this study experienced suggest the need for a more women-specific programs” (Freudenberg et al., 2007, p. 741). A study of HIV-positive inmates in Jacksonville, FL, reached the same conclusion (Lanier & Paoline, 2005). While the study found few differences in the male and females needs (housing, medical care, income support) there were significant behavioral differences. For example, men were more likely to abuse alcohol while women were more likely to have used crack (Lanier & Paoline, 2005). The authors concluded that “gender specific alcohol and drug interventions may be warranted” (Lanier & Paoline, 2005, p. 571).

Richie (2001) conducted interviews with 42 incarcerated and formerly incarcerated women. The article includes the following quote from an HIV-positive participant detained in an urban jail:

Each time [I go to jail], I just keep getting worse and worse because I can't keep up with all of the medicine I am supposed to be taking. Last time, I almost died...If I could just get some of this [medical problems] under control, then I could work on finding a place to live and finding a job. But I am just so sick all of the time now. (p. 373)

This quote speaks to the need to create community-based alternatives to incarceration programs and programs that allow criminally involved women to access seamless health care as they transition in and out of incarceration. In addition to improving health care outcomes, a multi-site study of HIV-positive and at-risk women in four urban areas, including New York City, found that “having a regular healthcare provider for more than 2 years...was significantly correlated with decreased risk of incarceration” (Sheu et al., 2002, p. 748).

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Rhode Island has developed a model program for identifying HIV positive inmates and linking them with health care both during incarceration and re-entry (Farley et al., 2000; Rich et al., 2001). Rhode Island requires that all jail and prison inmates be tested for HIV as part of a comprehensive program that includes posttest counseling, health education, substance abuse treatment, preventative medical care and referrals to community service providers (Farley et al., 2000). Between 1989 and 1994, 28% of all the women in Rhode Island who were diagnosed with HIV were identified through the prison testing program (Farley et al., 2000). Antiretroviral medication was well accepted by these women during their incarceration and 83% of them received follow up HIV care upon reentry, often with the same physician that had provided them care in prison (Farley et al., 2000). Case management services are also provided to facilitate access to housing and community based services (Rich et al., 2001). This program demonstrates that corrections can play a key role in reaching medically underserved populations, identifying HIV-positive individuals and linking them to care.

Housing

These studies about criminally involved HIV-positive women underscore the need for housing among people with HIV (Freudenberg et al., 2007; Lanier & Paoline, 2005; Rich et al., 2001; Richie, Freudenberg, & Page, 2001). Stable housing is key to promoting the health care and well-being of people with HIV (Aidala & Sumartojo, 2007; Cisneros, 2007). Only when basic needs, like housing, are met, can HIV-positive individuals focus on accessing medical care and meeting their treatment needs (Lanier & Paoline, 2005). Lack of housing promotes considerable instability in people's lives that may increase their risk behavior and reduce their medical adherence (Aidala, Cross, Stall, Harre, & Sumartojo, 2005; Elifson, Sterk, & Theall, 2007). A study of HIV-positive people living in New York between 1994 and 2002 found that among women, homelessness was associated with unsafe sex and exchanging sex for money or drugs (Aidala et al., 2006). Affordable housing programs operate locally and vary considerably across jurisdictions. Scott et al. (2007) compared HIV housing assistance in four major U.S. cities and found that New York City's comprehensive program, supported by city, state and federal dollars, was most successful in meeting the housing need of young HIV-positive women, when compared to New Orleans, Miami and Chicago.

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Stigma

The negative stigma faced by HIV-positive women represents another considerable barrier to their well-being. An online survey of 5,000 individuals conducted by amfAR (2008) found that:

- “59% said they would be somewhat or not at all comfortable with an HIV-positive woman serving as their childcare provider.” (¶ 4)
- 20% “would be somewhat or not at all comfortable having a close friend who is HIV positive.” (¶ 4)
- “Only 14% of respondents felt that HIV-positive women should have children.” (¶ 5)

The social stigma documented in this study represents one of three levels of stigma identified by Buseh and Stevens (2006) in their study of African American women with HIV. For one, women experience internal stigma that takes the shape of self-blame, shame and hopelessness. The second level of stigma is the social shunning and callousness identified in the amfAR survey. Rejection, fear, avoidance and verbal abuse by family or friends reflect this level of stigma. Institutional stigma is the third level of stigma identified by Buseh and Stevens. This stigma is experienced by HIV-positive women when they are treated poorly by social service agencies, medical providers, and correctional systems. Examples of this negative treatment include violations of confidentiality or marginalization that conveys a message of disregard and implies that these women are not deserving of respect. Buseh and Stevens (2006) found that the women in their study were able to overcome these multiple levels of stigma by being cautious about disclosure, identifying allies, “redefining stigma as ignorance and becoming advocates” (p. 2). This study offers specific coping mechanisms and illustrates that HIV-positive women can learn to manage the multiple levels of stigma in their lives. In addition to helping HIV-positive women cope with this structural barrier to care, attention must also be paid to how organizations and institutions treat HIV-positive women, with particular focus on how sexism, racism, classism and the stigmatization of sex work and drug use marginalize them.

MINORITY POPULATIONS

Given the demographics of this disease in the United States, the majority of the women in the research that is described in this paper are heterosexual African Americans in their 30s and 40s. There are, however, many sub-groups within this population of HIV-positive women, each with their own distinct needs and circumstances. This section will discuss research about four sub-groups including American Indian/Alaska Native (AIAN) women, Hispanic women, older women (defined in the literature as over 55 years old) and women who have sex with women (WSW).

American Indian/Alaska Native Women

Widespread racial misclassification of American Indians/Alaska Natives (AIAN) makes it difficult to estimate the number of AIAN people living with HIV. Bertolli, Lee and Sullivan (2007) examined the racial classifications in the federal HIV/AIDS Reporting System (HARS) of over 1,500 AIAN individuals receiving HIV care through the Indian Health Service and found that 30% had been racially misclassified, most often as Whites. The rate of misclassification in each of the six jurisdictions that were analyzed varied. In Los Angeles County, 54% of the AIAN people with HIV had been misclassified (Bertolli, Lee, & Sullivan, 2007). Almost 100,000 AIAN people live in New York City, making it the city with the largest AIAN population in the country (Evans-Campbell, Lindhorst, Huang, & Walters, 2006). New York City's Department of Health reports that 0.1% of HIV-positive women in New York are AIAN (New York City Department of Health and Mental Hygiene, 2007). This rate may underestimate the actual prevalence. A study of AIAN women in New York City conducted between 2000 and 2003 found that 6% of the sample was HIV positive (Evans-Campbell et al., 2006). Additionally, the participants also reported high rates of inter-personal violence (childhood abuse, rape, domestic violence).

Hispanic women/Latinas

Hispanic women in the United States are a very diverse group including monolingual and bilingual individuals, immigrants and U.S. born women, and people from multiple countries of origin, each with its own unique culture. In 2006, Hispanics comprised only 13% of the city's population, but 31% of the HIV-positive women in New York were Hispanic (Latino Commission on AIDS, n/d ; New York City Department of Health and Mental Hygiene, 2007). Most Hispanics in the U.S. (59%) are of Mexican origin, followed by Puerto Ricans who represent 9.6% of U.S. Hispanics (Guzman, 2001). Puerto Ricans, however, "account for the majority of HIV/AIDS cases among Hispanics in the United States" (Loue, 2006, p. 314). In New York, Puerto Ricans represent about half of the Hispanic population and are, by far, the largest Hispanic population in the state (Guzman, 2001). However, this search of the literature did not identify any articles specifically about Puerto Rican women living with AIDS in New York City.

A study of Central American HIV-positive immigrants in New York City reported that women were most often infected by their spouses and took a leading role in securing information and medical care for both themselves and their husbands because it was more culturally appropriate for women to seek this kind of assistance (Shedlin & Shulman, 2004). "The key elements for the provision of services to this population appear to be those that build on cultural norms and network human and institutional resources" (Shedlin & Shulman, 2004, p. 434). Schrimshaw's (2002) study of women with HIV in New York City found that Puerto Rican women reported higher levels of social conflict and depression and lower levels of social integration, compared to their Black and White counterparts. A comparison of monolingual (Spanish only) and bilingual (Spanish and English) people with HIV in Los Angeles



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found that although bilingual people were more acculturated than monolingual participants, there were no differences in health status between the two groups (van Servellen, Chang, & Lombardi, 2002). A similar comparison between U.S.-born and Central American-born women with HIV in Los Angeles found that U.S.-born Latinas were more likely to develop opportunistic infections (OI) (Wohl et al., 2003). The authors conclude that acculturation was associated with “more high-risk lifestyles and diminished social support,” placing US born Latinos at higher risk than Latinos born in Central America (p. 272).

Older women

Approximately 15% of the people with HIV in the US are over the age of 50 (Centers for Disease Control and Prevention, 2008). This estimate includes people who were over 50 at the time of their diagnosis, and people with HIV who have aged into this “older” age category. In New York City, 34% of the HIV-positive population is over 50 (New York City Department of Health and Mental Hygiene, 2007). Because most people with HIV under 50 years old and male, “Older women with HIV/AIDS constitute an invisible population that is often ignored by organizers of HIV prevention efforts as well as by HIV and aging organizations” (Emler, Tangenberg & Siverson, 2002, p. 229). Research with this population reports that older women are more psychosocially stable than their younger counterparts: they are less likely to be homeless, actively use drugs or engage in unsafe sex (Aidala et al., 2006; Emler, Tangenberg & Siverson, 2002; Gosselink & Myllykangas, 2007). Older women with HIV are also more likely to be connected to medical care and social services and report a greater number of co-morbid conditions and non-HIV-related medications than younger women (Emler, Tangenberg & Siverson, 2002; Shah et al., 2002).

...issues relating to childbearing and parenting ... were not central to these older women's lives.

In a focus group with older HIV-positive women in San Francisco, Emler et al. (2002) noted that participants conveyed “palpable excitement and relief” at the opportunity to meet and talk with other older women (p. 239). Many of the women's groups in which they had previously participated focused on issues relating to childbearing and parenting that were not central to these older women's lives. This group focused on learning about the “medical aspects of HIV and aging,” working through unresolved grief and AIDS-relating loss and building a network of peer social support (p. 239). The women in the group had spent much of their lives caring for others and this support group was an opportunity to learn more about caring for themselves and each other (Emler, Tangenberg & Siverson, 2002).

Women who have sex with women (WSW)

The US Centers for Disease Control and Prevention (CDC) and the New York City Department of Health collect information about the sex, transmission category, race/ethnicity, age, health status and residence of people diagnosed with HIV and AIDS. Information about sexual orientation or identity is not collected. Only information about specific sexual behavior, namely male-to-male sexual contact and high-risk heterosexual contact, is collected within the transmission category. From this,

Women who have sex with women (WSW) have been virtually ignored as a group at risk for contracting HIV. The CDC does not include female-to-female HIV transmission as an exposure category, and the prevalence of HIV infection among WSW is not specifically tracked (Cooperman, Simoni, & Lockhart, 2003, p. 51).

Indeed, the risk of HIV transmission during female-to-female sex is very low (Cooperman et al., 2003; Young, Friedman, & Case, 2005). The CDC reports “no confirmed cases of female-to-female transmission of HIV” (Centers for Disease Control and Prevention, 2006, p. 1). Nevertheless, WSW are encouraged to take precautions to reduce any possible sexual risk (e.g. use of dental dams during oral sex, condoms for sex toys).

Although there is little to no risk associated with female-to-female sex, WSW are still at risk for contracting HIV through sex with men and intravenous drug use (IDU). Thirty-four percent (34%) of the young female IDU participants in a multi-city study conducted between 1997 and 1999 self-identified as WSW (Friedman et al., 2003). The WSW participants reported more risk factors than their non-WSW counterparts. The WSW were more likely to have been homeless, institutionalized in a mental health facility, and incarcerated. They were also more likely to report having unprotected sex with MSM, exchanging sex for money or drugs, and high-risk drug use behaviors. In the study’s high prevalence sites, WSW were more likely to be HIV positive (Friedman et al., 2003). Other studies have also shown that WSW have higher HIV risk and higher rates of infection than other male and female injectors (Young et al., 2005). Friedman et al. (2003) suggest including “issues of sexual identity and same-sex sexual behaviors among women” into research and interventions for IDUs as these issues may help to explain variation in risk behaviors and rates of infection (p. 904).

Young, Friedman and Case (2005) used qualitative data collected from sexual minority women injectors in New York City and Boston to try to understand why WSW IDUs engage in more high-risk activity than non-WSW. They concluded that the “multiple marginalizations” experienced by WSW elevate their risk (Young et al., 2005, p. 111). While WSW experience strong support from other WSW (Cooperman et al., 2003), WSW are stigmatized within the larger IDU community, limiting their access to syringes and elevating their injection costs (Young et al., 2005). Similarly, the authors found that WSW IDUs were disconnected from the cities’ lesbian/gay/bisexual/transgender (LGBT) communities and marginalized by medical providers, shelters, drug treatment programs and criminal justice systems (Young et al., 2005). They conclude by stating, “We must insist on making sexual minority women injectors the central concern of efforts to address HIV risk among both “lesbians” and women drug users” (p. 115).



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Annotated **Bibliography**



Women Living With **HIV** and **AIDS** in **NYC**

A MAPPING PROJECT
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REVIEW



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EPIDEMIOLOGY/RESEARCH ISSUES

United States

Ellerbrock, T. V., Bush, T. J., Chamberland, M. E., & Oxtoby, M. J. (1991). Epidemiology of women with AIDS in the United States, 1981 through 1990. *JAMA*, *265*(22), 2971.

Presents a study which analyzed surveillance data for women with AIDS in the U.S. from 1981 to 1990. Comparison of the epidemiology of AIDS in women and heterosexual men; Categories of exposure in women and heterosexual men with AIDS; Median time for progression from HIV infection to AIDS.

Gollub, E. L. (1999). Human rights is a US problem, too: The case of women and HIV. *American Journal of Public Health*, *89* (10), 1479-1482.

“Overall, US AIDS incidence and mortality have shown significant declines since 1996, probably because of new antiviral therapies. For women, however, these benefits have been much less pronounced than for men. At the heart of women’s HIV risk is gender-based discrimination, which keeps women, and especially women of color, poor and dependent. Although human rights issues are often linked with AIDS issues abroad, in the US they receive insufficient attention in our response to women’s HIV risk. Advocacy from public health professionals is needed to overcome the longstanding paternalistic attitudes of federal agencies toward women and to change the paradigm of women’s HIV/AIDS prevention and care. Examples of unjust and punitive social policies that may affect women’s HIV risk include the 1996 welfare policy legislation, drug treatment policies for women, and women’s access to medical research and technology. The overriding public health response to AIDS consists of behavioral interventions aimed at the individual. But this approach will not successfully address the issues of women with AIDS until efforts are made to eliminate society’s unjust and unhealthy laws, policies, and practices.”

Henry J. Kaiser Family Foundation (2006). Women and HIV/AIDS in the United States. HIV/AIDS: HIV/AIDS Policy Fact Sheet

Ojikutu, B. O., & Stone, V. E. (2005). Women, inequality, and the burden of HIV. *New England Journal of Medicine*, *352* (7), 649-652.

“Comments on the burden of HIV which falls most heavily on women. Story of a young African woman and a young American woman and the striking similarities of their lives despite the different cultures and languages; Current statistics on the number of women with HIV and/or AIDS worldwide; Explanations for why the rate is so much higher for women than for men; Sociopolitical reasons which arises from the inequity between the sexes, class structures and the lack of health care; Need to address the sociopolitical causes in addition to handing out medicines.”

US Department of Health and Human Services. (2004). “AIDS and Women.” **HRSA Care Action**, from www.hab.hrsa.gov.

Wingood, G. (2003). Feminization of the HIV epidemic in the United States: Major research findings and future research needs. *Journal of Urban Health*, *80* (4; Suppl 3), iii67-iii76.

“This article describes several HIV prevention interventions that have demonstrated efficacy in reducing women’s risk of HIV and identifies key research questions to be addressed in the area of HIV prevention for women. The article is organized in a question-and-answer format for clarity of presentation. This format is particularly useful in the latter half, which focuses on specific questions that have emerged from past and ongoing research among women. Some of these research questions include the following:

- (a) How can researchers develop effective strategies that can prevent women from relapsing to risky sexual practices?
- (b) What are effective HIV prevention approaches for Latina women?
- (c) How can interventions be tailored to the needs of women living with HIV?
- (d) How can we improve the efficacy and cost effectiveness of comprehensive HIV prevention strategies for reducing HIV and other blood-borne and sexually transmitted infections among women?”

New York City

HIV/AIDS and STD Updates. (2008). *AIDS Patient Care & STDs*. 22(3), 259-262.

New York City’s overall death rate reached a record low in 2006 because of a decrease in AIDS-related deaths.

Hessol, N. A., Schneider, M., Greenblatt, R. M., Bacon, M., Barranday, Y., Holman, S., et al. (2001). Retention of women enrolled in a prospective study of human immunodeficiency virus infection: Impact of race, unstable housing, and use of human immunodeficiency virus therapy. *American Journal of Epidemiology*, 154(6), 563-573.

LOCATION: NYC (2 sites), Washington DC, Chicago, LA and San Francisco, CA

POPULATION: Women’s Interagency HIV Study (WIHS), includes 2,059 HIV-positive and 569 HIV-negative women who participated between 1993-1999.

FINDINGS: “Even though women and people of color represent an increasing proportion of US AIDS cases, few research studies include adequate representation of these populations...These results show that women with and at risk for HIV infection, especially African-American women, can be successfully recruited and retained in prospective studies.”

- Factors associated with retention among *HIV-infected* women included, African-American race, past experience in studies of HIV/AIDS, site of enrollment, and reported use of combination or HAART at the last visit.
- Recruitment and retention strategies included: collecting detailed tracking information and sending frequent appointment reminders (letters & phone calls), reimbursements/incentives, establishing trust and communication.
- Overall retention rate was 82%.

HIV Epidemiology and Field Services Program, New York City Department of Health and Mental Hygiene. (2007). HIV/AIDS in New York City, 2006: Females.

HIV Epidemiology and Field Services Program, New York City Department of Health and Mental Hygiene. (2007). HIV/AIDS in New York City, 2001-2006.



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New York State AIDS Advisory Council (2005). *Women in Peril: HIV & AIDS. The rising toll on Women of Color.*

PSYCHOSOCIAL ISSUES

Mental Health

Anastos, K., Schneider, M. F., Gange, S. J., Minkoff, H., Greenblatt, R. M., Feldman, J., et al. (2005). The association of race, sociodemographic, and behavioral characteristics with response to highly active antiretroviral therapy in women. *JAIDS: Journal of Acquired Immune Deficiency Syndromes*, 39(5), 537-544.

LOCATION: NYC (2), Washington DC, Chicago, LA and San Francisco, CA

SAMPLE: 961 women enrolled in the Women's Interagency HIV Study (WIHS) who met study criteria for HAART use, disease progression and clinical records.

FINDINGS: "White women had more favorable virologic, immunologic, and clinical responses to HAART. The poorer responses to HAART found in African American and Latina women, however, were explained largely by HAART discontinuation and to a lesser extent, by depression."

RECOMMENDATION: "Treating depression and ascertaining and addressing reasons for treatment discontinuation could substantially improve outcomes in African American and Latina women."

Catz, S. L., C. Gore-Felton, et al. (2002). Psychological distress among minority and low-income women living with HIV. *Behavioral Medicine*, 28(2), 53-60.

LOCATION: Baton Rouge, LA

SAMPLE: 100 HIV-positive women: low income (87%) and African American (84%).

FINDINGS: "The growing incidence of HIV infection among low-income and minority women makes it important to investigate how these women adjust to living with HIV and AIDS. Psychological distress associated with HIV infection may compound the adjustment difficulties and increase the barriers to care associated with living in poverty...The [participants'] levels of depression, stress, and anxiety symptoms were elevated relative to community norms. Greater anxiety and depression symptoms were associated with women who reported higher stress, using fewer active coping strategies, and perceiving less social support."

RECOMMENDATIONS: Many women had access to services but were not using them. Clinicians should encourage women to take advantage of these services.

Cooperman, N., & Simoni, J. (2005). Suicidal ideation and attempted suicide among women living with HIV/AIDS. *Journal of Behavioral Medicine*, 28(2), 149-156.

LOCATION: New York, NY

SAMPLE: 207 HIV-positive women, 44% black, 20% Hispanic, 16% Hispanic & Black

BACKGROUND: In the general population and among people with HIV, women are more likely to attempt suicide. Suicide attempts are highest in the time directly following diagnosis.

FINDINGS: “26% of the women reported attempting suicide since their HIV diagnosis [among these women, 50% had attempted suicide more than once]. Of those who made an attempt, 42% acted within the first month after diagnosis and 27% acted within the first week. AIDS diagnosis, psychiatric symptoms, and physical or sexual abuse were significant positive predictors of both suicidal ideation and attempts. Contrary to expectations, having children and being employed were also significant positive predictors. Spirituality was significantly negatively associated with suicidal ideation only.”

RECOMMENDATIONS: “These results suggest that suicide prevention measures should be implemented for HIV-positive women immediately after diagnosis. Specifically, interventions should target those with an AIDS diagnosis, psychiatric symptoms, an abuse history, children, or employment. The encouragement of spiritual connection seems to be a deterrent to suicidal thoughts and is a possible avenue for intervention.”

Dodds, S., Nuehring, E. M., Blaney, N. T., Blakley, T., Lizzotte, J.-M., Lopez, M., et al. (2004). Integrating mental health services into primary HIV care for women: The Whole Life Project. *Public Health Reports*, 119(1), 48-59.

LOCATION: Miami, FL

BACKGROUND: Summarizes the research which has shown high rates of “psychiatric disorders” including, depression, substance abuse and PTSD among women with HIV.

FINDINGS: This paper describes “The Whole Life project--a collaboration of the departments of Psychiatry and Obstetrics/Gynecology at the University of Miami School of Medicine—[that] integrated mental health services into primary HIV care for women.” ...Whole Life efforts have been sustained beyond the demonstration funding period as a result of the changes brought about in organizational structures, service delivery, and the providers’ conceptualization of health for HIV-infected women.”

RECOMMENDATIONS: Integrate psychiatric services into primary care in order to “more broadly and holistically conceptualize health for HIV-infected women.”

Feist-Price, S. & Wright, L. B. (2003). African American women living with HIV/AIDS: mental health issues. *Women & Therapy*, 26(1/2): 27.

“As with any other reaction to catastrophe or life threatening diseases, from the time African American women first learn of their HIV-positive serostatus they navigate various levels of acceptance and a multitude of mental health issues. This manuscript explores these issues related to African American women with HIV/AIDS. Careful consideration is given to the stages of adjustment and related mental health challenges that women might experience. Also explored are the reciprocal impact of children, other family members and significant others on the mental health status of African American women living with HIV/AIDS. Implications for clinical practice are also identified.”

Lorenz, K. A., Hays, R. D., Shapiro, M. F., Cleary, P. D., Asch, S. M., & Wenger, N. S. (2005). Religiousness and Spirituality Among HIV-Infected Americans. *Journal of Palliative Medicine*, 8(4), 774-781.

LOCATION: National multi-site

SAMPLE: 2266 HIV-positive adults interviewed between 1996-1998. (29% female)

FINDINGS: “80% of respondents reported a religious affiliation. 65% percent affirmed that religion and 85% that spirituality was “somewhat” or “very” important in their lives. A majority indicated that they “sometimes” or “often” rely on religious or spiritual means when making decisions (72%) or confront-



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ing problems (65%)...*Women, non-whites other than Hispanics, patients older than 45 years of age compared to those between 18 and 34 years of age, and more educated patients reported higher spirituality. Clinical stage was not associated with religiousness or spirituality.*"

RECOMMENDATIONS: "A large majority of HIV-infected patients in the United States affirm the importance of religiousness and spirituality. These findings support a comprehensive, humanistic approach to the care of HIV-infected patients."

Morrison, M. F., Petitto, J. M., Ten Have, T., Gettes, D. R., Chiappini, M. S., Weber, A. L., et al. (2002). Depressive and anxiety disorders in women With HIV infection. *American Journal of Psychiatry*, 159(5), 789-796.

LOCATION: North Central Florida

SAMPLE: HIV-positive (n=93) and HIV-negative (n=62) women

FINDINGS: "The rate of current major depressive disorder was four times higher in HIV-seropositive women (19.4%) than in HIV-seronegative women (4.8%) ... There was no significant between-group difference in the rate of anxiety disorders. However, HIV-seropositive women had significantly higher anxiety symptom scores than did HIV-seronegative women. Both groups had similar substance abuse/dependence histories. HIV-seropositive women without current substance abuse exhibited a significantly higher rate of major depressive disorder and more symptoms of depression and anxiety than did a group of HIV-seronegative women with similar demographic characteristics."

RECOMMENDATIONS: "These controlled, clinical findings extend recent epidemiologic findings and underscore the importance of adequate assessment and treatment of depression and anxiety in HIV-infected women."

Schrimshaw, E. W. (2002). Social Support, conflict, and integration among women living with HIV/AIDS. *Journal of Applied Social Psychology*, 32(10), 2022-2042.

LOCATION: New York, NY

SAMPLE: 146 HIV-positive women

FINDINGS: This survey data found that:

- Women who reported high levels of social integration (i.e. feeling a sense of belonging to a social network) were less likely to be depressed.
- Women who reported high levels of social conflict (i.e. tension with others, feeling disrespected) were more likely to be depressed.
- Perceived availability of social support (i.e. someone to talk to, receive assistance) was not associated with level of depression. "Women living with HIV/AIDS might fail to receive adequate support because of their continued role as caregivers and support providers to their families or because of a reluctance to disclose their HIV infection."

RECOMMENDATION: Generally speaking, the high levels of depression found in this sample speak to the need to provide therapeutic interventions. "Results suggest that intervention efforts should go beyond addressing support to further address the conflict and lack of integration experienced."

- Women of color being served by AIDS service organizations focused on or run by white, gay men may receive support without feeling a sense of belonging (social integration). Organizations must do more to accommodate these women and foster a sense of belonging with support group programs and education for family and caregivers.

- The high levels of social conflict experienced by the women “suggests the need for intervention that provides training and sensitization for caregivers and important others regarding how to best avoid conflicts, patronizing actions, or ignorant comments.”

Siegel, K., Karus, D., & Dean, L. (2004). Psychosocial characteristics of New York City HIV-infected women before and after the advent of HAART. *American Journal of Public Health, 94*(7), 1127-1132.

LOCATION: New York, NY

SAMPLE: 148 HIV-positive women. 74 interviewed between 1994-1996 and 74 interviewed between 2000-2002.

FINDINGS: “A significant difference between groups was found only with regard to adjustment to illness in their domestic environment, with poorer adjustment reported, on average, by women in the 2000-2002 sample...Although new treatments have significantly improved the physical health of those living with HIV/AIDS, no evidence was found that these treatments significantly improved psychological health for women.” The lack of difference may be explained by the fact that “women in both samples, most of whom were socioeconomically disadvantaged, faced numerous other life stressors independently associated with depression (e.g. drug or alcohol addiction, violence, poverty, being the sole caregiver of 1 or more dependent children), some of which posed a more imminent threat to their psychological and physical well-being than did HIV” or the possibility that HAART fell short of the women’s expectations.

RECOMMENDATIONS: “The data presented here indicate that a substantial proportion of HIV-infected women continue to be at risk for poor psychosocial adjustments to illness and that we must continue to develop, evaluate, and disseminate interventions aimed at improving these women’s mental health and quality of life.”

Sikkema, K. J., Hansen, N. B., Meade, C. S., Kochman, A., & Lee, R. S. (2005). Improvements in health-related quality of life following a group intervention for coping with AIDS-bereavement among HIV-infected men and women. *Quality of Life Research, 14*(4), 991-1005.

LOCATION: New York, NY and Milwaukee, WI

SAMPLE: HIV-positive individuals (85 women & 150 men) who had experienced and AIDS-related loss within the last two years. Recruited between 1997 and 1999. 53% African American

BACKGROUND: “Because of the double burden of coping both with their own illness and AIDS-related bereavement, these individuals are at particularly high risk for complicated grief reactions and subsequent physical and mental health problems, including poor quality of life.”

FINDINGS: “Participants were randomly assigned to a 12-week cognitive-behavioral bereavement coping group intervention or offered individual psychotherapy upon request. Quality of life was assessed at baseline and 2 weeks after the intervention. Participants in the group intervention demonstrated improvements in general health-related and HIV-specific quality of life, while those in the comparison remained the same or deteriorated ...the majority of change occurred in women...Women in the group intervention exhibited more improvements than men, and women in the comparison condition exhibited a deterioration in health-related quality of life...women attended an average of two sessions more than men did and men were four times as likely to dropout...”

RECOMMENDATIONS: “Cognitive-behavioral interventions may have a broad impact on both emotional and physical health...This group intervention may fill a gap in social support for women that does



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not exist for men. In particular, gay men have had a more unified response to the AIDS epidemic and have organized support services in place. Perhaps women have either less access or fewer options available in support services where they can contact other women experiencing similar issues”

Simoni, J. M., Bu, H., Goodry, E. J., & Montoya, H. D. (2005). Social support and depressive symptomatology among HIV-positive women: The mediating role of self-esteem and mastery. *Women & Health*, 42(4), 1-15.

LOCATION: New York, NY

SAMPLE: 373 HIV-positive women

FINDINGS: “HIV-positive women, who are disproportionately ethnic minority, face unique challenges to their psychosocial adaptation. Findings from [this] survey...indicated high levels of depressive symptomatology, which were inversely related to HIV-related social support from friends, relatives, partner, and groups organizations....Psychological resourcefulness [i.e. self-esteem and sense of control over one’s life] mediated the effects of social support on depressive symptomatology.”

- 61% met clinical criteria for depression – a rate that is four times higher than the general population.
- Women with poorer health were more depressed.

RECOMMENDATIONS: “Findings suggest the need to assess HIV-positive women for social isolation and depression and to provide them with interventions such as support groups that capitalize on their existing strengths, including their psychological resourcefulness.”

Simoni, J. M., & Cooperman, N. A. (2000). Stressors and strengths among women living with HIV/AIDS in New York City. *AIDS Care*, 12(3), 291-297.

LOCATION: New York, NY

SAMPLE: 373 HIV-positive women, primarily indigent African-Americans and Latinas, mean age 40 years old.

BACKGROUND: In 1998, NYC and New York State had the highest rates of women with HIV by city and state.

FINDINGS: “Participants reported considerable stressors. For example, 59% had been sexually abused and 69% physically abused at some point in their lives. [Average age of onset for sexual and physical abuse was 14 years old.] In the past 30 days, 9% reported having injected drugs. However, participants also reported considerable strengths, including high levels of spirituality, mastery and HIV-related social support [all of which were associated with less depression].” Mastery reflects the individual’s belief that what happens to them depends on their own actions.

RECOMMENDATIONS: “Findings suggest the need for thorough psychosocial evaluations of women living with HIV to facilitate psychological adaptation, including an exploration of their strengths and culturally-based competencies.” Treating depression “is particularly important since many HIV-positive individuals are prone to self-medicating through substance abuse and risky sex...Data also suggest spirituality should be explored as part of a strategy of identifying and bolstering cultural strengths.” Social support can be provided through peer support groups.

Substance Use

Kapadia, F., Vlahov, D., Yingfeng, W., Cohen, M. H., Greenblatt, R. M., Howard, A. A., et al. (2008). Impact of drug abuse treatment modalities on adherence to ART/HAART among a cohort of HIV seropositive women. *American Journal of Drug & Alcohol Abuse*, 34(2), 161-170.

LOCATION: Multi-site including New York (Bronx/Manhattan/Brooklyn), Washington DC, San Francisco, LA and Chicago.

SAMPLE: 573 HIV-positive women with a history of drug use who received HAART. Sample drawn from Women's Interagency HIV Study (WIHS) that enrolled HIV-positive women between 1994-1995.

FINDINGS: "Individuals who reported accessing any drug abuse treatment program were more likely to report adherence to antiretroviral regimens... Involvement in either a medication-based or medication-free program was similarly associated with improved adherence. Drug abuse treatment programs, irrespective of modality, are associated with improved adherence to antiretroviral therapies among drug users."

RECOMMENDATIONS: "Concerted efforts to enroll individuals with drug use histories in treatment programs are warranted to improve HIV disease outcomes."

Sharpe, T., Lee, L. M., Nakashima, A. K., Elam-Evans, L. D., & Fleming, P. L. (2004). Crack cocaine use and adherence to antiretroviral treatment among HIV-infected black women. *Journal of Community Health*, 29(2), 117-127.

LOCATION: Multi-site urban (including: Denver, Hartford, New Haven, Miami, Tampa, Atlanta, Detroit, Jersey City, Paterson, Phoenix, Tucson, Washington, LA)

SAMPLE: 1655 HIV-positive women enrolled in national CDC study between 1997 - 2000.

FINDINGS: "Crack use was more frequently reported among Black women than by women of other racial/ethnic groups in this analysis...Crack users and users of other drugs reported more difficulty adhering to ART compared with nonusers.

RECOMMENDATIONS: "HIV-infected Black women substance users, especially crack cocaine users, may require sustained treatment and counseling to help them reduce substance use and adhere to ART...comprehensive integrated care programs [should] include treatment of the infection, treatment of substance abuse and help with issues related to social marginalization."

Thorpe, L. E., Frederick, M., Pitt, J., Cheng, I., Watts, D. H., Buschur, S., et al. (2004). Effect of hard-drug use on CD4 cell percentage, HIV RNA level, and progression to AIDS-Defining Class C events among HIV-infected women. *JAIDS: Journal of Acquired Immune Deficiency Syndromes*, 37(3), 1423-1430.

LOCATION: Multi-site - New York, NY; Chicago, IL; San Juan, PR; Boston, MA, Worcester, MA; Houston, TX

SAMPLE: 1148 HIV-positive women enrolled in the Women and Infant Transmission Study (WITS) between 1989 and 1995.

FINDINGS: The participants were interviewed multiple times over 5 years and "outcomes were compared between hard-drug users (women using cocaine, heroin, methadone, or injecting drugs) and nonusers. Of 1148 women, 40% reported baseline hard-drug use during pregnancy. In multivariate analyses, hard-drug use was not associated with change in CD4 cell percentage, HIV RNA level, or all-cause mortality. Hard-drug users did, however, exhibit a higher risk of developing class C diagno-



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ses, especially herpes, pulmonary tuberculosis, and recurrent pneumonia. Hard-drug-using women may have a higher risk for nonfatal opportunistic infections.”

Von Unger, H., & Collins, P. Y. (2005). Transforming the meaning of HIV/AIDS in recovery from substance use: A qualitative study of HIV-positive women in New York. *Health Care for Women International*, 26(4), 308-324.

LOCATION: New York, NY

SAMPLE: 15 HIV-positive women living in a residential drug treatment program. Primarily African American, average age of 37, polysubstance users.

FINDINGS: Qualitative interviews revealed the following five themes:

1. Many participants who were actively using drugs when diagnosed report being “too caught up to care.”
2. HIV diagnosis “provided a reason to increase drug use...[or] to relapse.”
3. HIV diagnosis provided a motivation for change.
4. HIV provided motivation to abstain from drugs.
5. “Attending to HIV-specific needs is a crucial element of successful recovery from substance use.”

“For most participants, HIV did not constitute the main reason for starting their recovery. The dual diagnosis program, however, facilitates an important transformation of the meaning of HIV/AIDS. Previously viewed as just another reason to use drugs, women now increasingly perceive their HIV infection as an incentive to stay clean and sober...This [study] confirms the limited significance of HIV in the context of the stressful lives of many low-income, ethnic minority women with HIV/AIDS in the United States.[the data also illustrate] that HIV-positive, drug-using women are a diverse group of individuals who respond to HIV in varied ways...Almost all participants acknowledged that they gained important knowledge about HIV prevention, medication, and adherence issues since entering the dual diagnosis program. For many, this was the first time they had access to HIV-related information.”

RECOMMENDATIONS: “Comprehensive treatment programs must address the complex social, medical, and mental health needs of women dually diagnosed with chemical dependence and HIV/AIDS. Programs that are tailored to meet these multilayered needs can be of great value in transforming women’s HIV infection into part of the fabric that sustains their recovery from substance abuse.”

Violence & Abuse

Cohen, M., Deamant, C. et al. (2000). Domestic violence and childhood sexual abuse in HIV-infected women and women at risk for HIV. *American Journal of Public Health*, 90(4), 560-565.

LOCATION: National multi-site study

SAMPLE: 1288 HIV-positive and 357 HIV-negative women participating in Women’s Interagency HIV Study (WIHS).

FINDINGS: The lifetime prevalence of domestic violence was 66% and 67%, respectively...One quarter of the women reported recent abuse, and 31% of the HIV-seropositive women and 27% of the HIV-seronegative women reported childhood sexual abuse. Childhood sexual abuse was strongly associated with a lifetime history of domestic violence and high-risk behaviors, including using drugs, having more than 10 male

sexual partners and having male partners at risk for HIV infection, and exchanging sex for drugs, money, or shelter...Our data support the hypothesis of a continuum of risk, with early childhood abuse leading to later domestic violence, which may increase the risk of behaviors leading to HIV infection.”

Henny, K., Kidder, D. et al. (2007) Physical and sexual abuse among homeless and unstably housed adults living with HIV: Prevalence and associated risks. *AIDS and Behavior*, 11 (6), 842-853.

LOCATION: Baltimore, Chicago, and Los Angeles

SAMPLE: HIV-positive homeless or unstably housed men and women

FINDINGS: “About 77% of men and 86% of women reported ever experiencing abuse. *Women were at greater risk than men for intimate partner physical abuse, childhood sexual abuse (CSA), and adulthood sexual abuse.* Men and women experiencing intimate partner physical abuse reported increased risk of unprotected sex. Other risks associated with abuse include sex exchange; lifetime alcohol abuse; and depressive symptoms. Abuse prevalence among sample exceeds those found in other samples of general USA, HIV-seropositive, and homeless populations.”

RECOMMENDATIONS: “Identifying persons at risk of abuse is needed to reduce risk among homeless or unstably housed persons living with HIV.”

Lang, D. L., Salazar, L. F. et al. (2007). Associations between recent gender-based violence and pregnancy, sexually transmitted infections, condom use practices, and negotiation of sexual practices among HIV-positive women. *JAIDS*, 46 (2), 216-221.

LOCATION: southeastern United States

FINDINGS: Data finds an “association between gender based violence and pregnancy, sexually transmitted infections, condom use and negotiation of sexual practices.”

RECOMMENDATION: The article emphasizes the need for screening for abuse among HIV-positive women.

Pence, B. W., Reif, S., et al. (2007). Minorities, the poor, and survivors of abuse: HIV-infected patients in the US deep South. *Southern Medical Journal*, 100(11), 1114-1122.

LOCATION: Five southeastern states

SAMPLE: 611 HIV-positive men and women interviewed 2001-2002; 64% African American, 31% female.

FINDINGS: “Women and racial/ethnic minorities were less likely to be on antiretrovirals and to have viral loads less than 400. Probable psychiatric disorders (54%) and history of childhood sexual (30%) and physical abuse (21%) were common.”

RECOMMENDATIONS: “Prevention and care systems need to address the HIV epidemic’s shift into poor, minority, and female populations. High levels of trauma and probable psychiatric disorders indicate a need to assess for and address these conditions in HIV clinical care.”

Simoni, J. M., & Ng, M. T. (2000). Trauma, coping, and depression among women with HIV/AIDS in New York City. *AIDS Care*, 12(5), 567-580.

LOCATION: New York, NY

SAMPLE: 230 HIV-positive women

FINDINGS: “Results revealed a high prevalence of abuse in childhood (50%) and adulthood (68%); 7% reported physical assault or rape in the last 90 days. As expected, childhood abuse was significantly



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correlated with both adult and recent trauma, and each type of trauma correlated with [depression] scores... [A]ssociation between childhood abuse and [depression] scores persisted even after controlling for relevant demographic variables, more recent trauma and coping strategies.”

RECOMMENDATIONS: Interventions to improve the psychological functioning of women living with HIV.

Zierler, S., Cunningham, W. E. et al. (2000). Violence victimization after HIV infection in a US probability sample of adult patients in primary care. *American Journal of Public Health*, 90(2), 208-215.

LOCATION: National study

SAMPLE: 2864 HIV-positive individuals interviewed between 1996 and 1997.

FINDINGS: “This study estimated the proportion of HIV-infected adults who have been assaulted by a partner or someone important to them since their HIV diagnosis and the extent to which they reported HIV-seropositive status as a cause of the violence. Overall, 20.5% of the women, 11.5% of the men who reported having sex with men, and 7.5% of the heterosexual men reported physical harm since diagnosis, of whom nearly half reported HIV-seropositive status as a cause of violent episodes.”

RECOMMENDATIONS: “HIV-related care is an appropriate setting for routine assessment of violence. Programs to cross-train staff in antiviolence agencies and HIV care facilities need to be developed for men and women with HIV infection.”

Sikkema, K. J., Hansen, N. B. et al. (2004). The clinical significance of change in trauma-related symptoms following a pilot group intervention for coping with HIV-AIDS and childhood sexual trauma. *AIDS and Behavior*, 8(3), 277-91.

LOCATION: New York, NY and New Haven, CT

SAMPLE: 28 HIV-positive individuals (21 women, 7 men). Among the women, 67% were African American and had an income of less than \$10,000/year. 85% were heterosexual.

BACKGROUND: “The association between sexual abuse and HIV risk is well documented, yet little empirical data exists on treatment approaches integrating the psychological impact of sexual abuse and HIV disease.”

FINDINGS: This study tested a 16 week group intervention and found that “a theoretically based, stress and coping group intervention can improve trauma-related symptoms among HIV-infected individuals who were sexually abused as children.... More than 75% of participants showed improvement on 1 or more subscales of the Trauma Symptom Inventory, with the majority of improvements within domains related to trauma symptoms and behavioral difficulties...Group therapy appears to be well suited for the treatment of traumatized individuals who may otherwise maintain stances of isolation and avoidance. We believe that a critical component of the intervention described here was the social support derived from group members (especially as it related to realizing that sexual abuse was not uncommon).”

RECOMMENDATIONS: “These preliminary findings support the need for the conduct of research trials to identify mental health and secondary prevention intervention models that can assist those with HIV-AIDS who have experienced childhood sexual abuse.”

Family/Children

Fiore, T., Flanigan, T., Hogan, J., Cram, R., Schuman, P., Schoenbaum, E., et al. (2001). HIV infection in families of HIV-positive and 'at-risk' HIV-negative women. *AIDS Care*, 13(2), 209-214.

LOCATION: Bronx, NY; Baltimore, MD; Providence, RI; Detroit, MI

SAMPLE: 871 HIV-positive and 439 HIV-negative at-risk women participating in HIV Epidemiology Research Study (HERS)

FINDINGS: "Multiple HIV infections are remarkably common in families of HIV-positive women and among high-risk HIV-negative women from the same communities...In the seropositive cohort, 35% (n=307) of the women had a family member with HIV infection. Of these 307 women, 38% reported having a sibling, 24% a husband and 27% had more than one family member with HIV/AIDS. Forty-nine per cent of Latina women, 34% of black women, and 21% of white women reported having a family member with HIV/AIDS...Latina and black women were significantly more likely than white women to have a sibling, extended family member or more than one family member with HIV/AIDS."

RECOMMENDATIONS: "The high prevalence of HIV within families, particularly in the families of Latina and black women, mandates attention in planning both prevention and care... Innovative methods are needed to provide support, care and HIV prevention to families with multiple HIV-infected members."

Latham, B. C., Sowell, R. L. et al. (2001). Family functioning and motivation for childbearing among HIV-infected women at increased risk for pregnancy. *Journal of Family Nursing*, 7 (4): 345.

LOCATION: southern United States

SAMPLE: Participants were predominantly single (82.2%), African American women (86.7%) with annual incomes of less than \$10,000 (65.5%), with a mean age of 31.2 years.

FINDINGS: "Women reported that their families functioned moderately well...level of education, life satisfaction, and coping through avoidance and coping by seeking social support were positively associated with family functioning. In contrast, a history of interpersonal verbal violence and a history of drug use were negatively associated with family functioning.

RECOMMENDATIONS: Study findings support the need for comprehensive nursing interventions that include addressing family issues if HIV-infected women are to be provided quality care.

Letteney, S. & LaPorte, H.H. (2004). Deconstructing stigma: Perceptions of HIV-seropositive mothers and their disclosure to children. *Social Work in Health Care*, 38 (3), 105-123.

LOCATION: New York, NY

SAMPLE: 88 HIV-positive women with children.

FINDINGS: "This study addressed the perceptions of stigma and disclosure behavior of HIV-seropositive mothers...Differences were found between disclosure groups in the use of secrecy as a stigma management tool and in perceived devaluation-discrimination associated with an HIV diagnosis. Nondisclosers to children were significantly more likely than disclosers to use secrecy as a stigma management tool, and to feel devalued and discriminated against as a result of HIV serostatus."



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RECOMMENDATIONS: “Disclosure of parental HIV serostatus to children is an important aspect of continuous care and custody planning. Secrecy and perceptions of devaluation and discrimination related to HIV diagnosis should be seen as barriers to disclosure of serostatus to children.”

Schuster, M. A., Kanouse, D. E. et al. (2000). HIV-infected parents and their children in the United States. *American Journal of Public Health, 90* (7): 1074-1081.

LOCATION: Multi-site, national study.

SAMPLE: 2864 HIV-positive people interviewed between 1996 and 1997.

FINDINGS: “This study sought to determine the number, characteristics, and living situations of children of HIV-infected adults... 28% of infected adults in care had children. *Women were more likely than men to have children (60% vs 18%) and to live with them (76% vs 34%).* 21% of parents had been hospitalized during the previous 6 months, and 10% had probably been drug dependent in the previous year. Parents continued to have children after being diagnosed with HIV: 12% of all women conceived and bore their youngest child after diagnosis, and another 10% conceived before but gave birth after diagnosis.

RECOMMENDATIONS: “Clinical and support services for people affected by the HIV epidemic should have a family focus.”

Serovich, J., McDowell, T., & Graftsky, E. (2008). Women’s report of regret of HIV disclosure to family, friends and sex partners. *AIDS and Behavior, 12*(2), 227-231.

LOCATION: Unidentified midwestern city.

SAMPLE: 73 HIV-positive women recruited between 2001-2004.

FINDINGS: “Participants experienced little regret [as a consequence of disclosing their HIV serostatus]...Fifty nine percent of women experienced no regret and 71% had regret percentages that were less than 10%...The more satisfied the women were with the relationship, the less likely regret was reported. Therefore, it is not surprising that regret is more likely to be experienced when peripheral relationship and neighbors know of one’s serostatus...There was no significant differences in regret between first and second hand disclosures.”

RECOMMENDATIONS: “Future researchers should explore why differential experiences in regret may occur and how regret is experienced by HIV-positive women. Strategies could then be developed to manage regret when it is experienced...The results from this study should be considered encouraging for both HIV-positive women and professionals who assist them with their disclosure decisions...It is also encouraging for professionals to know that the majority of those who have disclosed do not regret doing so.”

Serovich, J. M., Craft, S. M., & Hae-Jin, Y. (2007). Women’s HIV disclosure to immediate family. *AIDS Patient Care & STDs, 21*(12), 970-980.

LOCATION: Unidentified Midwestern state.

SAMPLE: 125 primarily single (48.8%), HIV-positive African American (68%) adult women. Data collection occurred between 2001 and 2006.

FINDINGS: “Previous researchers have comprehensively documented rates of HIV disclosure to family at discrete time periods yet none have taken a dynamic approach to this phenomenon. The purpose of this study is to address the trajectory of HIV serostatus disclosure to family members over time. Results indicated that women were most likely to disclose their HIV status within the first seven years after diagnosis,

and mothers and sisters were most likely to be told. Rates of disclosure were not significantly impacted by indicators of disease progression, frequency of contact, physical proximity, or relationship satisfaction.”

RECOMMENDATIONS: “Clinicians who work with families affected by HIV need to address the gender gaps in disclosure knowledge in order to increase social support in an attempt to reduce any negative emotional impact that disclosure may have on women.”

Serovich, J. M., Kimberly, J. A., Mosack, K. E., & Lewis, T. L. (2001). The role of family and friend social support in reducing emotional distress among HIV-positive women. *AIDS Care*, 13(3), 335-341.

LOCATION: Unidentified Midwestern city.

SAMPLE: 24 HIV -positive women receiving care at university medical clinic. 54% African American, average age = 39.5 years.

FINDINGS: “Perceived social support, rather than actual social support was correlated with mental health...[W]hile women perceived friends as more supportive than family, family support appears to be indicative of mental health...Perceived family support for HIV-positive women predicts an increase in mental health across several areas, including reducing anxiety, stress, depressive symptoms and loneliness over the past few days and past year.”

RECOMMENDATIONS: “Perception of support is more important than actual support.” Family members do not have to live nearby or provide actual support in order to benefit HIV-positive women.

Simoni, J. M. & Davis, M. L. (2000). Mothers with HIV/AIDS and their children: disclosure and guardianship issues. *Women & Health*, 31(1), 39.

LOCATION: New York, NY

SAMPLE: HIV-positive women

FINDINGS: Discusses issues on disclosure of mothers with AIDS/HIV to their children and arranging for future care. Comparison of maternal disclosure in older and younger children; Implications for future research and provision of services.

Sexuality/Prevention for Positives

Aidala, A. A., Gunjeong, L., Garbers, S., & Chiasson, M. A. (2006). Sexual behaviors and sexual risk in a prospective cohort of HIV-positive men and women in New York City, 1994-2002: Implications for prevention *AIDS Education & Prevention*, 18(1), 12-32.

LOCATION: New York, NY

SAMPLE: 968 HIV-positive men (579) and women (389) interviewed between 1994-2002 participating in Community Health Advisory and Information Network (CHAIN) Project.

FINDINGS: This study is unique because it followed a group of participants over an eight year period offering information about how sexual behavior changes over time. “Many persons were not sexually active at all for months at a time; some continued to have multiple partners. Over one third [33%] of the cohort had one or more periods when they had engaged in unprotected sex with a partner who was HIV-negative or status unknown (unsafe sex) and one in five [20%] reported exchanging sex. Periods of unsafe sex alternated with periods of safer sex...Our study indicates that HIV sexual and



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drug-related risk behaviors, sexual partnering, sexual orientation, and contextual factors like housing status and service utilization change over time.” Findings about women include:

- “The great majority of women were involved in partner relationships at some point during the study period.”
- “Recent experience with exchanging sex was also strongly associated with unsafe sex among women, as well as homelessness and drug use.”
- “Among women as well as with men who had sex with women only, having a spouse or steady partner was strongly associated with unsafe sex.”
- “Current drug use...was an independent predictor of unsafe sex in women, and is associated with exchanging sex among all sexual profile groups.”

RECOMMENDATIONS: Continue current emphasis on “prevention for positives,” include prevention messages in medical care. “The association of risk behaviors with current substance use and homelessness suggests that innovative ways of reaching HIV-positive populations outside of the medical care setting, particularly those who are facing competing life priorities, are also needed.”

Demmer, C. (2002). Impact of improved treatments on perceptions about HIV and safer sex among inner-city HIV-infected men and women. *Journal of Community Health, 27*(1), 63-73.

LOCATION: New York, NY

SAMPLE: 196 HIV-positive individuals, primarily African American and Hispanic, 27% female.

FINDINGS: “This study assessed the impact of HIV treatment advances on HIV-infected individuals living in inner-city areas...Almost the entire sample had heard of the latest HIV treatments, and 75% were currently on protease inhibitor regimens. One-third of the sample reported that AIDS was a less serious threat nowadays and that being HIV-positive was not a big deal. Fifteen percent of respondents believed that protease inhibitor combination therapies reduced the risk of HIV transmission, and 10% believed that these treatments reduced need for safer sex practices. As in previous studies of other populations, a significant percentage (23%) of respondents practiced safer sex less often since new HIV treatments arrived. HIV prevention programs need to focus more attention on HIV-infected individuals in inner city areas. Interventions for these individuals need to address changing attitudes and behaviors stemming from HIV treatment advances...It was found that heterosexual and gay males were less likely to practice safer sex nowadays than females.”

Kanouse, D. E., Collins, R. L., Miu, A., & Berry, S. H. (2005). HIV-infected population national data. *JAIDS: Journal of Acquired Immune Deficiency Syndromes, 38*, S6-S7.

LOCATION: National study

SAMPLE: 1232 sexually active HIV-infected women aged 18–50 years

FINDINGS: “47% had used condoms as a form of contraception in the past 12 months, with lower use among women who had tubal ligations or used oral contraceptives.”

RECOMMENDATIONS: Need for counselors and clinicians to reinforce attitudes that are conducive to condom use.

Keegan, A., Lambert, S., & Petrak, J. (2005). Sex and relationships for HIV-positive women since HAART: A qualitative study. *AIDS Patient Care & STDs, 19*(10), 645-654.

LOCATION: London, England

SAMPLE: 21 HIV-positive heterosexual women

- 67% Black African (in the UK 61% of women living with HIV are black Africans, the majority of whom acquired HIV through heterosexual sex in Africa); 29% white European
- Ages 22-54
- Time since diagnosis: 18 months to 13 years

FINDINGS: The researchers interviewed the participants individually about their experiences with sex since HIV and found that most (62%) of these HIV-positive women were sexually active but “reported a range of sexual and relationship difficulties that appear to be relatively unchanged despite the advent of HAART.” Dominant themes identified in this study included:

1. “Difficulties with sexual functioning, in particular lowered libido and enjoyment and reduced intimacy.”
2. “Barriers to forming new relationships: fears of HIV disclosure, fears of infecting partners.” The women reported no consistent preference for HIV-positive or HIV- partners, “either choice raised issues.”
3. “Coping strategies: included relationship avoidance and having casual partners to avoid disclosure...The relationship aspirations of women living with HIV are no different from those expressed by women generally...[women] desire ongoing intimacy and would aim for acceptance within a supportive, loving relationship with a partner they can trust.”
4. “Safer sex: personal dislike of condoms, lack of control, lack of suitable alternatives.” Generally able to negotiate condoms in early stages of relationship, but condom use declined over time. Some confusion about what constituted safer sex.

RECOMMENDATIONS: “Culturally appropriate, focused psychosexual and couples work should be more readily available for women living with HIV and their partners.”

Massad, L. S., Evans, C. T., Wilson, T. E., Golub, E. T., Sanchez-Keeland, L., Minkoff, H., et al. (2007). Contraceptive use among U.S. women with HIV. *Journal of Women's Health*, 16(5), 657-666.

LOCATION: Multi-site – Brooklyn, Bronx, Chicago, LA, San Francisco, Washington DC

SAMPLE: HIV-positive (n=2031) and HIV-negative (n=753) women participating in the Women's Inter-agency HIV Study (WIHS) between 1994-2005.

FINDINGS: The women were interviewed every six months reported using the following methods of contraception: barrier methods (male or female condoms) reported at 30.5%-36.3% of the visits, sterilization at 21.8%-26.5% of the visits, hormones at less than 10% of the visits. In more than 30% of the visits, women reported using no contraception.

- HIV-positive and HIV-negative women reported similar levels of condom use.
- HIV-positive women were less likely to report hormonal contraception use and more likely to have been sterilized, when compared to HIV-negative women.
- Among HIV-positive women, barrier use was more likely among women who had been pregnant and among those with higher CD4 counts.

RECOMMENDATIONS: “Underuse of highly effective contraception and barriers leaves women with HIV at risk for unintended pregnancy and disease transmission...Continuing investigation is needed to define what women with HIV understand about sexual transmission of HIV and to explore strategies to improve condom use rates...Sterilized women are unlikely to use condoms concomitantly, and inter-



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sive education is needed to persuade women who no longer need barriers as contraception about the importance of barrier use for disease prevention.”

McGowan, J. P., Shah, S. S., Ganea, C. E., Blum, S., Ernst, J. A., Irwin, K. L., et al. (2004). Risk behavior for transmission of Human Immunodeficiency Virus (HIV) among HIV-seropositive individuals in an urban setting. *Clinical Infectious Diseases*, 38(1), 122-127.

LOCATION: Bronx, NY

SAMPLE: 256 HIV-positive individuals

FINDINGS: After learning that the result of an HIV test was positive, 106 subjects (41%) had unprotected sex, 63 (25%) had a new sexually transmitted disease diagnosis, and 38 (15%) used injection drugs. *Unprotected sex was reported by 50% of women, 29% of heterosexual men, and 42% of men who have sex with men, and it was reported more often by persons with a history of trading sex for money or drugs. In multivariate analysis, unprotected sex was associated with a history of trading sex for money or drugs and use of highly active antiretroviral therapy.* In short, unprotected sex after HIV diagnosis was reported more often by “women than heterosexual men (but not more than by MSM)... [and people] who reported trading sex for money or drugs.”

RECOMMENDATIONS: “Ongoing risk-reduction counseling and substance abuse treatment for HIV-infected persons are needed to reduce behaviors associated with HIV transmission.”

Miller, M., Korves, C. T., & Fernandez, T. (2007). The social epidemiology of HIV transmission among African American women who use drugs and their social network members. *AIDS Care*, 19(7), 858-865.

LOCATION: New York, NY

SAMPLE: 180 Black women (40 HIV-positive) with drug use histories recruited between 2002 and 2004.

FINDINGS: “Serious discussions evaluating HIV transmission risk were not occurring within many [social] networks, since only half of the women and half of their network members discussed and disclosed an HIV status. In a context of high background HIV prevalence, low levels of HIV status disclosure, and a notable lack of knowledge of one’s own HIV status, mixing patterns virtually insure contact between infectious and susceptible individuals...The stigma associate with a positive HIV infection status, combined with a collective denial surrounding the HIV epidemic often found in the communities most affected, likely contributes to the silence maintain with women’s egocentric networks”

- 22% of the women tested HIV-positive, only 16% knew that they were positive before being tested by study staff.
- “Sex work was associated with an HIV-seropositive status.”
- The women reported that about half (51%) of the people in their social network had disclosed an HIV status to them but only 7% of these network members, 73% of whom were sex or drug use partners, had disclosed that they were HIV-positive.
- “Women who knew themselves to be HIV-infected were more likely than other women to report HIV-infected network members.”

RECOMMENDATIONS: “HIV infected Black Americans are less likely to receive antiretroviral therapy than others particularly if they also use illicit drugs. Until systems are in place that insure comprehensive, quality care for HIV infected individuals, particularly those who are or become uninsured, it is unlikely that the stigma and denial surrounding HIV will be ameliorated...The importance of knowing

one's HIV serostatus, as well as that of one's network members, is a social network level message that is not widely disseminated.”

Montgomery, J. P., Mokotoff, E. D. et al. (2003). The extent of bisexual behaviour in HIV-infected men and implications for transmission to their female sex partners. *AIDS Care*, 15(6), 829-837.

LOCATION: National study involving health departments in Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Los Angeles County, Michigan, New Jersey, New Mexico, South Carolina, and Washington.

SAMPLE: HIV-positive individuals interviewed between January 1995 through July 2000; 5,156 MSM, and 3,139 women.

BACKGROUND: “Heterosexual transmission of HIV is a growing problem for women, but many women do not know how their partners acquired HIV.”

FINDINGS: “The proportion of MSM who reported having sex with women (MSM/MSW) varied by race: 34% of black MSM, 26% of Hispanic MSM, and 13% of white MSM. While 14% of white women acknowledged having a bisexual partner, only 6% of black and 6% of Hispanic women reported having a bisexual partner. Most behaviourally bisexual men identified as either bisexual (59%) or homosexual (26%). Among MSM/MSW, 30% had more female partners than male partners, while only 10% had more male partners than female partners. These data suggest that bisexual activity is relatively common among black and Hispanic HIV-infected MSM, few identify as heterosexual, and their female partners may not know of their bisexual activity. “

Wilson, T. E., Vlahav, D., Crystal, S., Absalon, J., Klein, S.J., Remein, R. H., et al. (2006). Integrating HIV prevention activities into the HIV medical care setting: A report from the NYC HIV centers consortium. *Journal of Urban Health*, 83(1), 18-30.

Reports on the challenges of promoting sexual risk reduction among HIV positive individuals. Describes the need for evidence-based approaches to reducing risk for people with mental health and substance abuse issues, improving access to care and risk reduction counseling. “To date, there is very little information available regarding how to tailor risk reduction programs to the needs of women, adolescents, minority and immigrant populations, persons with mental illness, incarcerated populations, or active substance users.”

Wilson, T. E., Gore, M. E., Gange, S. J., Greenblatt, R., Cohen, M., Minkoff, H., et al. (2004). Changes in sexual behavior among HIV-infected women after initiation of HAART. *American Journal of Public Health*, 94(7), 1141-1146.

LOCATION: National, multi-site study

SAMPLE: 724 HIV-positive women in Women's Interagency HIV Study (WIHS) who reported receiving HAART between 1996 and 2001.

FINDINGS: “Initiation of HAART regimes may be related to continuation of or increases in sexual risk behavior.” 87% of the women reported engaging in sexual activity, 23% reported not using condoms consistently. “Sexually active women were less likely to report 2 or more partners during a 6-month period after HAART initiation than before HAART initiation. However, the risk for unprotected sex was higher after HAART initiation than before HAART initiation among all sexually active women.”



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RECOMMENDATIONS: “Our study suggests that these women and their partners should receive services that will promote the knowledge and skills necessary for effective prevention of transmission of HIV. Such an educational program may include addressing the impact of HAART on risks for disease transmission at initiation and continuing similar counseling strategies throughout the course of treatment.”

Wingood, G. M., Diclemente, T. R. J., Mikhail, I., Lang, D. L., McCree, D. H., Davies, S. L., et al. (2004). A randomized controlled trial to reduce HIV transmission risk behaviors and sexually transmitted diseases among women living With HIV. *JAIDS*, 37, S58-S67.

LOCATION: Alabama and Georgia – mid-size and small cities

SAMPLE: 415 HIV-positive women, 84% black

FINDINGS: Subjects were randomized to two groups: one received risk reduction counseling (intervention) and the other received information about adherence and nutrition (control). Each group of women met for four sessions; the groups were co-led by a trained female health educator and a trained HIV-positive female peer educator. Surveys were conducted 6 and 12 months after the intervention to measure the impact of these groups on women’s sexual risk behaviors. Participants in the risk reduction group reported fewer unprotected vaginal intercourse acts, fewer bacterial STDs, and were less likely to report never using a condom than the women in the control group. “Women in the intervention reported greater knowledge of HIV transmission risk behaviors and fewer partner-related barriers to using condoms, had higher condom use self-efficacy, and demonstrated greater skill in using condoms”

RECOMMENDATIONS: “[B]uilding social support networks among women living with HIV is critical, particularly given the often limited numbers of AIDS service organizations available for women.” Interventions for women should be “gender tailored,” including support to reduce barriers to participation (i.e. childcare, transportation).

Service Utilization

Brown, V. B., & Smereck, G. A. D. (2000). Change in perceived barriers and facilitators to treatment among women with HIV/AIDS as a function of psychosocial service utilization. *AIDS Patient Care & STDs*, 14(7), 381-389.

LOCATION: Culver City, CA, Detroit, MI, San Antonio, TX

SAMPLE: 185 HIV-positive women who were participating in three different programs designed to reduce barriers to services and care in the mid-1990s. 42% African American, 40% Latina, 14% Caucasian. Average age: 34.

FINDINGS: “Clients in the three programs reported a decrease in perceived barriers to care from the time of their intake/enrollment to later interviews...Clients’ responses did not reflect increases in facilitators” The article includes a lists of 17 barriers and 11 facilitators. Perceived barriers included transportation, affordability, confidentiality, keeping appointments and identifying services. Facilitators included learning information considered important and friendly and caring staff.

RECOMMENDATIONS: Innovative service models can reduce barriers to service.

Note this study is almost a decade old and needs may have changed over time.

Bunting, S. M., Bevier, D. J., & Baker, S. K. (1999). Poor women living with HIV: Self-identified needs. *Journal of Community Health Nursing*, 16(1), 41-52.

LOCATION: Unidentified midsouth city

SAMPLE: 48 HIV-positive women were surveyed about their needs. 94% were African American; 83% had incomes below \$5,000; average age 30 years old; 78% with children under 15.

FINDINGS: The women were most likely to report psychosocial needs, including need for support groups as the majority had not disclosed their status to anyone. Other needs included physical, legal and financial needs.

RECOMMENDATIONS: Support groups to reduce isolation, transportation and child care to access services, counseling about HIV education, reproductive decisions and risk reduction, job programs, case management to access income assistance programs,

Note this study is almost a decade old and needs may have changed over time.

Lehrman, S. E., Gentry, D. et al. (2001). Outcomes of HIV/AIDS case management in New York. *AIDS Care*, 13(4), 481-492.

LOCATION: New York State

SAMPLE: 588 HIV-positive men and women

FINDINGS: “Females, individuals whose mode of HIV transmission was heterosexual contact, clients whose children were living with them, the inadequately housed, and those without a high school diploma had significantly more needs than other clients.”

RECOMMENDATIONS: Among other things, this “study supports case management models that provide intensive services to women with children.”

MEDICAL CARE

Access to Care & Adherence

Burke, J. K. (2003). Dissatisfaction with medical care among women with HIV: Dimensions and associated factors. *AIDS Care*, 15(4): 451.

LOCATION: National multi-site study.

SAMPLE: 1303 HIV-positive men and women

BACKGROUND: “Studies have shown that women with HIV/AIDS in the USA are less likely than men to have access to appropriate health care and to utilize services, including the latest antiretroviral drug therapies. One explanation for this underutilization is patient dissatisfaction with medical care. Dissatisfaction with care has been shown to be associated not only with treatment underutilization, but also with discontinuity of care and poor clinical outcomes.”

FINDINGS: “Women were most dissatisfied with access to care and the technical quality of care, and least dissatisfied with financial aspects of care and their providers’ interpersonal manner. Women who reported poor health, who had depressive symptomatology, who were not receiving antiretroviral therapy (ART), who had no consistent care providers or who were Hispanic/Latina were more likely to be dissatisfied across most dimensions of care.



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RECOMMENDATIONS: Enhance clinical care for women with HIV/AIDS.

Cunningham, C. O., Sohler, N. L., McCoy, K., Heller, D., & Selwyn, P. A. (2005). Health care access and utilization patterns in unstably housed HIV-infected individuals in New York City. *AIDS Patient Care and STDs*, 19(10), 690-695.

LOCATION: New York City

SAMPLE: 150 HIV-positive people living in single room occupancy (SRO) hotels served by CitiWide Harm Reduction. Fifty-nine (39%) of the participants were women.

FINDINGS: "Access to and utilization of care was high with 91% reporting having a regular provider, 95% identifying a non-emergency department clinic or office as their usual location of care. Additionally, 45% reported at least one ED visit, and 30% at least one hospitalization within the previous 6 months...*individuals who reported using acute care services (ED visits and hospitalizations) were more likely to be female.*"

RECOMMENDATIONS: "Understanding HIV-related health services access and utilization patterns among marginalized populations is essential to improve their HIV care. These patterns of high levels of access to and utilization of health care services contradict clinical experiences and other studies, and require further exploration...We believe, however, that the most likely explanation of these surprising findings is that having a regular health care provider and obtaining regular care may be conceptualized differently in this population than in other populations, or be health care providers."

Kenagy, G. P., Linsk, N. L. et al. (2003). Service utilization, service barriers, and gender among HIV-positive consumers in primary care. *AIDS Patient Care and STDs*, 17(5), 235-244.

LOCATION: Chicago, IL

SAMPLE: 161 HIV-positive men and women

FINDINGS: "Men were more likely than women to use alcohol and other drugs during sexual activity. Men were also more likely to use HIV medication. *Women, however, were more likely to have someone to coordinate their HIV care.* Close to half (47.2%) of these primary case patients reported at least one unmet service need, most frequently dental care, housing support and transportation."

RECOMMENDATIONS: "These findings suggest a continued need for HIV-related community-based services as well as increased attention to the unique experiences of both men and women within the HIV service system."

Women of Color Policy Network & D. Pulane Lucas. (2006). *We speak: New York City women living with HIV/AIDS speak about their needs.* United Way of New York City.

CO-MORBIDITIES

Anemia

Levine, A. M., & Berhane, K. (2001). Prevalence and correlates of anemia in a large cohort of HIV-infected women: Women's Interagency HIV Study. *JAIDS*, 26(1), 28-35.

LOCATION: National multi-site study

SAMPLE: 2056 HIV-positive and 569 HIV-negative women

FINDINGS: 37% of HIV-positive women and 17% of HIV-negative women were anemic

Cancer

Hessol, N. A., Seaberg, E. C., Preston-Martin, S., Massad, L. S., Sacks, H. S., Silver, S., et al. (2004). Cancer risk among participants in the Women's Interagency HIV Study. *JAIDS*, 36(4), 978-985.

LOCATION: Multi-site

SAMPLE: 1950 women (1554 HIV infected, 391 HIV uninfected, and 5 HIV seroconverters), participating in the Women's Interagency HIV Study (WIHS).

BACKGROUND: "The HIV epidemic has been associated with an increased incidence of specific cancers. However, less is known about cancers occurring in HIV-infected women than men."

FINDINGS: "Among all the participants, 48 cancers were diagnosed during study follow-up. Among HIV-infected women, significantly increased incidence rates were observed for all cancer types, Kaposi sarcoma, non-Hodgkin lymphoma (NHL), and lung cancer when compared with SEER rates. While the incidence rate of NHL among HIV-infected women was significantly lower during the era of highly active antiretroviral therapy (HAART) compared with the pre-HAART era, the incidence of NHL among HIV-infected WIHS participants remained significantly higher than in the US population."

RECOMMENDATIONS: "In the HAART era, the higher rates of cancer among HIV-infected women, coupled with increased life expectancy, should lead to more intensive cancer screening and prevention efforts in this population."

Massad, L. S., Evans, C. et al. (2007). Hysterectomy among women with HIV: Indications and incidence. *JAIDS*, 44(5): 566-568.

This data comes from the Women's Interagency HIV Study.

The article describes hysterectomy rates and indications among women with HIV as compared with at-risk HIV-seronegative women. Hysterectomy is considered the second most common major surgical procedure among U.S. women after cesarean section. It was concluded that women with HIV are more likely than uninfected women to require a hysterectomy, most often for cervical neoplasia.



DENTAL HEALTH

Shiboski, C. H., Cohen, M., Weber, K., Shansky, A., Malvin, K., & Greenblatt, R. M. (2005). Factors associated with use of dental services among HIV-infected and high-risk uninfected women. *Journal of the American Dental Association*, 136(9), 1242-1255.

LOCATION: Northern California and Chicago sites of the Women's Interagency HIV Study (WIHS).

SAMPLE: 363 women (298 HIV-positive, 65 HIV-negative), participating in the Women's Interagency HIV Study (WIHS) between 1998 and 2000. Subjects were predominantly black and unemployed and had a history of using injected drugs.

FINDINGS: "Not using dental care was most prevalent among HIV-negative women, particularly in Chicago....The strongest predictors of nonuse of dental care included being of a race other than white, fear of dentists and perception of poor or fair oral health."

RECOMMENDATIONS: "The Ryan White Comprehensive AIDS Resources Emergency Act facilitates dental care access for people who are HIV-positive, and is the likely explanation for the higher prevalence of dental care use in this group compared with uninfected women at high risk of becoming infected. This underscores the need for Medicaid to include dental coverage for low-income populations in all states."

OBESITY

Kruzich, L. A., Marquis, G. S., Wilson, C. M. & Stephensen, C. B. (2004). HIV-infected US youth are at high risk of obesity and poor diet quality: A challenge for improving short- and long-term health outcomes. *Journal of the American Dietetic Association*, 104(10), 1554-1560.

LOCATION: Multi-site, national sample

SAMPLE: Participants included 264 HIV-infected and 127 HIV-uninfected youth 13 to 23 years old (75.2% women; 67.3% African American; 20.5% Hispanic) at 14 clinic sites.

FINDINGS: About half (51.7%) of participants were overweight or obese. Obesity was positively associated with being a woman, living independently, watching television >3 hours per day, previous dieting, and being from the northeastern or southern United States. Youth who were HIV uninfected or HIV infected with CD4 counts over 500 had similar obesity rates; overweight (25%) and obesity (20%) was prevalent among women even with CD4 counts less than 200. HIV infection was associated with a lower-quality diet.

RECOMMENDATIONS: "Obesity is a common nutrition problem for both HIV-infected and uninfected youth; however, HIV-infected youth are at increased risk of developing metabolic abnormalities. Culturally appropriate, client-focused nutrition education will help youth improve their diet and increase physical activity to reduce health consequences associated with both obesity and HIV infection."

Mulligan, K., Anastos, K., Justman, J., Freeman, R., Wichienkuer, P., Robison, E., et al. (2005). Fat distribution in HIV-infected women in the United States DEXA substudy in the Women's Interagency HIV Study. *JAIDS*, 38 (1), 18-22.

LOCATION: Multi-site

SAMPLE: Subset of individuals participating in the Women's Interagency HIV Study (WIHS) including 171 HIV-positive, 88 HIV-negative women.

FINDINGS: The majority of both HIV-positive and HIV-negative women were overweight and many were obese. The specific study findings described the distribution of fat between trunk and leg regions.

PNEUMONIA

Kohli, R., Yungtai, L., Homel, P., Flanigan, T. P., Gardner, L. I., Howard, A. A., et al. (2006). Bacterial pneumonia, HIV therapy, and disease progression among HIV-infected women in the HIV Epidemiologic Research (HER) Study. *Clinical Infectious Diseases*, 43(1), 90-98.

LOCATION: Four US Cities

SAMPLE: 885 HIV-positive and 425 HIV-negative women with a history of injection drug use or high-risk sexual behavior interviewed between 1993-2000.

FINDINGS: "The rate of bacterial pneumonia among 885 HIV-infected women was 8.5 cases per 100 person-years, compared with 0.7 cases per 100 person-years in 425 HIV-uninfected women....High rates of bacterial pneumonia persist among HIV-infected women."

RECOMMENDATIONS: "Interventions that improve HAART utilization and promote smoking cessation among HIV-infected women are warranted."

SYPHILIS

Chesson, H. W., Heffelfinger, J. D., Voigt, R. F., & Collins, D. (2005). Estimates of primary and secondary syphilis rates in persons with HIV in the United States, 2002. *Sexually Transmitted Diseases*, 32(5), 265-269.

FINDINGS: "The estimated rate of syphilis in persons with HIV is considerably higher than that of the general population." Rates are lower among women with HIV than men with HIV. The rates of syphilis are as follows:

- Persons living with HIV: 186 per 100,000
- *Women living with HIV: 25 per 100,000 HIV-infected women,*
- HIV-infected men who have sex with women only: 60 per 100,000
- HIV-infected men who have sex with men: 336 per 100,000

25% of the reported cases of syphilis in 2002 occurred in persons with HIV.

RECOMMENDATION: Provide "sexually transmitted disease prevention and control services to HIV-infected persons."

Pregnancy & Vertical Transmission

Cesarean delivery for HIV-positive women. (2000). *Birth: Issues in Perinatal Care*, 27(3): 220. "Reports on the American College of Obstetrics and Gynecologists recommendation to provide cesarean delivery [at 38 weeks gestation] for HIV-positive women with high viral loads...to reduce risk of HIV transmission."



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Prenatal HIV testing and antiretroviral prophylaxis at an urban hospital” Atlanta, Georgia, 1997-2000. (2004). *JAMA: Journal of the American Medical Association*, 291(9), 1061-1062.

Discusses prenatal HIV testing and antiretroviral prophylaxis at an urban hospital in Atlanta, Georgia during the period of 1997-2000. Efforts of the US Public Health Service to reduce perinatal HIV transmission in children born to women identified as HIV infected; Results of an analysis of the incidence of perinatal HIV infection in infants born at Grady Memorial Hospital; Challenges to universal prevention of infant HIV infections; Statistics on the risk of HIV transmission in exposed infants; CDC Editorial Note on perinatal transmission of HIV and prevention programs for drug-addicted mothers.

Blair, J. M., Hanson, D. L. et al. (2004). Trends in pregnancy rates among women with Human Immunodeficiency Virus. *Obstetrics & Gynecology*, 103(4), 663-668.

LOCATION: National multi-site study

SAMPLE: 8,857 HIV-positive women aged 15 to 44 years old enrolled between 1992 and 2001.

FINDINGS: Pregnancy rate at enrollment was 16%; thereafter, an average of 5.5% of women became pregnant annually. Pregnancies were more likely to occur in younger women, healthier women and women prescribed HAART. There were significantly higher rates of pregnancy during 1997 through 2001.

RECOMMENDATIONS: The increase in pregnancy rates during the era of widespread use of highly active antiretroviral therapy illustrates the continued need for comprehensive prevention and treatment services.

Bryant, A. S., Leighty, R. M., Xianlin, S., Read, J. S., Brouwers, P., Turpin, D. B., et al. (2007). Predictors of repeat pregnancy among HIV-1 infected women. *JAIDS*, 44(1), 87-92.

LOCATION: Manhattan and Brooklyn, NY; Chicago, IL; Boston and Worcester, MA; San Juan, Puerto Rico; Houston, TX.

SAMPLE: Women and Infants Transmission Study (WITS), which began in 1989, has enrolled 2,630 HIV -positive pregnant women. 2,246 of these women were included in this study.

FINDINGS: The article shows that HIV-positive women who are younger and healthier (higher CD4 counts and lower viral loads) are more likely to have more than one pregnancy. Lower educational status is also associated with repeat pregnancy. 22% of the women had a least one repeat pregnancy during the study period. Of these women, 23% had more than one repeat pregnancy. The number of women who have a repeat pregnancy increased over time.

RECOMMENDATIONS: “As women live longer with HIV-1 disease, information such as this will be valuable for clinicians, public health officials, and policy makers alike, to aid in counseling and planning for the reproductive needs of these women” (p. 91).

Craft, S., Delaney, R., Bautista, D., & Serovich, J. (2007). Pregnancy decisions among women with HIV. *AIDS and Behavior*, 11(9), 927-935.

LOCATION: unidentified Midwestern city

SAMPLE: 74 HIV-positive women, 70% African American

BACKGROUND: “Nearly 80% of women currently infected with HIV are of childbearing age. As women of childbearing age continue to be at risk of contracting HIV, there will be an increased need for choices about whether or not to have biological children. The purpose of this exploratory study was to investigate the influence of partners, physicians, and family members on pregnancy decisions, as well as the impact of HIV stigma on these decisions.”

FINDINGS: 26% of the women chose to become pregnant since diagnosis.

- “Younger women were more likely to choose pregnancy.”
- “Additional factors included fear of transmitting HIV to their child, personal health-related concerns, and desire to have children.”
- “The opinions of family members, friends and the media were outweighed by personal desires and concerns for those women who chose to become pregnant.”
- “Medical personnel were more influential upon the decision to terminate a pregnancy than the choice to become pregnant.”
- “The relative influence of intimate partners during and after pregnancy is not clear.”
- “Women who reported higher levels of personalized stigma and negative self-image were more likely to choose to become pregnant.”

RECOMMENDATIONS: “Pregnancy offers an important intervention opportunity...The results of this study emphasize the importance of HIV-positive women of child-bearing age receiving quick and accurate information about pregnancy and neonatal HIV transmission...In addition these results emphasize the need for pregnant women to be tested for HIV, and to subsequently be provided with information on neonatal transmission of HIV.”

Dominguez, K. L., Lindegren, M. L., et al. (2003). Increasing trend of Cesarean deliveries in HIV-infected women in the United States from 1994 to 2000. *JAIDS*, 33(2): 232.

Examines the trends in and factors associated with cesarean deliveries among HIV-infected women in the U.S. Pediatric spectrum of HIV disease; Univariate analysis of characteristics of HIV-infected women and their HIV-exposed infants by mode of delivery; Use of multiple logistic regression.

Ickovics, J. R., T. E. Wilson, et al. (2002). Prenatal and postpartum Zidovudine adherence among pregnant women with HIV. *JAIDS*, 30(3): 311.

LOCATION: Brooklyn, NY; Miami, FL; Connecticut; North Carolina

SAMPLE: 53 HIV-positive pregnant women

BACKGROUND: “Adherence to HIV treatment regimens during pregnancy may affect efforts to eliminate vertical transmission and influence the emergence of drug-resistant HIV strains that can affect maternal health and the risk of vertically-transmitted resistant strains.”

FINDINGS: “Adherence to Zidovudine was extremely low and declined significantly 3 weeks postpartum.”

RECOMMENDATIONS: “Clinical emphasis must be placed on enhancing adherence during and particularly after pregnancy when Zidovudine is continued for a mother’s own care.”

Kirshenbaum, S.B. Hirky, A.E., Correale, J., Goldstein, R.B., Johnson, M.O., Rotheram-Borus, M.J. & Ehrhardt, A.A. (2004). “Throwing the Dice”: Pregnancy decision-making among HIV-positive women in four U.S. cities. *Perspectives on Sexual & Reproductive Health*, 36 (3), 106-113.

LOCATION: New York, Los Angeles, Milwaukee, San Francisco

SAMPLE: 56 HIV-positive women between the ages of 20-55. 60% Black, 21% Hispanic.

FINDINGS: “Regardless of women’s pregnancy experiences or intentions, reproductive decision-making themes included the perceived risk of vertical transmission, which was often overestimated; beliefs about vertical transmission risk reduction strategies; desire for motherhood; stigma; religious values;



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attitudes of partners and health care providers; and the impact of the mother's health and longevity on the child. Most women who did not want children after their diagnosis cited vertical transmission risk as the reason, and most of these women already had children. Those who became pregnant or desired children after their diagnosis seemed more confident in the efficacy of risk reduction strategies and often did not already have children."

RECOMMENDATIONS: "HIV-positive and at-risk women of childbearing age may benefit from counseling interventions sensitive to factors that influence infected women's pregnancy decisions...The misconceptions and misinformation reported suggest directions for family planning education and counseling. Counseling may be complicated by health care provider opinions, expressed directly or indirectly, that may jeopardize a woman's ability to make independent and informed decisions. As women with HIV live longer and healthier lives, better informed women may advocate more strongly for their reproductive rights."

Sarnquist, C. C., Cunningham, S.D., et al. (2007). The effectiveness of state and national policy on the implementation of perinatal HIV prevention interventions. *American Journal of Public Health, 97*(6), 1041-1046.

LOCATION: California

SAMPLE: 496 HIV-positive women and their infants, between 1987 and 2002

BACKGROUND: "The 1994 and 1995 US Public Health Service Guidelines regarding HIV testing and treatment for pregnant women and the resulting 1995 California law mandating an HIV test and treatment offer to every pregnant woman aim to reduce perinatal HIV transmission. However, the effectiveness of such policies after implementation is often unclear. [We] compared rates of offers of HIV tests and treatment before and after 1996."

FINDINGS: "We found significant increases in offers of HIV tests and offers of treatment when we compared women who delivered between 1987 and 1995 with those who delivered between 1996 and 2002. Receipt of prenatal care was the major predictor of both test and treatment offer."

RECOMMENDATIONS: "National guidelines and the 1996 California law improved health care for these women, which may lessen the risk of perinatal HIV transmission."

Sauer, M.V. (2006). American physicians remain slow to embrace the reproductive needs of human immunodeficiency virus-infected patients. *Fertility & Sterility, 85*(2), 295-297.

LOCATION: Author works at Columbia Presbyterian Medical Center

FINDINGS: (This is an opinion piece/editorial.) "Nearly 1 million Americans are infected with HIV. Most are living well and enjoying productive lives. Yet few programs in the United States permit unrestricted access to assisted reproduction for HIV-seropositive patients. Some of these individuals have conventional problems causing infertility. Many others are attempting to minimize viral transmission to their spouse or offspring. European centers remain far ahead of those in the United States in advancing techniques and offering services to safeguard the uninfected while providing effective, affordable care to the HIV-seropositive patient."

Siegel, K., & Schrimshaw, E. W. (2001). Reasons and justifications for considering pregnancy among women living with HIV/AIDS. *Psychology of Women Quarterly, 25*(2), 112-123.

LOCATION: New York, NY

SAMPLE: 51 HIV positive women

FINDINGS: “Women reported three major reasons for wanting a child: (1) her husband/boyfriend really wants children, (2) having missed out on raising her other children, and (3) believing that a child would make her feel complete, fulfilled, and happy. Women also reported several justifications that they believed offset the risks of pregnancy, including: (1) other HIV-infected women were having healthy babies, (2) feeling optimistic about having a healthy baby due to the prophylactic effects of AZT (zidovudine), (3) having faith that God will protect the child, (4) being young and “healthy” will prevent transmission, and (5) feeling that she is better able to raise a child now.”

RECOMMENDATION: “These findings suggest that to make fully informed pregnancy decisions, women should be encouraged to explore their reasons for wanting pregnancy, as well as discuss the potential risks.”

Webber, M. P., Chazotte, C. et al. (2003). Implementation of expedited human immunodeficiency virus testing of women delivering infants in a large New York city hospital. *Obstetrics & Gynecology*, 101(5), 982.

LOCATION: New York, NY

SAMPLE: Chart reviews of 1115 women admitted to hospital for labor and delivery between October and December 2000.

BACKGROUND: “Since August 1999, New York has required expedited HIV testing of pregnant women in labor or their newborns, with results available within 48 hours if no intrapregnancy test result was available. We documented the frequency and circumstances of expedited HIV testing, the time required for a result to be available, and hospital factors associated with different intervals.”

FINDINGS: “13.6% were tested under the expedited HIV testing procedure, and none were found to be HIV positive. 27% of women having expedited HIV testing had documentation of testing during prenatal care that was unavailable or overlooked during admission. Expedited HIV testing results were available at 48 hours or less time for 96% of the women, although results for women admitted Friday to Sunday took longer than weekday results. Expedited HIV testing results were available before delivery for 3.3% of women and less than 12 hours after birth for 31.7% of infants.”

RECOMMENDATIONS: “We found excellent compliance with the 48-hour time limit for expedited HIV testing but report lapses in access to prenatal HIV testing documentation, resulting in frequent duplicative testing. Further, the potential for optimal neonatal prophylaxis within 12 hours of birth was limited, as the turnaround time for HIV results exceeded 12 hours for two thirds of the infants in our sample.”

Welles, S. L., Bauer, G. R., Larussa, P. S., Colgrove, R. C., & Pitt, J. (2007). Time trends for HIV-1 antiretroviral resistance among antiretroviral-experienced and naive pregnant women in New York City during 1991 to early 2001. *JAIDS*, 44(3), 329-335.

LOCATION: New York, NY

SAMPLE: HIV-positive pregnant women

FINDINGS: “Although the prevalence of ART resistance was 15% among ART-experienced women from 1991 to 1994, alarmingly high rates of ART resistance (34%) are seen among these drug-experienced women enrolled during 1999 to early 2001. Moreover, resistance patterns included mutations to multiple classes of ART, with 19% of ART-experienced women having ART resistance mutations to NNRTIs and 16% of all ART-experienced women being resistant to PIs in the later years of follow-up. These findings are of great concern because not only could multiclass resistance to multiple ART potentially reduce the efficacy of treatment for prevention of mother-to-child transmission but the wide spectrum of ART resistance could limit treatment options for women as they progress through their infection.”



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RECOMMENDATIONS: “Our findings suggest that increasing rates of HIV-1 ART resistance among HIV-positive pregnant women could become a major consideration in selecting maternal ART treatment and prevention of mother-to-child transmission of HIV-1 in US population centers...A particular emphasis should be placed on educating patients about how even short discontinuations of ART, or treatment holidays, can increase the likelihood of developing resistance.”

Wilson, T. E., Ickovics, J. R., Royce, R., Fernandez, M. I., Lampe, M., & Koenig, L. J. (2004). Prenatal care utilization and the implementation of prophylaxis to prevent perinatal HIV-1 transmission. *Maternal & Child Health Journal*, 8(1), 13-18.

LOCATION: Brooklyn, NY; Miami, FL; Connecticut; North Carolina

SAMPLE: 303 HIV-positive pregnant women enrolled between 1996 and 1998; 73% African American, 18% Hispanic.

FINDINGS: Many women with HIV are at risk for not receiving prenatal care. “39% of women did not receive adequate prenatal care; nearly one quarter of women did not begin care within the recommended timeframe, and approximately one-fifth of women received fewer than the recommended number of prenatal care visits from the time of entry into care until delivery. Those classified as less than adequate in terms of receipt of recommended visits were at increased risk for not receiving ARV during the prenatal care period and during labor and delivery, and were more likely to have had an infant subsequently diagnosed with HIV infection...Lower adherence to prenatal care appointments is an important risk factor for not receiving full HIV prophylactic regimens.”

Wilson, T. E., Koenig, L. et al. (2003). Contraception use, family planning, and unprotected sex: Few differences among HIV-infected and uninfected postpartum women in four US states. *JAIDS*, 33(5), 608-613.

“Describes pregnancy intentions and contraceptive use among postpartum samples of women with and at risk for HIV infection. Inconsistent condom use associated with postpartum alcohol use. Few differences detected in reproductive behaviors as a function of HIV serostatus. Importance of counseling to decrease sexual risk behaviors.”

STRUCTURAL FACTORS

Criminal Justice Systems

Farley, J. L., Adelson Mitty, J., Lally, M. A., Burzynski, J. N., Tashima, K., Rich, J. D., et al. (2000). Comprehensive medical care among HIV-Positive incarcerated women: The Rhode Island experience. *Journal of Women's Health & Gender-Based Medicine*, 9(1), 51-56.

LOCATION: Rhode Island, esp. Providence

SAMPLE: Medical records of 110 women with HIV who were incarcerated in Rhode Island between 1989 and 1994 were reviewed. 43% black, 43% white, 12% Latina.

FINDINGS: During this time period, 28% (172 of 623) of the women diagnosed with HIV in RI were

identified through the prison's mandatory testing program. The paper describes the logistics of providing mandatory HIV testing in RI jails and prisons and the re-entry program that transitions HIV-positive prisoners to community care.

- “Antiretroviral therapy was well accepted [by incarcerated women] and followed community standards.”
- “Continuity of medical care after release was facilitated by the same physician caring for the patient in the community setting, with 83% of women following up for HIV care after release”
- “Participants...showed a statistically significant reduction in recidivism (defined as reincarceration for any reason) of program participants within the first year of the program.”

RECOMMENDATIONS: “Corrections can play a key role in reaching medically underserved populations, identifying HIV-positive individuals and linking them to care. Prison HIV testing programs should include posttest counseling, health education, substance abuse treatment, community referrals and preventative medical care.”

Freudenberg, N., Moseley, J., Labriola, M., Daniels, J., & Murrill, C. (2007). Comparison of health and social characteristics of people leaving New York City jails by age, gender, and race/ethnicity: Implications for public health interventions. *Public Health Reports*, 122(6), 733-743.

LOCATION: New York, NY

SAMPLE: 1,946 individuals leaving jail between 1997 and 2004. Sample included 704 women. Approximately 10% of these women were HIV-positive.

FINDINGS: “Compared with men, women were more likely to be homeless, use illicit drugs, report drug charges at index arrest, have health problems, and be parents.” Women were less likely to have been tested for HIV but reported higher rates of HIV.

RECOMMENDATIONS: “Jails concentrate individuals with multifaceted health and social problems, providing opportunities to engage at-risk populations in comprehensive reentry programs. Gender, age, and ethnic/racial differences among incarcerated populations require that interventions be tailored to the specific needs of these different groups...Given that many health and reentry programs for women in jail are still developed by men for a male model of needs, the problems women in this study experienced suggest the need for more women-specific programs.”

Lanier, M. M., & Paoline, E. A. (2005). Expressed needs and behavioral risk factors of HIV-positive inmates. *International Journal of Offender Therapy & Comparative Criminology*, 49(5), 561-573.

LOCATION: Jacksonville, FL

SAMPLE: HIV -positive 91 men, 57 women in Duval County Jail in 2000. (82% non-white)

FINDINGS: “This pilot study compares the needs of HIV-positive male and female jail detainees. Results illustrate surprisingly few differences between men and women and their HIV-related needs. The primary need identified for both males and females was post release housing...followed by HIV care and medication, cash and medical benefits....The results suggest no gender differences in terms of general health or emotional problems...We did find behavioral differences: More women (80.4%) engaged in prostitution. However, we did find that quite a few males (36.3%) did engage in prostitution... Men in this population tended to drink more, and women smoked more crack cocaine.”



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RECOMMENDATIONS: “Gender-specific alcohol and drug interventions may be warranted...more emphasis should be placed on meeting the basic survival needs of HIV-positive inmates. Only when this hierarchy of needs has been satisfied can inmates and program administrators focus on HIV treatment needs. This is not to relegate HIV treatment needs to a lower status, it simply acknowledges that this population is facing homelessness and other more immediate concerns that may take precedence over long-term treatment.”

Rich, J. D., Holmes, L., Salas, C., Macalino, G., Davis, D., Ryczek, J., et al. (2001). Successful linkage of medical care and community services for HIV-positive offenders being released from prison. *Journal of Urban Health*, 78(2), 279-289.

LOCATION: Providence, RI

SAMPLE: 97 HIV-positive individuals coming out of the Rhode Island prison over a three year period. 28 (29%) of the participants were women, but gender was not used to analyze the data so it is not clear if/how men and women’s experiences differed.

FINDINGS: Re-entry programs can help people with HIV to transition between prison and the community. People with HIV want to access care in order to stay healthy and will participate in transition programs. The initial period after release is critical and housing and psychosocial needs are often unmet. “Project Bridge has demonstrated that it is possible to maintain HIV-positive ex-offenders in medical care through the provision of ongoing case management services following prison release. Ex-offenders will access HIV-related health care after release when given adequate support.”

Richie, B. E. (2001). Challenges incarcerated women face as they return to their communities: Findings from life history interviews. *Crime and Delinquency*, 47(3), 368-389.

LOCATION: not specified

SAMPLE: 42 formerly incarcerated women. Does not specify how many of these women are HIV-positive but text includes a quote from one woman with HIV.

FINDINGS: “This article uses results of a qualitative research project to describe the challenges that incarcerated women face as they return to their communities from jail or prison.” The discussion about health care includes data from one participant with HIV who describes being sick “all of the time” and the stress of being homeless and going in and out of jail. The author notes that “most of the women I interviewed did, in fact, report a temporary improvement in their health status while incarcerated.”

RECOMMENDATIONS: “Women need comprehensive programs, better treatment, wrap-around services, empowerment programs, and opportunities for self-sufficiency. Discharge planning programs, ex-offender peer group support, mother-child programs, and intermediate sanctions all emerged as potential programmatic initiatives.”

Sheu, M., Hogan, J., Allsworth, J., Stein, M., Vlahov, D., Schoenbaum, E. E., et al. (2002). Continuity of medical care and risk of incarceration in HIV-positive and high-risk HIV-negative women. *Journal of Women's Health*, 11(8), 743.

LOCATION: New York, NY; Providence, RI; Baltimore, MD; and Detroit, MI.

SAMPLE: HIV Epidemiology Research (HER) Study: 871 HIV-positive and 439 high-risk HIV- urban women, ages 16-55 years old. All participants had a history of injection drug use or high-risk sexual behavior and were enrolled between 1993-1995.

FINDINGS: “12% of women were incarcerated within 1 year post enrollment. *Continuity of care with a single healthcare provider for more than 2 years prior to enrollment in the study was associated with decreased rates of incarceration even after adjusting for possible confounding factors....*History of prior incarceration and recent drug use were associated with increased risk of incarceration.”

RECOMMENDATIONS: “Continuity of medical care by a single healthcare provider was associated with decreased likelihood of incarceration, suggesting that the provider may play an important role in designing interventions to prevent incarceration in this high-risk population.”

Housing

Aidala, A. A., Gunjeong, L., Garbers, S., & Chiasson, M. A. (2006). Sexual behaviors and sexual risk in a prospective cohort of HIV-positive men and women in New York City, 1994-2002: Implications for prevention *AIDS Education & Prevention*, 18(1), 12-32.

LOCATION: New York, NY

SAMPLE: 968 HIV-positive men (579) and women (389) interviewed between 1994-2002 participating in Community Health Advisory and Information Network (CHAIN) Project.

FINDINGS: • “Recent experience with exchanging sex was also strongly associated with unsafe sex among women, as well as homelessness and drug use.”

- “Housing status was variously associated with HIV risk behaviors in this study as in others, especially among women for whom homelessness was a major risk factor for both unsafe sex and exchanging sex.”

RECOMMENDATIONS: “The association of risk behaviors with current substance use and homelessness suggests that innovative ways of reaching HIV-positive populations outside of the medical care setting, particularly those who are facing competing life priorities, are also needed.”

Scott, A., Ellen, J., Clum, G., & Leonard, L. (2007). HIV and housing assistance in four U.S. cities: Variations in local experience. *AIDS and Behavior*, 11, S140-S148.

LOCATION: New York City, New Orleans, Miami, and Chicago

SAMPLE: 46 HIV-positive women between the ages of 18 and 24 who were receiving medical care at a Adolescent Trial Network (ATN) clinic. Interviews conducted between 2004 and 2005.

FINDINGS: “This paper provides an account of how young, HIV-positive women manage their lives on limited budgets. The study findings elucidate city-to-city variability in housing assistance, and how this manifests in locality specific differences in the experience of HIV. Our research suggests that the receipt of housing assistance has ramifications for women’s engagement in care, and for their health. Women not receiving aid often move frequently in and out of homelessness, or “double up” with others in complex household arrangements to share costs. Women with long-term housing assistance, while still struggling financially, possess a stable base from which to approach daily life and HIV care.”

- “Eight of the nine women interviewed in New York City received HIV related housing assistance; the ninth women had chose to opt out of assistance. Four women lived alone, a phenomenon rarely seen elsewhere.”
- Other cities either did not have HIV-specific housing programs, or had programs only for people with AIDS (people with HIV were not eligible). New York’s program, which was supported by city, state and federal funds, was more comprehensive than the other programs that relied largely on federal funds.



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RECOMMENDATIONS: “This account suggests a need for empirical research assessing the impact of local variations in housing assistance on specific health outcomes for those with HIV. It also highlights the importance of understanding local contexts when designing housing interventions at both the individual and structural levels.”

Stigma

AmfAR. (2008). Stigma clings stubbornly to women living with HIV/AIDS. AmfAR: New York. This press release describes findings from an online survey of nearly 5,000 people in the United States. Findings reflected strong negative stigma against HIV-positive women. For example, 59% said they “would be somewhat or not at all comfortable with an HIV-positive woman serving as their childcare provider” and 20% “would be somewhat or not at all comfortable having a close friend who is HIV positive...only 14% of respondents felt that HIV-positive women should have children.”

Buseh, A.G. & Stevens, P.E. (2006). Constrained but not determined by stigma: Resistance by African American women living with HIV. *Women & Health, 44* (3), 1-18.

LOCATION: Wisconsin (primarily urban areas, some rural)

POPULATION: 29 HIV-positive African American women. Average age was 40 years old; average income \$9,390. Each woman interviewed 10 times over 2 years about their life histories and experiences living with HIV.

FINDINGS: These women experienced HIV stigma on multiple levels:

- Internally: existential despair (thinking life is over, feelings of shame, self-blame)
- Socially: shunning and callousness (people reacting with fear, avoidance, verbal abuse, rejection by family or friends)
- Institutionally: disregard (treated poorly in welfare offices, hospitals and prison, confidentiality not upheld, marginalized, compounded by racism)

“While participants were constrained by this multi-layered cultural negativity about HIV, they refused to be determined by it. Their stories demonstrate how they resisted stigma. Over time, by enlisting support, facing the illness, disclosing only at strategic times, *redefining stigma as ignorance*, and *becoming advocates*, they were able to challenge and oppose the shame and discredit that HIV infection had brought into their lives.”

RECOMMENDATIONS: “Research is urgently needed to anticipate, understand, and combat HIV stigma in the African American cultural context because African Americans have the highest HIV incidence, HIV/AIDS prevalence, and HIV mortality... The elements of stigma resistance described in this study may be starting points for designing participatory interventions for and with African American women living with HIV.”

SPECIAL POPULATIONS

American Indians/Alaska Natives

Bertolli, J., Lee, L. M., & Sullivan, P. S. (2007). Racial misidentification of American Indians/Alaska Natives in the HIV/AIDS reporting systems of five states and one urban health jurisdiction, U.S., 1984-2002. *Public Health Reports*, 122(3), 382-392.

LOCATION: Urban area: LA. States: AK, AZ, CA, OK, WA

SAMPLE: The HIV/AIDS Reporting Systems (HARS) racial classifications of 1,523 AI/AN individuals recorded as receiving HIV care in the Indian Health Service National Patient Information and Reporting System (NPIRS) were examined.

FINDINGS: 30% of the AI/AN individuals in HARS had been racially misclassified. The degree of error ranged from 3.7% in Alaska to 55% in California. 70% had been misclassified as white, 15% as Hispanic, 11% as black and 2% as Asian/Pacific Islander. Urban residence at the time of diagnosis was significantly associated with racial misclassification in HARS.

RECOMMENDATIONS: "Our findings add to the evidence that racial misidentification of AI/AN in surveillance data can result in underestimation of AI/AN HIV/AIDS case counts. Racial misidentification must be addressed to ensure that HIV/AIDS surveillance data can be used as the basis for equitable resource allocation decisions, and to inform and mobilize public health action."

Evans-Campbell, T., Lindhorst, T., Huang, B., & Walters, K. L. (2006). Interpersonal violence in the lives of urban American Indian and Alaska Native women: Implications for health, mental health, and help-seeking. *American Journal of Public Health*, 96(8), 1416-1422.

LOCATION: New York, NY

SAMPLE: 112 adult American Indian/Alaska Native (AIAN) women interviewed between 2000 and 2003. 6% (n=7) of this sample was HIV-positive (a higher HIV rate than for AIAN women in general)

FINDINGS: Participants reported high rates of inter-personal violence, including childhood physical abuse, rape and domestic violence. "A history of interpersonal violence was associated with depression, dysphoria, help-seeking behaviors, and an increase in high-HIV risk sexual behaviors."

- 60% of AIAN living in urban areas
- New York city is the urban area with the largest AIAN population in the United States (n=98,922)

RECOMMENDATIONS: Scholars and practitioners should promote culturally responsive standards of training for violence prevention efforts aimed specifically at urban AIAN women."

Hispanic Women/Latinas

Schrimshaw, E. W. (2002). Social Support, conflict, and integration among women living with HIV/AIDS. *Journal of Applied Social Psychology*, 32(10), 2022-2042.

LOCATION: New York, NY

SAMPLE: 146 HIV-positive women, including Puerto Rican, African American and non-hispanic white



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FINDINGS: This survey data found that Puerto Rican women reported higher levels of depression than white or African American women. Puerto Rican women also reported higher levels of social conflict and lower levels of social integration.

Shedlin, M. G., & Shulman, L. (2004). Qualitative needs assessment of HIV services among Dominican, Mexican and Central American immigrant populations living in the New York City area. *AIDS Care*, 16(4), 434-445.

LOCATION: New York City

SAMPLE: 27 HIV-positive men and 30 HIV-positive women from Mexico, the Dominican Republic and Central America ranging in age from 19-61 participated in focus groups in 2001.

FINDINGS: Results included detailed information on cultural meanings of HIV/AIDS; experience of stigma and rejection; testing issues; and satisfaction with services. Gendered findings include:

- Women report being infected by their spouses.
- Women more likely to seek information, served as information resource for men.
- “Women were more likely to seek care in general, and sooner than men, if they were sick.” Women also encouraged men to seek care.
- “Women were described...as having more access, reasons and opportunities/requirements for testing...more culturally appropriate and acceptable for women to seek any kind of health care.”
- Women more likely to join support groups than men.
- Women more likely to discuss “the difficulties of taking the medicines than men.”

RECOMMENDATIONS: “Data support the conclusion that to be effective in reaching and providing services to these immigrant groups, it is crucial to understand the environment from which they come and the impact of immigration. Poverty, repressive governments, lack of education/literacy, ethnicity, class, color-based stigma and cultural norms are crucial factors in determining their attitudes, motivations, decisions and behavior... The key elements for the provision of services to this population appear to be those that build on cultural norms and network human and institutional resources.”

van Servellen, G., Chang, B., & Lombardi, E. (2002). Acculturation, socioeconomic vulnerability, and quality of life in spanish-speaking and bilingual latino HIV-infected men and women. *Western Journal of Nursing Research*, 24(3), 246.

LOCATION: Los Angeles, CA

SAMPLE: 89 Latino HIV-positive individuals. Sample included men and women but data was not analyzed by gender, so not clear how men and women differed.

FINDINGS: The study measured the health-related quality of life (HRQOL) of monolingual and bilingual low-income, Latino men and women living with HIV. “The monolingual group had significantly lower levels of acculturation but did not differ from the bilingual group on any dimension of health status...The results did not support the hypothesis that acculturation mediates the impact of health status on HRQOL.” Findings from other studies about gendered differences in quality of life experiences among Latinos/as were included in background section: Hispanic women are more likely to delay HIV testing than Hispanic men.

Wohl, A. R., Lu, S., Turner, J., Kovacs, A., Witt, M., Squires, K., et al. (2003). Risk of opportunistic infection in the HAART era among HIV-infected Latinos born in the United States compared to Latinos born in Mexico and Central America. *AIDS Patient Care & STDs*, 17(6), 267-275.

LOCATION: Los Angeles, CA

SAMPLE: 803 Latinos in treatment for HIV

FINDINGS: “U.S.-born Latino women were more likely than Central American-born Latino women to develop an OI [opportunistic infection] from 1996 to 2000...These HAART era data suggest that variation in OI risk among Latinos may also be explained by acculturation factors, such as loss of social support systems and negative lifestyle changes [among US born Latinos].”

Older women

Aidala, A. A., Gunjeong, L., Garbers, S., & Chiasson, M. A. (2006). Sexual behaviors and sexual risk in a prospective cohort of HIV-positive men and women in New York City, 1994-2002: Implications for prevention *AIDS Education & Prevention*, 18(1), 12-32.

LOCATION: New York, NY

SAMPLE: 968 HIV-positive men (579) and women (389) interviewed between 1994-2002 participating in Community Health Advisory and Information Network (CHAIN) Project.

FINDINGS: • “Older women (compared to younger women) and Black and Hispanic women (compared with White women) were less likely to report unsafe sex.”

Emlet, C.A., Tangenberg, K. & Siverson, C. (2002). A Feminist approach to practice in working with midlife and older women with HIV/AIDS. *Affilia: Journal of Women & Social Work* 17 (2), 229-241.

LOCATION: San Francisco, CA

SAMPLE: 7 HIV -positive women between the ages of 45-56 who participated in a peer support group beginning in 1999.

BACKGROUND: “Older women with HIV/AIDS constitute an invisible population that is often ignored by organizers of HIV prevention efforts as well as by HIV and aging organizations.” The exact number of people over 50 with HIV is hard to determine because of demographic data on age is not uniformly collected, but it is estimated to be 15% of the HIV-positive population. This includes people who were diagnosed when they were over 50 and people who have “aged into” this category.

FINDINGS: Four major themes:

1. “First, there was palpable excitement and relief among the women because they had never before met exclusively with other HIV-positive women their age. The women observed that they did not relate to the issues addressed in other women’s HIV support groups which often focused on pregnancy, vertical transmission, parenting and child care.”
2. Older women want more information about the “medical aspects of HIV and aging.”
3. In contrast to younger women that experience high levels of instability (homelessness, drug use, incarceration, etc), older women are more psychosocially stable: adequately housed, not actively using drugs, connected to medical care and mental health support.
4. Older women with HIV may be extremely isolated and benefit from opportunities to interact in groups with other HIV-positive women. Older women may have experienced multiple AIDS-related loss and have unresolved grief issues.

RECOMMENDATIONS: “AIDS service organizations, the aging network, and policy makers must begin to recognize the critical need to support and assist older women with HIV/AIDS...The support



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group is a natural venue for older women with HIV. For women who have spent much of their lives in the role of caregiver, perhaps to the neglect of their own need for medical care, the group offers a healthier expression for their caregiving tendencies.”

Gosselink, C.A. & Myllykangas, S.A. (2007). The leisure experiences of older U.S. women living with HIV/AIDS. *Health Care for Women International* 28,(1), 3-20.

LOCATION: Unidentified Midwestern state

SAMPLE: 4 HIV-positive women over the age of 50

FINDINGS: “Findings pointed to differences in time for, access to, and meaning of leisure in pre- vs. post-infection leisure for these women.” Before infection, leisure time was spent with other people (friends and family) smoking, drinking (going to bars), engaging in outdoor activities (camping, gardening), going to movies and traveling. The women were all employed and owned cars, so leisure activities were readily accessible to them. After diagnosis, the women were under-employed and had less income to spend on leisure activities. Also, none of them owned cars so getting around was more difficult. Their health also kept them from participating in activities with others, staying home alone on “bad days.” More time was spent alone or with pets, in family focused and spiritual (church) activities. “As the disease progressed, however, each woman exhibited resilience in transcending systemic barriers to derive a spiritual view of leisure as a metaphor for the meaning of life.”

Sara, S. (2008, May 18). Despite HIV, fighting to maintain health and a positive attitude. *New York Times*.

This article describes a support group for African American and Hispanic HIV-positive women over 50 at Iris House, an AIDS service organization in Harlem, NY.

Shah, S. S., McGowan, J. P., Smith, C., Blum, S., & Klein, R. S. (2002). Comorbid conditions, treatment, and health maintenance in older persons with Human Immunodeficiency Virus infection in New York City. *Clinical Infectious Diseases*, 35(10), 1238-1243.

LOCATION: New York, NY

SAMPLE: 198 HIV-positive individuals over 55 years old who attended HIV clinics between 1990 and 1998. Sample included 57 (29%) women.

FINDINGS: Among the women, “79% had a Papanicolaou smear within 1 year, and 53% had a mammogram within 2 years.” Of the patients who received care after 1996:

- 89% had co-morbid conditions (mean number of conditions, 2.4)
- 81% received HIV-unrelated medications (mean number of medications, 2.7).

RECOMMENDATIONS: Comorbid conditions and use of concurrent HIV-unrelated medications need not adversely affect treatment of HIV-infected older individuals, but increased attention to health maintenance may be necessary.

Women who have sex with women (WSW)

Cooperman, N. A., Simoni, J. M., & Lockhart, D. W. (2003). Abuse, social support, and depression among HIV-positive heterosexual, bisexual, and lesbian women. *Journal of Lesbian Studies*, 7(4), 49-66.

LOCATION: New York, NY

SAMPLE: 373 HIV-positive women. African American (44%), Hispanic (25%), African American and Hispanic (17%).

BACKGROUND: Women who have sex with women (WSW) have been “virtually ignored” as an HIV risk group. Research has found high rates of risky behavior among WSW including injection and non-injection drug use, sex work, multiple partners and unprotected sex. Studies have also found that HIV-positive women have high rates of depression and abuse histories.

FINDINGS: “75% reported experiencing physical or sexual abuse at some point in their lives...child physical and sexual abuse and adult sexual abuse were significantly associated with depression...Lesbian/bisexual women reported higher rates of lifetime sexual and physical abuse than heterosexual women. However, there were no differences between the groups in total depression scores. Lesbian/bisexual women had significantly greater support from friends and groups/organizations than the heterosexual women.”

Friedman, S. R., Ompad, D. C., Maslow, C., Young, R., Case, P., Hudson, S. M., et al. (2003). HIV prevalence, risk behaviors, and high-risk sexual and injection networks among young women injectors who have sex with women. *American Journal of Public Health*, 93(6), 902-906.

SAMPLE: 803 female IDUs living in 5 different cities, including New York, and recruited between 1997 and 1999. 274 of these women identified as lesbian or bisexual.

FINDINGS: Women who have sex with women (WSW) “injection drug users have higher HIV prevalence and incidence rates and a greater likelihood of engaging in high-risk injection and sexual practices with men. WSW injection drug users were also more likely to have been institutionalized or homeless, to have engaged in riskier behaviors, to have had high-risk sexual and injection networks and to have been anti-hepatitis B virus-positive. In high HIV prevalence sites, WSW injection drug users were more likely to have been infected with HIV.”

RECOMMENDATIONS: “Studies of drug users and other populations should consider sexual identity and sex between women, which may help explain variations in homelessness, institutionalization, behavior, networks, and infection rates. Research and interventions targeting IDUs should incorporate issues of sexual identity and same-sex sexual behaviors among women and find ways to deal with related social and economic issues.”

Young, R. M., Friedman, S. R., & Case, P. (2005). Exploring an HIV paradox: An ethnography of sexual minority women injectors. *Journal of Lesbian Studies*, 9(3), 103-116.

LOCATION: New York, NY and Boston

SAMPLE: 65 sexual minority women injectors

FINDINGS: “HIV risk and infection are markedly increased among sexual minority women injectors compared to other injecting drug users...Neither the presence of gay or bisexual men in risk networks, nor a sense of invulnerability due to lesbian (or other sexual minority) identity seem to be plausible explanations of increased HIV among sexual minority women injectors. However, multiple marginalization was found to be pervasive and to have severe consequences that can be traced to increased HIV risk for many women in the study.”

