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United Way
of New York City

We Speak:

New York City Women Living with HIV/AIDS Speak about Their Needs

Report Summary

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New York City Women Living with HIV/AIDS Speak about Their Needs

A Report Prepared for
United Way of New York City

By The Women of Color Policy Network
The Wagner School of Public Service
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June, 2006

Report Summary

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THE WOMEN AND FAMILIES INITIATIVE (WFI)

Launched in 1992, The Women & Families with HIV/AIDS Initiative (WFI)—represents a unique jointly-funded public-private partnership in which the New York State Department of Health AIDS Institute provides programmatic oversight and United Way of New York City provides technical assistance and fiscal administration. Over the years, the partnership has evolved to a higher level of collaboration in providing support to the subcontracting agencies.

WFI community-based service providers are:

- The Church Avenue Merchants Block Association
- Community Healthcare Network: Dr. Betty Shabazz & Queens Health Centers
- Harlem Dowling – West Side Center for Children and Family Services
- Iris House
- United Bronx Parents
- The Women's Center at Montefiore Medical Center
- Ryan-Nena Community Health Center
- Planned Parenthood of New York City
- VIP Community Services
- Gay Men's Health Crisis (GMHC)

The WFI aims to expand availability of HIV-related services for women and their families and strengthen the referral linkages between hospital HIV counseling and testing programs and community-based health and social services. The funding is intended to enhance the provision of and access to HIV services for women. The initiative specifically targets HIV-infected women and their families who reside in some of New York City's most impoverished communities with the highest concentrations of HIV/AIDS diagnoses.

The women and families served though WFI typically have difficulty accessing health care and require frequent personal contact to ensure the receipt of services. Family centered case management and supportive services are the principal services under this initiative. Using a team approach to service delivery, WFI provides or refers HIV-positive women and their family members to entitlements, counseling, advocacy, support groups, workshops, transportation/escort, medical respite, homemaking, emergency cash assistance, and 24-hour crisis intervention services; as well as medical, mental health, substance use, guardianship/permanency planning, structured socialization, and other supportive services.

The women in this study received HIV/AIDS-related services through WFI partner agencies. We are pleased that almost all of the women in this study are currently accessing primary medical care (99%) and gynecological care (96%), and that 87% utilize support groups and 82% case management services, but they represent a small percentage of women impacted by HIV/AIDS. Additional funding is needed to promote public/private partnerships to expand and enhance further service delivery systems.

ACKNOWLEDGEMENTS

United Way of New York City (UWNYC) provided funding for this study. We deeply appreciate the commitment demonstrated by UWNYC to our efforts and to seeing this document published. We especially thank the women who participated in our study. They courageously agreed to share their stories with us and patiently responded to our questions. This report exists because of their support.

We also would like to acknowledge the principal investigator of the project, Walter Stafford, Ph.D., Professor of Urban Planning and Public Policy at New York University's Robert F. Wagner School of Public Service, and Director of the Women of Color Policy Network (WOCPN). Dr. Stafford and the WOCPN staff: Diana Salas, Assistant Research Scientist; Melissa Mendez, Assistant Research Scientist; Angela Dews, Executive Director; and interns who worked tirelessly through each phase of the project. A special thanks goes to Premanjali Devadutt, Consultant.

We gratefully acknowledge the assistance of interviewers who have done an outstanding job capturing the stories and challenges of HIV-positive women in New York City. The thoughtful commentary and helpful suggestions offered by the Emerging Needs Advisory Committee also are very much appreciated. The members of the advisory committee are:

- Shirley Gayle, Church Avenue Merchants Block Association, Inc. (CAMBA)
- Janet Goldberg, Community Healthcare Network (Dr. Betty Shabazz & Queens Center)
- Talata Reeves, Gay Men's Health Crisis
- Tara Herlocher, Harlem Dowling - West Side Center for Children and Family Services
- Marie St. Cyr, MSW, Iris House
- Daphne Hazel, Planned Parenthood of New York City, Inc.
- Matt Hamilton, Ryan-NENA Community Health Center
- Delores Anderson, United Bronx Parents, Inc.
- Adonica Matthews, VIP Community Services
- Kimberleigh J. Smith, Federation of Protestant Welfare Agencies and Women's HIV Collaborative of New York
- Anitra Pivnick, Ph.D., The Women's Center at Montefiore Medical Center
- Karen Bovell, New York State Department of Health AIDS Institute

Finally, we would like to express our gratitude to D. Pulane Lucas, MBA, for managing the project, and numerous other individuals who provided assistance in the research for and preparation of this document.

EXECUTIVE SUMMARY

New York City is the nation's epicenter for women living with HIV/AIDS. In 2001, almost 20% of women in the United States living with AIDS resided in New York City, where 88% of them were women of color (blacks comprised 55% and Latinas 33%) (UWNYC, 2002). In 2000, 52% of all New York City women infected with AIDS resided in 10 neighborhoods known to have the city's highest concentrations of poverty.[1] These neighborhoods are among those recognized for having a set of socioeconomic and geo-political conditions that contribute to risky behaviors for HIV infection (*See* Report Summary for more details). Conditions of poverty have been linked directly and indirectly to increased risk for HIV infection (CDC, 2004).

Recognizing the importance of effective service delivery for HIV-positive women, United Way of New York City (UWNYC) commissioned New York University's Women of Color Policy Network to conduct a needs assessment of this population. UWNYC believes that better understanding the needs of women will inform the manner in which resources are allocated, strategies formulated, and services delivered.

This study examines the needs of HIV-positive women in New York City. Study participants are female clients from agencies that are part of the Women and Families Initiative (WFI) of UWNYC.

I. STUDY GOALS

Several goals guided our work:

1. To end the invisibility of women with HIV/AIDS by allowing them to speak for themselves;
2. To collect, synthesize, and interpret comprehensive data critical for service providers and decision-makers concerned with HIV/AIDS policies and programs;
3. To provide agencies with information essential for better understanding the needs of HIV-positive women;
4. To explore the manner in which multiple forces bear upon the lives of women infected with HIV/AIDS in New York City.

II. KEY RESEARCH QUESTIONS

The study addresses the following key research questions:

1. What are the met, unmet, and emerging[2] needs of HIV-positive women and their families?
2. What effect has living with HIV/AIDS had on the lives of women and their families?
3. What factors contribute to complexity in the lives of women infected with HIV/AIDS?

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[1] WOCPN tabulation based on The New York City Department of Health and Mental Hygiene data.

[2] Emerging needs arise from concerns and challenges that women in our study anticipate will happen in the future. Each woman anticipates a unique set of emerging needs that if not addressed in a timely manner may adversely affect her and members of her family.

III. SAMPLE CHARACTERISTICS

- A non-random sample size: 139 women.
- Age range: 19 to 72 years old.
- Black women comprised almost 70%; Latinas 31%.
- 109 (78%) women are native born; 30 (22%) were born outside the U.S. mainland.[3]
- Over half of the respondents had not attained a GED or high school diploma.
- The majority of the sample self-identified as heterosexual or straight; 23 (17%) classified themselves as lesbian or bisexual.
- Almost 75% of respondents were not currently married or living with a partner.
- Thirty-six women (26%) are married or living with a partner.
- More than half of respondents have responsibility for minor children.
- The majority of the women are not currently working.
- Three out of four of women are Food Stamp recipients, 31 (22%) Temporary Assistance for Needy Families (TANF) recipients, 59 (42%) are Supplemental Security Income (SSI) recipients.
- Eighty-six women (62%) are HIV-positive but had not received an AIDS diagnosis.
- Thirty women (22%) have been diagnosed with AIDS.[4]

IV. STATISTICAL ANALYSIS

We performed qualitative and quantitative data analyses. The women's responses were analyzed using a variety of statistical procedures, including chi-square and logistic regression. Subgroup analyses were conducted on selected demographic characteristics, (i.e., age, race, education, marital status, minor child responsibility, sexual orientation, and nativity).

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[3] Women born outside the U.S. mainland include those born in the Commonwealth of Puerto Rico. As residents of the U.S., Puerto Ricans may have better access to medical and social services than individuals born outside the U.S. mainland. We did not capture how long women had lived in their native country or on their native island.

[4] Twenty-three women (17% of respondents) did not reveal their HIV/AIDS status.

V. KEY FINDINGS

This study documents the interwoven relationship between the feminization of poverty and the feminization of HIV/AIDS and supports prior research that links poverty with increases in the likelihood of HIV infection among poor women of color. The work highlights the tremendous service and program needs of HIV-positive women and their families. In this report, we discuss how these needs are shaped by social, economic, cultural, and political contexts and how they manifest through personal and structural concerns.

We identified 11 principal findings derived from both *personal* and *structural* concerns highlighted by women in the sample. *Personal* dimensions are defined by physical, psychological, emotional factors; as well as intimate, familial, and other interpersonal relations. *Structural* aspects are externally derived macro-level dynamics, such as policy, social, economic, cultural, and political forces. The confluence of personal factors and structural forces limits the ability of many women in these communities to negotiate risk in their lives.

1. Women in Need of Services

As a complex, biological, behavioral, and social phenomenon, HIV/AIDS creates a complexity of needs in the lives of HIV-positive women. These needs are defined by factors inclusive of age, race/ethnicity, education level, socioeconomic status, minor child responsibilities, progression of disease, and more (Squires, 2003).

- Almost half of the women wanted educational and employment services but were not receiving them.
- Roughly 10% of single women[5] and women with spouses or partners needed but were not receiving childcare or after-school services.
- Compared to single women:
  - Women with spouses and partners are four times more likely to need but not receive childcare and after-school services.
  - Women with spouses or partners are almost three times more likely to have an unmet need for home attendant services.
- Compared to women without minor child responsibilities:
  - Women responsible for a minor child are almost six times more likely to want but not receive family/parenting services;
  - Women responsible for a minor child are seven times more likely to want but not receive mental health services for a child and childcare/after-school services; and
  - Women responsible for a minor child are two to three times more likely to have unmet financial/entitlement, basic living, home attendant, and spiritual services needs.

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[5] Single women are comprised of women who have never married, as well as those who are widowed, separated, or divorced.

- Compared to U.S.-born black and Hispanic women:
  - Women born outside the U.S. are twice as likely to want but not receive legal/correctional services;
  - Women born outside the U.S. are three times as likely to want but not receive holistic services;
  - Women born outside the U.S. are four times more likely to want but not receive group therapy; and
  - Women born outside the U.S. are almost five times more likely to want but not receive case management services.

2. Mental Health Services for Women and Families

High levels of anxiety and depression can disrupt effective medical management of HIV/AIDS in women and lead to emotional distress, poorer health outcomes, missed medical appointments, failure to follow health provider instructions, and failure to adhere to prescribed HIV medications and treatments (Catz *et al*., 2002).

- Twenty-five women (18% of respondents) indicated that they had a mental illness.
- Twenty-six women in the study also expressed a need for the mental health services for their children.

3. Children in Need of Services

Children whose mothers have HIV/AIDS have enormous needs that if not addressed will place children at risk for emotional, nutritional, educational, and behavioral problems, as well as early pregnancy, substance abuse, and suicide as they get older (Roth, 1994; Aronson, 1995; Pivnick & Villegas, 2000).

- As HIV symptoms progress, women will increasingly look to their minor children to assist them. It is not uncommon for the children of HIV-positive women to need a break from care giving responsibilities.
- Multiple generations often reside in the households of HIV-positive women. Many women live with minor and adult children, and/or grandchildren.
- Women living with HIV/AIDS are concerned about their minor children's engagement in risky behaviors.
- Ten women in our sample have an HIV-positive minor child.

4. Partners and Spouses in Need of Services

Partners and spouses of HIV-positive women need mental health services, domestic violence prevention, medical care and information, and other supportive services to meet their needs and help them adjust to life with HIV/AIDS.

- Of the 36 women with a partner or spouse, 32% believe that as a result of their HIV status, partners will need services to cope.

- Of the 38 women with HIV-positive partners or spouses, 28 (74%) indicated that their partners also are receiving services for his or her HIV status.
- Thirty-six women in our sample indicated concern about partner violence as it relates to disclosing their HIV status.

5. Lack of Power in Relationships

Violence towards women is a growing concern. Childhood sexual abuse, domestic violence, and partner abuse place women at greater risk for exposure to HIV/AIDS and other sexually transmitted diseases. Violence towards women also increases the risk for serious health problems, inclusive of physical harm, stress and depression, risky behaviors, and low self-esteem (Hogben *et al*., 2001).

- Overall, 65% of respondents had experienced an abusive relationship. Sixty-nine percent of U.S.-born, and 50% of women born outside the U.S. had been in an abusive relationship.
- Compared to U.S.-born women:
    - Non-U.S.-born women are twice as likely to have ever been in an abusive relationship.
    - Non-U.S.-born women are twice as likely to have ever been concerned that someone might physically hurt them when disclosing their HIV/AIDS status
- Thirty-eight percent of the women had provided sex in exchange for drugs, money, or a place to stay.
- Compared to women born outside the U.S.:
    - U.S.-born women are five times more likely to have provided sex in exchange for drugs, money, or a place to stay.
    - U.S.-born women are almost three times more likely to have been forced to have sex without their consent.

6. Employment and Educational Opportunities

Women, especially women with limited education, have few opportunities of securing a decent paying job. For women with HIV/AIDS, whose illness is designated as a disability under federal law (HIV/AIDS is covered under the 1990 American Disability Act), the transition from disability-related unemployment to employment is even more difficult.

- Twenty-seven women (19%) are working.
- Of the 31 current TANF recipients, 6 (19%) are working now.
- Of the 59 current SSI recipients, 12 (20%) respondents are working.
- Ninety-eight women (81% of respondents) would like additional information on job training and educational programs.
- Seventy-five women (60% of respondents) expect to work over the next 12 months.

7. Nutrition

Women living with the virus are encouraged to follow a prescribed nutritional regimen. Failure to maintain healthy eating habits may negatively impact immune functioning and consequently increase disease progression (Mackle, 2001). Low-income HIV-positive women who reside in communities at risk face numerous obstacles to obtaining reasonably-priced healthy foods.

- Twenty-nine respondents (21%) do not receive nutritional counseling.

  Thirty-three respondents (24%) do not have enough food for themselves and their families to eat.
- Of the 47 women who stated that they have had difficulty purchasing foods recommended by their nutritional counselor, 34 (72%) are Food Stamp recipients.
- Thirty-eight women (28%) receive nutritious foods from their agency; 46 women (33%) access food from pantries.

8. Housing

Affordable housing in a safe environment is essential to the well-being of women and the families living with HIV/AIDS.

- Almost three out of four respondents reside in permanent rental housing.
- Ninety percent of respondents (110 women) receive assistance from a government agency to pay their rent or mortgage.
- Thirty-three women (24%) indicated that their housing or living arrangement had worsened in the last year.
- Sixty-six women (51%) will look for another place to live in the upcoming year.
- Three women (2%) indicated they are currently homeless.[6]

9. Significance of Governmental Support

For many poor and low-income HIV-positive women, government support serves as a stabilizing force in their lives, helping them meet economic, social, medical, and housing needs. Yet, securing governmental support is becoming increasingly difficult in an environment of welfare reform and reduced funding for social welfare programs.

- Three out of four respondents indicated they became Food Stamp and Medicaid recipients after their diagnosis, reflecting jumps of 26% and 29% respectively.
- After HIV diagnosis, the number of TANF recipients declined by 54.4%; while SSI recipients jumped 80%, a leap from 12 recipients before HIV diagnosis to 59 after diagnosis.
- One respondent indicated she received Medicare prior to HIV diagnosis. Medicare recipients rose to 11 following HIV diagnosis, a 90% increase.

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[6] One woman resided with friends/relatives, and two women lived in transitional housing.

- Forty-two women (43% of respondents) had experienced problems obtaining government assistance.

10. Current Utilization of HIV-Related Services

Sero-positive women seek supportive and case management services to assist them in reducing and overcoming barriers to health, mental health, social, housing, employment, and educational and other services. These barriers are particularly problematic for poor, vulnerable women. Increasingly, women from diverse backgrounds and with various demographic characteristics seek HIV-related services.

- Nearly all women currently access primary medical care (99%) and gynecological care (96%).
- Compared to Latinas:
    - Black women are three times more likely to currently use specialty medical care[7] and group therapy.
    - Black women also are four times more likely to take advantage currently of support groups and 11 times more likely to access other mental health services.[8]
- Compared to women without minor child responsibility:
    - Women with responsibilities for a minor child are almost five times more likely to access family/parenting and holistic services, and mental health care for services for their children.
    - Women who are responsible for minor children also are more than eight times as likely to use childcare and after-school services.

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[7] Specialty medical care includes health services related to medication side effects or other medical conditions, such as eye and skin care, diabetic and cancer treatments, and care for digestive and neurological disorders.

[8] Other mental health services are delivered by psychiatrists, psychologists, psychiatric nurses or social workers in a hospital or clinical setting, and not supportive services, such as individual therapy or support groups, offered through local HIV/AIDS service organizations.

11. Challenges to HIV-Prevention

Effective HIV/AIDS prevention and intervention initiatives are designed to halt virus transmission, reduce barriers to early diagnosis, and decrease the number of reinfections. Yet, HIV/AIDS prevention and intervention strategies are not always sensitive to the educational levels, ethnic and cultural contexts, socioeconomic backgrounds, gender inequality in relationships, and the intimate dynamics of sexual relations of poor and low-income women of color. Women use—and do not use—condoms for many reasons. The meanings associated with condom use are complicated and multidimensional (Pivnick, 1993). While some women associate condom use with birth control, HIV/AIDS protection, and love and concern for one's partner, others associate the use of condoms with the lack of intimacy and suspicion of sexual infidelity, particularly those in long-term relationships.

- While slightly more than three out of four women in our sample (98 respondents or 77%) believe that there is sufficient information about HIV/AIDS prevention available, three out of four (96 respondents or 75%) also feel that there are better ways to provide HIV/AIDS prevention information.

- When asked about HIV prevention information, 84 women (64% of respondents) indicated that they could have done something to avoid contracting HIV.

VI. CONCLUSION

In this report, we have discussed HIV-positive women within the context of their communities. We also have sought to shed light on their needs and concerns, which often are defined by conditions of poverty. Our primary goal in conducting this study has been to give voice to a diverse group of women. This work is significant because it highlights the needs of women of color with HIV/AIDS, a population that has largely been neglected by major segments of the public, elected officials, and the media.

Fortunately, for many women residing in New York City, the extent of devastation from HIV/AIDS in their lives has been mitigated in part by the programs and services offered through a network of HIV/AIDS service organizations. Yet, service providers face their own unique set of challenges, often defined by the same forces that influence the lives of women they serve. HIV/AIDS service organizations, particularly those serving women of color, struggle to survive themselves in an environment of under-funding, allocation cutbacks, shifting funding priorities, human resource limitations, and diminishing political will and support. While structural changes are needed desperately to eradicate conditions of poverty in communities at risk, service providers must have the human and financial resources to equip and empower HIV-positive women to transform their lives in the midst of the poverty in which they live. With a variety of support systems, it is hoped that poor sero-positive women increasingly can become more self-sufficient and advocates of change in their own lives, families, and communities.

This study presents a wealth of information on the needs of women living with HIV/AIDS. We have sought to elevate their needs by giving them voice through the presentation of their own words. (*See* Report Summary and full report for actual comments made by study participants.) Through this work, women in our study have spoken about their present and future needs, and those of their children and partners. It is our hope that somebody is listening to our call to action.

VII. RECOMMENDATIONS

The interplay of racism, sexism, and socioeconomic factors are blamed for much of the health disparity experienced between HIV-positive women of color, men, and white women (Ginty, 2005). Inequality is linked to the rising HIV/AIDS epidemic among women, reflecting alarming gender gaps in resources and power (Joint United Nations Program on HIV/AIDS, 2004). Additionally, compared to white women, black women are 25 times more likely to be HIV-positive (Ginty, 2005). Disparities in employment status, education, household income, medical care and insurance, and social services (Bossette *et al*., 1998; Barkan *et. al*., 1998; Pinn, 1992; Clancy and Massion, 1992) combined with the manner in which sexual relations are governed between men and women, leave many women powerless and vulnerable to HIV infection. The interplay of these and other forces together places a tremendously heavy burden on HIV-positive women in New York City.

Our recommendations address three major areas: service models, emerging needs, and resources. (*See* Report Summary for more details.)

MODELS OF SERVICE

1. Foster collaborations between non-profits, private corporations, and government service networks to better meet the needs of women and their families. Encourage multi-level coordination and collaboration among community-based organizations, government, and the private sector to provide comprehensive family-centered services that prioritize the needs of women as a central focus in the family group.

2. Increase provision of capacity-building resources for agencies that specialize in and expand family-focused services. Enhance and increase the number of programs and services specifically targeting HIV-positive women and their children.

EMERGING NEEDS OF WOMEN

1. Formulate ongoing strategic plans to address emerging needs based on the evolving epidemiology of the virus.

2. Encourage and support the development of collaborative efforts among providers to better address the multi-layered complex issues of women and their families through mental health services for positive women their spouses, partners, and their children.

3. Fund and create special programs to identify and serve aging women and women in new immigrant communities.

RESOURCE IDENTIFICATION

1. Increase financial resources to non-profit agencies serving women with HIV/AIDS.

2. Provide funding to HIV/AIDS service organizations to strengthen domestic violence prevention programs and services for women and their entire families.

3. Increase funding to HIV/AIDS-risk-reduction interventions that have demonstrated effectiveness in changing behavior and reducing transmission risk.

4. Provide funding to agencies and organizations that educate and train women living with HIV/AIDS who are interested in earning their GED, acquiring critical life skills, and preparing for employment opportunities.

5. Support and collaborate with organizations that are utilizing effective strategies to facilitate and support HIV-positive women's entry, reentry, and advancement in the labor market.

6. Support organizations that build and provide access to safe, adequate, and affordable housing.

REPORT SUMMARY

I. INTRODUCTION

On December 13, 2004, in recognition of the 18th annual World AIDS Day, a *New York Times* editorial highlighted one of the critical realities of the era: the feminization of HIV/AIDS. At the time the editorial appeared, women constituted nearly half of the world's 40 million people with HIV/AIDS, up from 35% in 1985. Young women between the ages of 15 and 24 years old accounted for a startling 62% of the women with HIV (UNAIDS, 2004). While the skills and labor of women have contributed to burgeoning economies around the world, the feminization of HIV/AIDS threatens to reverse years of economic development.

Influenced in part by the unanticipated onslaught of the epidemic on women, particularly women in the developing world, both the United States and the United Nations Security Council declared AIDS a global security threat—the first time a disease had invoked such a response. Facing the reality that families and communities were dissolving under the burden of the disease, the UN General Assembly issued a Declaration of Commitment on HIV/AIDS in 2001. They indicated mounting concern about the health of women and young girls and expressed alarm that the disease presented a serious impediment to the global development goal of ending poverty, which the Assembly had adopted in its Millennium Declaration in 2000.

The feminization of the HIV/AIDS epidemic registered more slowly in the United States, even though the lives of black women and Latinas, two of its most impoverished women's groups, were being threatened by the spread of the virus. Infection rates among black women, whose poverty rates had deepened drastically in the late 1990s, increased faster than among any other racial/gender groups. By 2003, the rate of AIDS diagnoses for black women had risen to 50 for every 100,000 women, 25 times the rate for white women. The rate for Hispanic women was 12 per 100,000. Black women and Latinas, who made up about one-quarter of the nation's women, were 83% of women with AIDS. AIDS had become the leading cause of death for black women ages 25-34 and one of the four leading causes of death for Hispanic women 35-44 (CDC, 2003)

The rate of AIDS diagnoses among women is closely related to the feminization of poverty, according to recent studies from the Center for Disease Control and Prevention (CDC, 2003) and a study in Los Angeles (Simon *et al*., 1998), which documented that poverty and high unemployment rates are strongly related to the HIV infection rate among black women. Surprisingly, however, there have been few recent studies on women with AIDS in New York City, although by 2003, nearly 20% of all the women in the United States living with HIV/AIDS resided in the city, making it the national epicenter of the virus for women (CDC, 2001).

Cognizant of the global and national trends of women with HIV/AIDS and New York City's role as the epicenter, the United Way of New York City undertook a study of the current and emerging needs of New York City women living with the virus. During the course of the research, the study took on added significance when it became apparent that, despite the United Nation's announcement that 2004 - 2005 was dedicated to women with AIDS, the issues of women in New York City remained largely invisible.

II. BACKGROUND

During the earliest stages of the epidemic, women—especially women of color—were rendered invisible through a web of government, market, policy, research, civic and philanthropic decisions that have proven nearly intractable. For women, the policy omissions were sequential, moving from silence about the problem in general, to recommendations to regulate the behavior of homosexual men, to an emphasis on medication. Government leaders and agencies were especially silent about women, even though the first woman died from AIDS in 1981 (Chambers, 1999), and there was evidence that women in prison had the virus (Law, 2003). The federal government refused to fund research proposals to study these early signs of trouble for women (Bowleg, 1992). Philanthropic institutions, which are critical in filling vacuums created by government policies, often have been slow in providing resources for supportive network building for women of color in general and the HIV/AIDS populations more specifically (Chambers, 1999).

Critical research linking HIV/AIDS in women to poverty, economic exclusion, and to their subsequent powerlessness and vulnerability did not begin to gather momentum until the late 1980s. Three consequences of these research gaps have been the lingering focus on the individual risk behaviors of women of color, the reinforcement of long-standing racial stereotypes about their sexual behavior, and the absence of services that focus on the specific needs of women. The failure to develop supportive organizations for women of color also reflected the women's limited financial resources, the communities' latent sexism, and the mistaken belief that associated the virus with homosexuals, a belief reinforced by the homophobia in some sectors**.** It is not insignificant that in New York City, the epicenter of the women's HIV crisis, it took 12 years before Iris House, one of the first supportive services nonprofit organizations designated specifically for women with HIV/AIDS, was created in Harlem. Even then, the founders faced an uphill struggle convincing supporters that their proposal for comprehensive services, including services for children and families, was a needed substitute for the service model developed for gay men.

Today, 25 years after the discovery of HIV, in what may be called the third wave of service development for lower-income women with HIV/AIDS, the silence is being broken by a growing awareness of the widespread suffering of women with the virus and a guarded acknowledgment that the silence has been caused in part by structural forces that reinforce a trilogy of racism, sexism, and poverty. This third wave has been marked by an increasing diversity of women seeking services, including new immigrants and older women. It is also marked by new pressures on women to negotiate services for themselves and their families with the diminution of welfare assistance.

The significance of this study lies in its ability to examine the complexity of needs facing women infected with HIV/AIDS by analyzing their responses to a host of questions pertaining to the impact of living with the virus on them and their families. In this study, we hear from black women and Latinas from diverse backgrounds through quantitative and qualitative data. The women voluntarily participated in this research project to help us better understand the needs of HIV-positive women and their families. Study participants identified their met, unmet, and emerging social, medical, housing, economic, personal, and family needs, while highlighting the support systems that allow them to realize fuller and more meaningful lives.

III. METHODOLOGY

This study examines the needs of HIV-positive women in New York City. We interviewed 150 clients and omitted 11 cases from the dataset, leaving 139 participants in the sample.[9] Study participants are female clients from agencies that are part of the Women and Families Initiative (WFI) of UWNYC. WFI is comprised of 10 New York City-based not-for-profit AIDS service organizations (ASOs). The study benefited from the responses of clients who participated in interviews with quantitative and qualitative components.

A. STUDY GOALS

Several goals guided our work:

1. To end the invisibility of women with HIV/AIDS by allowing them to speak for themselves;
2. To collect, synthesize, and interpret comprehensive data critical for funders, service providers, and decision-makers concerned with HIV/AIDS policies and programs;
3. To provide agencies with information essential for better understanding the needs of HIV-positive women;
4. To explore the manner in which multiple forces bear upon the lives of women infected with HIV/AIDS in New York City.

B. KEY RESEARCH QUESTIONS

The study addresses the following key research questions:

1. What are the met, unmet, and emerging[10] needs of HIV-positive women and their families?
2. What effect has living with HIV/AIDS had on the lives of women and their families?
3. What factors contribute to complexity in the lives of women infected with HIV/AIDS?

C. SURVEY INSTRUMENTS

We developed a client survey instrument, consisting of qualitative and quantitative measures, that covered a range of topical areas, including risk behaviors, disclosure, housing, employment, personal relationships, as well as entitlement services, medical care utilization, and individual and neighborhood characteristics. We produced English and Spanish versions of the survey. The English version was piloted twice before commencing interviews.

Researchers interviewed 150 clients (more than 10% of the WFI population) between August 2004 and February 2005. All study participants who completed the survey received a

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[9] Cases were omitted from the sample due to: (1) under-representation (one Native American, two whites, two bi-racial clients, and one transgender individual), (2) ineligibility (two HIV-negative women), and lack of information (three surveys were incomplete).

[10] Emerging needs arise from concerns and challenges that women in our study anticipate will happen in the future. Each woman anticipates a unique set of emerging needs that if not addressed in a timely manner may adversely affect her and members of her family.

$25 stipend. Researchers asked study participants open- and closed-ended questions to gain insight into their emerging and anticipated needs in order to better capture the complexity of their lives.

D. SAMPLE CHARACTERISTICS

The following describes the sample.

- A non-random sample size: 139 women
- Age range: 19 to 72 years old
- Black women comprised almost 70%; Latinas 31%.
- While the majority of black women identified as African American, 13% indicated their birthplace as Nigeria, Jamaica, Haiti, Trinidad, Barbados, or Guyana.
- Among Latinas, 63% were native-born. Twenty-one percent were born in Puerto Rico, while 16% were born in Peru, Honduras, Dominican Republic, Cuba or Nicaragua.
- Eight women (6%) indicated Spanish as their primary language, and 18 (13%) were bilingual.
- One hundred and nine (78%) women are native born; 30 (22%) were born outside the U.S. mainland.[11]
- Over half of the respondents had not attained a GED or high school diploma.
- Thirty-one women (22%) had attained a GED or graduated high school, and thirty- three (24%) women had completed trade school, some college or graduate school.
- The majority of the sample self-identified as heterosexual or straight; 23 (16%) classified themselves as lesbian or bisexual.
- Almost 75 percent of respondents were not currently married or living with a partner.
- Thirty-six women (26%) are married or living with a partner.
- More than half of respondents have responsibility for minor children.
- Sixty-three women (87% of respondents) have minor children residing with them.
- The majority of the women are not currently working.
- Three out of four of women are recipients of Food Stamps, 31 (22%) Temporary Assistance for Needy Families (TANF), 59 (42%) receive Supplemental Security Income (SSI).

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[11] Women born outside the U.S. mainland include those born in the Commonwealth of Puerto Rico. As residents of the U.S., Puerto Ricans may have better access to medical and social services than individuals born outside the U.S. mainland. We did not capture how long women had lived in their native country or on their native island.

- Eighty-six women (62%) are HIV-positive, but had not received an AIDS diagnosis.
- Thirty women (21.6%) have been diagnosed with AIDS.[12]

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[12] Twenty-three women (17% of respondents) did not reveal their HIV/AIDS status.

IV. CONTEXT OF WOMEN IN THE STUDY

A. NEW YORK CITY: THE DOMESTIC EPICENTER OF WOMEN WITH HIV/AIDS

New York City is the nation's epicenter for women living with HIV/AIDS. In 2001, almost 20% of women in the United States living with AIDS resided in New York City, where 88% of them were women of color (blacks comprised 55% and Latinas 33%) (UWNYC, 2002). In 2000, 52% of all New York City women infected with AIDS resided in 10 neighborhoods known to have the city's highest concentrations of poverty.[13] These "communities at risk" are among those recognized for having a set of socio economic and geo-political conditions that contribute to risky behaviors for HIV infection. Conditions of poverty have been linked directly and indirectly to increased risk for HIV infection (CDC, 2004).

Poor and low-income HIV-positive women encounter a myriad of challenges that limit access to and utilization of health, mental health, social, housing, employment, educational, and other services. These barriers are particularly problematic for vulnerable women with a complexity of needs, who must maneuver geographically and institutionally fragmented service delivery systems.

B. COMMUNITIES AT RISK

Over half of the women in our sample reside in communities at risk. These communities are products of structural forces, including structural violence,[14] which undermine the residents' social norms and communication patterns, increasing their economic and social vulnerability. Indicators of communities at risk in this report include:

- high proportion of low-income, female-headed households
- high poverty rates
- high unemployment rates
- low employment to population ratios
- low education attainment
- poor housing
- lack of health insurance
- disparities in health
- high death rates due to homicide and drug and alcohol use

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[13] WOCPN tabulation based on The New York City Department of Health and Mental Hygiene data.

[14] Personal or direct violence occurs when an actor commits the violence. Structural violence is indirect and largely institutionalized. It is reflected in unequal power and consequently unequal life chances (Lane *et al*, 2004). Indicators of structural violence used by Lane *et al* (2004) are HIV/AIDS and other STI's, incarceration, limited STI services, population demographics, and homophobia.

Mirroring the overall concentration of HIV-positive women in the city, close to 70% of study respondents reside in nine of the 42 United Hospital Fund (UHF) neighborhoods[15] (*See* Table 1: Distribution by UHF Neighborhoods).

Table 1: Distribution by UHF Neighborhoods

UHF Code	Neighborhood Name	% Distribution of Study Sample (2004)	% Distribution of Women Living with HIV/AIDS (through June 2003)[16]	% Adult Deaths from AIDS (2001)[17]
103	1. Fordham– Bronx Park	6.9	4.9	4.9
104	2. Pelham-Throgs Neck	7.6	4.6	3.3
105	3. Crotona-Tremont	9.7	6.2	6.6
106	4. Highbridge-Morrisania	5.5	6.5	6.7
107	5. Hunts Point-Mott Haven	4.6	3.9	3.9
203	6. Bedford/Stuyvesant-Crown Heights	20.0	7.9	8.9
207	7. East Flatbush-Flatbush	5.5	4.8	4.3
302	8. Central Harlem-Morningside Heights	5.5	5.2	5.0
303	9. East Harlem	4.1	3.5	4.1
Subtotal		69.6	47.6	47.7

In 2000, these nine communities represented 24% of the city's population,[18] yet they also represented:

- 48% of all women living with HIV/AIDS in the city, in 2004, and
- 48% of all of the persons who died from AIDS in 2001. [19]

An examination of communities at risk affords more in-depth analyses of trends, such as the feminization of poverty and the feminization of HIV/AIDS, and allows placement of economic, social, and health-related population shifts within historical and contemporary contexts.

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[15] UHF neighborhoods "correspond to a geographic area within New York City that is an aggregate of between 1 and 9 zip codes but that is smaller than a borough. UHF neighborhoods reflect catchment areas for certain healthcare facilities" (New York City Department of Health and Mental Hygiene-HIV Epidemiology Program (HEP). Available online at http://www.nyc.gov/html/doh/html/ah/hivtables2003.shtml. See Appendix A for more information on UHF neighborhoods, and Appendix B for a map illustrating the distribution of Women Living with HIV/AIDS by UHF Neighborhoods through June 2003.

[16] Network tabulations based on NYC Department of Health and Mental Hygiene HIV/AIDS Surveillance Unit 2003.

[17] Network tabulations based on Community Health Profiles 2001 data.

[18] Network tabulations based on 2000 census data.

[19] Network tabulations based on data from the NYC Department of Health and Mental Hygiene.

V. KEY FINDINGS

This study documents the interwoven relationship between the feminization of poverty and the feminization of HIV/AIDS and supports prior research that links poverty with increases in the likelihood of HIV infection among poor women of color. The work highlights the tremendous service and program needs of HIV-positive women and their families. In this report, we discuss how these needs are shaped by social, economic, cultural, and political contexts and how they manifest through personal and structural concerns.

We identified 11 principal findings derived from both *personal* and *structural* concerns highlighted by women in the sample. *Personal* dimensions are defined by physical, psychological, and emotional factors, as well as intimate, familial, and other interpersonal relations. *Structural* aspects are externally derived macro-level dynamics, such as policy, social, economic, cultural, and political forces. The confluence of personal factors and structural forces limits the ability of many women in these communities to negotiate risk in their lives.

A. PERCEIVING EMERGING NEEDS: PERSONAL CONCERNS

1. Women in Need of Services

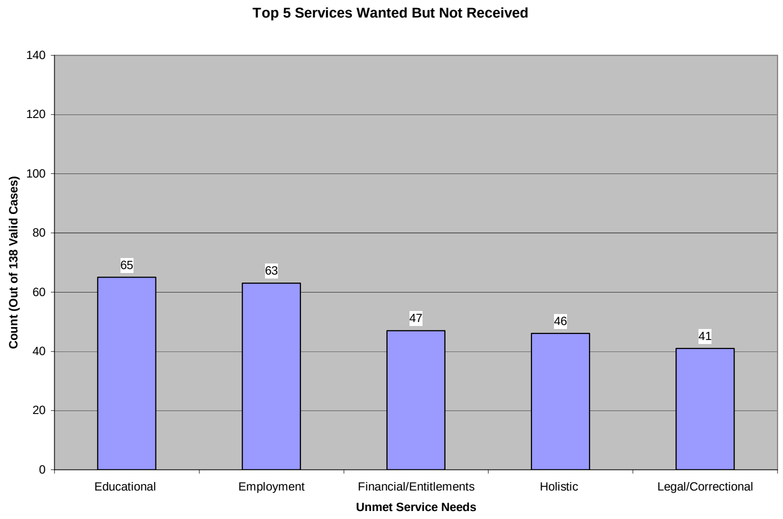
> *"I will never forgive my husband. He never told me how he got it, but he had women outside . . . .* [It's] *machismo, macho. Latino men, they don't want to use a condom. Women don't want to talk about it. They don't talk to their husbands about it,"* shared a Dominican widow.

* * *

HIV-positive women manage a complexity of challenges that emerge from biological, behavioral, social, and economic phenomenon. These challenges prompt a variety of needs in their lives defined by age, race/ethnicity, education level, socioeconomic status, minor child responsibilities, disease progression, and more (Squires, 2003). More specifically, as increasing numbers of sero-positive women seek educational and employment opportunities, they will face multiple barriers (Hackl *et al*., 1997; Metcalfe, *et al*., 1998; Ickovics *et al*., 2001; Cook *et al*., 2004). Employment programs and educational services are vital in helping women overcome barriers and access opportunities (The Lewin Group, 2000).

- Almost half of the women in the sample wanted educational and employment services but were not receiving these services (*See* Figure 1: Top 5 Services Wanted But Not Received).

Figure 1: Top 5 Services Wanted But Not Received



- Roughly 10% of single women[20] and women with spouses or partners indicated they needed but were not receiving childcare or after-school services.
- Women with spouses and partners are four times more likely to need but not receive childcare and after-school services than single women.
- Women with spouses or partners also are almost three times more likely to have an unmet need for home attendant services, compared to single women.

As the fastest growing group with newly diagnosed AIDS cases in the United States, HIV-positive women—particularly African American—often find themselves shouldering the burden of caring for children, partners, and other family members. In addition to caring for children, many HIV-infected women are also caring for another HIV-infected adult or child. Being female and having a child in the household are predictors of delaying care for oneself. HIV-positive women who live with an HIV-positive person are nearly twice as likely to prioritize the care of another HIV-positive person above her own (Stein *et al*., 2000).

- Among women in our sample, having responsibility for minor children is a significant predictor of a number of unmet services needs. Compared to women without minor child responsibilities, those caring for a minor child are:
    - almost six times more likely to want but not receive family/parenting services;
    - seven times more likely to want but not receive mental health services for a child and childcare/after-school services; and
    - two to three times more likely to have unmet financial/entitlement, basic living, home attendant, and spiritual services needs.

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[20] Single women are comprised of women who have never married, as well as those who are widowed, separated, or divorced.

- Our findings suggest that black and Hispanic women born outside the U.S. mainland have significantly different unmet service needs, compared to U.S.-born black and Hispanic women. Women born outside the U.S. mainland are:
    - twice as likely to want but not receive legal/correctional services;
    - three times as likely to want but not receive holistic services;
    - four times more likely to want but not receive group therapy; and
    - almost five times more likely to want but not receive case management services.

Women in the sample indicated a number of emerging services needs, which fell into four categories: mental health, medical services and education, disclosure, and domestic violence. (*See* full report for more details on the emerging services needs of women.)

Emerging Services Needs of Women
Mental Health Medical Services and Health Education Disclosure Support Domestic Violence Prevention

Women in our sample commented on their need for HIV/AIDS-related services and support:

> *"I thought it was a punishment. I didn't want to deal with it. I suspected, but I shut down. I didn't want to get help. I started thinking about what people look like. I said: 'Oh my God, I'm going to look like that.' Everybody is going to know. My family is going to suffer,"* a single Hispanic woman from the Bronx shared.

* * *

> *"We need services for the lesbian, gay community—relationship counseling, support groups. If me and my lover break up, I'm going to need somebody to talk to. At my* [agency] *they had something* [for gay women]. *I don't know what happened,"* stated a 46-year-old lesbian who currently lives with her partner.

* * *

> *"The first regimen that I was on was Crixivan, AZT and Epivir. . . . It was one of the first inhibitors that came out. There weren't many studies on women. Most of the studies were being done on men. So, all this lipodystrophy stuff was coming out. Your body starts to deform [with this medication]. . . . Women started screaming about it. I read an article in the POZ magazine. I didn't even know that the medication was the reason that my stomach was getting big. I read the article and went to my doctor and he switched the medication. The damage was already done. . . . He had to have known, and I think that all these doctors that*

prescribe medications to people like us should have this information," lamented a Bronx mother.

* * *

"When I first heard about it, I didn't want to be around people with AIDS. I didn't know how you got it. First, I cried and I wanted to die. At group, I saw others with the same thing. So, I tell people. I helped one woman talk about it," said a 55-year-old black woman.

* * *

"My son's father used to beat me to death. I'll never forget that," a 52-year-old Black woman, now living in Harlem, recalled. *"Sometimes it flashes back. He used to beat me with pipes. He took me in the alley. He beat me bad."*

* * *

"My family has always been abusive," a 21-year-old mother said. *"I was too young to know what the people was doing to me. I was between the ages of 10 and 16. ACS* [Administration for Children's Services] *came and took me out the house, and they put me back there three years later, and I started to go through the same things all over again."*

* * *

2. Mental Health Services for Women and Families

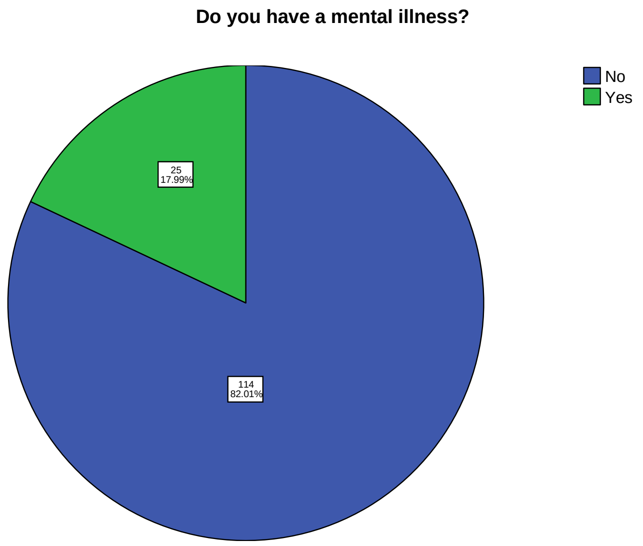
> *"I was going with someone who passed away. Everybody kept telling me that he had this. It was there staring me in the face. I was in denial for some reason. I had heard about AIDS. I didn't want anything to do with it. I feared subconsciously that, because of my behavior and shooting drugs, I suspected. But, it was a shock when they confirmed it,"* said 50-year-old Puerto Rican woman.

* * *

Research links HIV/AIDS discovery and symptoms to poor mental health in women (Bing *et al.*, 2001; Ickovics *et al.*, 2001; Evans *et al.*, 2002; Catz, *et al.*, 2002). Psychological distress can accelerate disease progression at every stage, from the moment of seroconversion notification to the final stages of life (Cook *et al.*, 2004; Catz *et al.*, 2002). Mental health problems may be more acute during early stages of HIV infection when health begins to deteriorate (Tostes *et al.*, 2004). As HIV-related symptoms increase, the severity of psychiatric disorders may intensify (Bing *et al.*, 2001). High levels of anxiety and depression can disrupt effective medical management and lead to emotional distress, resulting in poorer health outcomes, missed medical appointments, and failure to follow health provider instructions or adhere to HIV medications and treatments (Catz, *et al.*, 2002). Depression may negatively impact innate immunity by decreasing natural killer cell activity in HIV-positive women (Evans *et al.*, 2002). HIV-positive women with chronic depression symptoms also are twice as likely to die as women with limited or no depressive symptoms (Ickovics *et al.*, 2001; Cook *et al.*, 2004).

An analysis of our data reveals that twenty-five women in our sample (18% of respondents) indicated that they had a mental illness; these include bipolar disorder, anxiety, depression, etc. (*See* Figure 2: Mental Illness).

Figure 2: Mental Illness



Study respondents shared:

> *"It took me a long time to accept that I was a person living with this condition. Depression, anger—I didn't know what to do or who to take it out on. I went for four years through emotions to get to this point,"* said a 46-year-old Bronx lesbian. "*I think I've accepted that this is what it is."*

* * *

> *"I wish I didn't have it. It's driving me up the wall. I still have a lot of anger inside of me. I don't sleep at all . . . just thinking I'm going to die,"* a 40-year-old Hispanic woman from the Bronx commented.

* * *

Women in the study also expressed a need for mental health services for their children and partners. The women shared:

> *"We are going through the loss of my husband, and it's hurting my son a lot. He's being teased and bullied about his father's death* [from HIV-related illness]. *And he doesn't feel comfortable any more in that school. This is an everyday thing. It's not one day yes, one day no. My son cries about this every day. I took him to counseling twice, but he was getting angry about it, so I had to stop . . . . It was affecting his school work,"* lamented the mother of a 10-year-old.

* * *

> *"I want to get* [my son] *prepared for the outcomes or whatever. He does the laundry. He does the shopping. He pretty much does anything I ask him to do. He knows how to wash, clean, sew clothes, cook, all that. . . . He needs therapy too because he has in his mindset that as long as I can walk, talk, and get up and run like a battery that he's okay. But what happens the day that I can't walk, talk, or eventually can't function, what do you do then? It's time for him to get some therapy or treatment now so, God forbid, when something comes to him, that he can handle it,"* a 43-year-old widow explained.

* * *

> *"My husband will need services. He doesn't show emotions. I'm concerned about him and my youngest when I die. He doesn't talk too much. He's a private person. He won't go for services. He'll try to solve it himself. He's a man, and he's a Puerto Rican. He'll need counseling and therapy. I'm working on it. Because he's part of the family, they* [the agency] *will help him,"* a 48-year-old Hispanic woman said.

* * *

> *"We've tried services, but he refused everything he was offered. He's from Jamaica, and they look down upon it* [HIV/AIDS], *and he's afraid how his family is going to react. . . . I've been married one year and six months. . . . I need help with my marriage,"* commented a 38-year-old black woman.

* * *

“He needs [his] *own services, mental health, drug treatment services, but he won’t go,”* a 52-year-old woman from Trinidad stated about her partner.

*   *   *

3. Children in Need of Services

> *"We are going through the loss of my husband, and it's hurting my son a lot. He's being teased and bullied about his father's death* [from HIV-related illness]. *And he doesn't feel comfortable any more in that school. This is an everyday thing. It's not one day 'yes,' one day 'no.' My son cries about this every day. I took him to counseling twice, but he was getting angry about it, so I had to stop. . . . It was affecting his school work,"* lamented the mother of a 10-year-old boy who is being harassed at school because of his father's death from the virus.

* * *

Mothers infected with HIV/AIDS are concerned about their children's well-being and future care (Antle *et al*., 2001). The children of HIV-positive mothers face challenges that place them at risk for emotional, nutritional, educational, and behavioral problems, as well as early pregnancy, substance abuse, HIV-infection, and suicide as they get older (Roth, 1994; Aronson, 1995; Pivnick & Villegas, 2000). For children in more disadvantaged communities, these risks often are more acute due to social, economic, and environmental conditions. Consequently, children whose mothers are living with HIV/AIDS have multiple needs. If the children are orphaned, their needs increase exponentially (Pivnick & Villegas, 2000).

Our findings indicate that mental health, children's care (i.e., respite, afterschool, and child care services), health education, medical care and information, and personal development services are the most frequently needed services women would like for their children. (*See* full report for more details on the emerging services needs of children.)

Emerging Services Needs for Children
Mental Health
Children's Care
Health Education
Medical Care and Information
Personal Development

Twenty-six women in the study (19% of respondents) expressed a need for mental health services for their children.

> *"My son sleeps with me since his father passed,"* a 36-year-old widow whose husband died of HIV-related illness said. *"My husband died in his sleep. Now he [her 10-year-old son] thinks I will die in my sleep."*

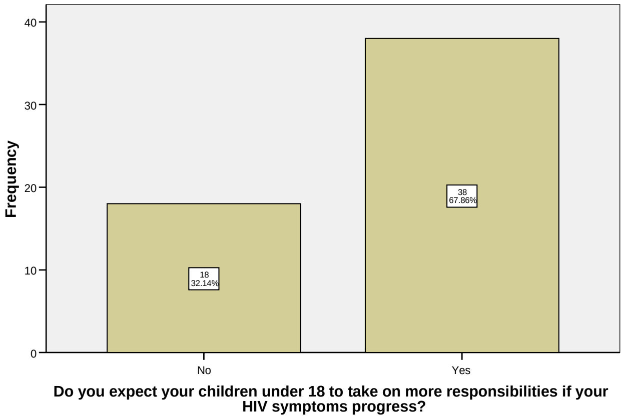
* * *

> *"My youngest daughter was 16 when her father passed away. I was sick a lot of the times; she was going through that teenage thing, and all that. She gets counseling, and I'll make sure she continues with services until she finishes high school. Then it's up to her,"* stated a 56-year-old Puerto Rican widow.

* * *

- An analysis of study findings reveals:
    - As HIV symptoms progress, women indicated that they will increasingly look to their minor children to assist them. In addition to caring for their mothers, these children often assume greater responsibility for their siblings and their households in general. (*See* Figure 3: Expect Children to Take on More Responsibilities.)
    - Since being diagnosed with HIV, 46 women (53% of respondents) indicated that their adult children have taken on more responsibilities.

Figure 3: Expect Children to Take on More Responsibilities



- Our findings suggest that many of the women live with minor and adult children and/or grandchildren. It is not uncommon for the children of HIV-positive women to need a break from care giving responsibilities. Some respondents indicated that they and their children would benefit from safe, affordable after-school programs, as well as child and respite care services. Other respondents, who indicated an interest in returning to work or school, hoped to find supportive services for children.

Study participants shared:

> *"I want to work full-time,"* commented the mother of an HIV-positive girl. *"I need after-school care for my daughter to work full-time."*

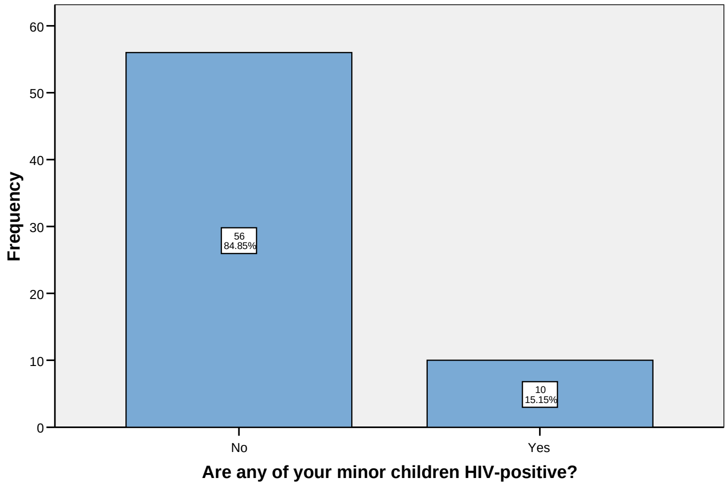
* * *

> *"We need childcare for her* [referring to her daughter]. *Sometimes it's hard because I get tired. The 15-year-old helps when I need a break,"* said a 45-year-old black mother who lives with her minor and adult children, as well as grandchildren.

* * *

Study respondents indicated that their children are in need of health education and medical care and information, particularly in relation to HIV/AIDS prevention. The rate of infection is very high among adolescents. Compared to HIV-positive adults, sero-positive male and female youth are more than twice as likely to participate in high risk activities (e.g., unprotected anal, genital, or oral sex; exchanging sex for drugs, money, or a place to stay; and sharing unclear needles during intravenous drug use) (Diamond & Buskin, 2000). In discussing the needs of adolescent children, the women in our sample revealed two distinct aspects of concern related to prevention. First, they expressed concern about the risky behaviors in which their minor children engaged. For many mothers who are managing life with the disease, it is even more disconcerting when they see the very same patterns and conditions that placed them at risk mirrored in the life of their children. Second, a few women in the study, whose children were born with HIV, indicated that their adolescent children are becoming sexually active and struggling with issues of disclosure and possible transmission to others. Ten women in our sample had minor children who had tested positive for HIV (*See* Figure 4: Minor HIV-Positive Child).

Figure 4: Minor HIV-Positive Child



Study participants shared with us the needs of minor children.

"I tell her not to tell her friends about her status. She has one friend with HIV, but, for the most part, they (her friends) don't know," shared a 52-year-old widow and mother of a 10-year-old HIV-positive girl, who is an "A" student.

* * *

"*I have a teenage daughter and she's very sexually active,*" said a 34-year-old black woman who is in recovery and living in the Bronx. "*So, I'm worried about what can happen to her. She knows about me, but she still does what she does. She's 15 years old. She lives in Arkansas with my mother. My mother adopted them. But when she was up here* [lived in New York], *she was having sex with* *four and five guys at one time. I found out because she got drunk one night and told my mother. . . . She's like I was when I was a teenager."*

*   *   *

"My nephew is positive. He's known for years, but now he's a teenager, and he has questions. I think that there should be a place where kids should be able to go and cope with [their status], *totally separate from the parents, where they can feel comfortable. We are so focused on the adults that we are forgetting about the children and them getting to their teenage years. I found out when I was 24, so before that I did have my teenage years. I had my life. But to have a kid born with it and then . . . to have him realize that he can't have sex. That's hard, because that's the rest of your life,"* said a 36-year-old Puerto Rican woman from the Bronx.

*   *   *

4. Partners and Spouses in Need of Services

> *"He doesn't want to* [go to services]. *He feels like once he acknowledges that he has this* [HIV/AIDS] *that it will start taking over his body like it did mine. I got pneumonia in both of my lungs, my blood started clotting. I didn't have none of this before I found out,"* lamented a 21-year-old woman from Manhattan about her positive partner.

* * *

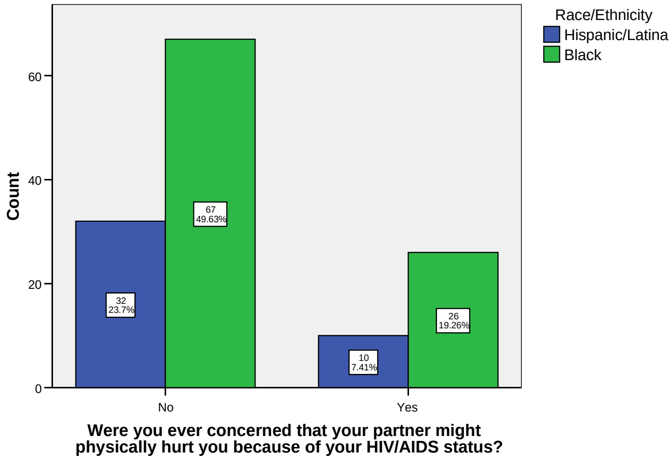
Little is known about the needs of lesbian, bisexual (male and female), and heterosexual partners and spouses of HIV-positive women of color (Jones *et al*., 2003; Brooks *et al*., 2003). Reasons for the lack of information range from the misperception that sero-positive minority women are disproportionately single heads of their households (Jones *et al*., 2003) and are not likely to have partners, to the disproportionate amount of research that has focused on HIV-positive gay white men (Brooks *et al*., 2003). In our study, we have sought to gain a glimpse of partners' needs through participants' responses. Our findings indicate that 26% of the women in our sample are married or living with a partner. Of the women who indicated they had a partner or spouse, 32% believe that as a result of their own HIV status, their partners will need services to cope. Of the 38 women in our study who had HIV-positive partners or spouses, 28 (74%) indicated that their partners also were receiving services for his or her HIV status. Women in our study believe that their partners and spouses can benefit from mental health, domestic violence prevention, health literacy, and health education. (*See* full report for more details on the emerging services needs of partners and spouses.)

Emerging Partner and Spouse Services Needs
Mental Health
Domestic Violence Prevention
Health Literacy
Health Education

Further analysis of our findings implies:

- Thirty-six women in our sample (10 or 24% of Latina, and 26 or 28% of black respondents) indicated concern about partner violence as it relates to their HIV status (*See* Figure 5: Concerned about Partner Violence by Race/Ethnicity).

Figure 5: Concerned about Partner Violence by Race/Ethnicity



The women in our sample discussed their partners' needs:

> *"She needs services. Every time I get sick she's suffering. She don't like to see me like that. She's not getting services now. She needs someone to talk to her long term as long as she's with me,"* shared a 46-year-old Puerto Rican lesbian about her partner.

* * *

> *"I have anger management problems. I stabbed my husband three times . . . . That's why he doesn't raise his hand no more. He learned his lesson not to knock my teeth out no more, not to break my nose, not to bruise my body and my face. This is the person I'm with now. That is the type of person he used to be. Alcohol makes you abusive, and he's an alcoholic . . . . He doesn't drink anymore now, but when you're drinking you think violent thoughts and right away you want to fight the world,"* stated a disabled Bronx woman.

* * *

Health literacy[21] is an increasing concern among HIV/AIDS medical and supportive service providers. Weak health care networks, lack of trust and familiarity with health care providers (Smith, 2003), inadequate health insurance coverage (Smith, 2003), and health illiteracy help create barriers to accessing and utilizing medical care and health-related information (Kalichman *et al.*, 2000). Low levels of health literacy are associated with less knowledge and understanding of chronic illnesses (Kalichman, et al., 2000); an inability to understand medical forms, diagnosis, instructions (Pirisi, 2000); poor adherence to medication regimens (Kalichman, *et al.*, 2000); and poor health (Hixon, 2004) among HIV-negative and HIV-positive persons. These outcomes are even more likely among Spanish-speakers (Leyva,

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[21] Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Leyva *et al*., 2005).

2005) and the elderly (Baker *et al*., 2000). The women in our sample expressed a need for health literacy services and health education for their partners and spouses.

> "*I want him to understand what it means to be sick,*" explained a Hispanic woman from Queens. "*It's not just reading a pamphlet. He needs education, and he needs to understand that stress is not good for us.*"

* * *

> "*He's very unaware of how serious this is. A lot of countries really don't know much about it. When I first tried to tell him, he didn't know what it was . . . . He'll need it* [services] *for the long term because his English is not good,*" complained a Latina about her foreign-born partner's lack of knowledge about HIV/AIDS.

* * *

5. Lack of Power in Relationships

> *"I didn't tell my partner for fear that he would try to physically hurt me. We have unprotected sex,"* lamented a 37-year-old Manhattan woman.

* * *

Violence towards women is a growing concern. Numerous studies have documented widespread abuse towards women (Thomas & Beasley, 1993; Hamburger *et al*., 2004). Childhood sexual abuse (Wyatt *et al*., 2005; Cohen *et al*., 2000), domestic violence (Stanhope, 1996; Cohen *et al*., 2000), and partner abuse (Wingood & DiClemente, 1997; Saul *et al*, 2000) place women at greater risk for exposure to HIV/AIDS and other sexually transmitted diseases. Violence towards women also increases the risk for serious health problems, inclusive of physical harm, stress and depression, risky behaviors, and low self-esteem (Hogben *et al*., 2001). Physical violence, sexual assault, and emotional and/or psychological abuse may be inflicted on women by partners, parents, children, or other caregivers. Immigrant and disabled women are particularly vulnerable to abuse and violence. Language barriers, fear of deportation, and economic and emotional dependency may contribute to women's silent suffering (New York City Mayor's Office to Combat Domestic Violence, 2006).

Women in our sample commented on domestic violence concerns in relation to their partners or spouses.

> *"My partner has an anger management problem, and he blows up very easily. He gets stressed out very fast. I told him he needs help. He needs someone to talk to. He needs to release the anger inside. I tell him that you release it on me, and that's not good because when you release it on me, I release it on you and nothing ends up great,"* confessed a woman with a long-term partner.

* * *

Analysis of our findings reveals:

- Overall, 65% of respondents had experienced an abusive relationship (*See* Figure 6: Abusive Relationship by Nativity[22]).
- Subgroup comparison reveals that 69% of U.S.-born women, and 50% of women born outside the U.S. mainland had been in an abusive relationship.
- Compared to U.S.-born women, non-U.S. mainland-born women are twice as likely to have ever been in an abusive relationship.
- Women born outside the U.S. mainland are twice as likely to have ever been concerned that someone might physically hurt them when disclosing their HIV/AIDS status, compared to native-born women.

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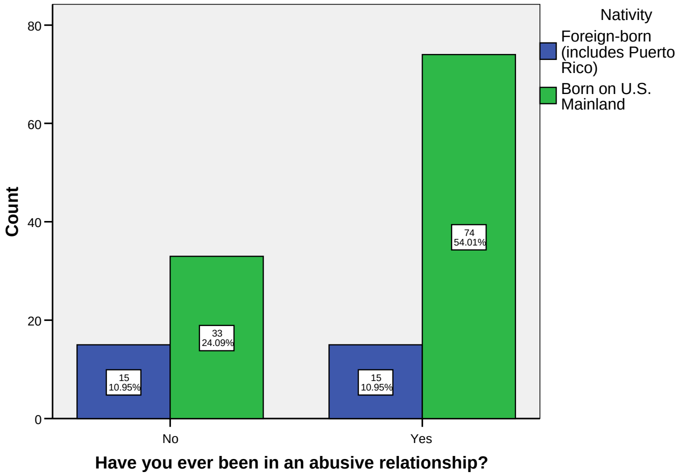
[22] Operationalized as born on the U.S. mainland and born outside the U.S. mainland.

Figure 6: Abusive Relationship by Nativity



Further analysis suggests:

- Thirty-eight percent of the women in the study indicated they had provided sex in exchange for drugs, money, or a place to stay.
- While 45% of U.S.-born women stated they had engaged in such activities, 13% of women born outside the U.S. mainland indicated they had.
- Compared with women born outside the U.S. mainland:
  - Native-born women are five times more likely to have provided sex in exchange for drugs, money, or a place to stay.
- Native-born women are almost three times more likely to have been forced to have sex without their consent.

B. PERCEIVING EMERGING NEEDS: STRUCTURAL CONCERNS

1. Employment and Educational Opportunities

> *"I'm learning to read and how to work. I never had a job. I took care of my mother and brother. I'm trying to get into* [a job training or education] *program"*, said a 49-year-old black women with a 9th grade education.

* * *

Shifts in the American economy have led to rising unemployment rates in many inner city neighborhoods. In large part, declines in job opportunities result from the expansion of technology and the relocation of factories and businesses to the suburbs, South, and overseas (Wilson, 1996). Women with little or no skills have been disproportionately affected. Joblessness and low wages have contributed to the growth of poverty in many urban areas (Wilson, 1996). Since 2003, New York City has witnessed an economic recovery. During this most recent upswing in the job market, black and Hispanic men have faired much better than their female counterparts (Levitan, 2006). Black and Hispanic women overall saw relatively small improvement in employment rates from 2003 to 2005. Compared to black and white women, Latinas continue to suffer the lowest jobholding rates; and women less than 25 years of age failed to benefit from improvement in the job market during this period (Levitan, 2006).

Poor and low-income HIV-positive women increasingly are looking forward to productive futures and seeking educational, training, and employment opportunities (Pokempner & Roberts, 2001). Many hope to fulfill long-held dreams of improving life for themselves and their families. An improving job market, along with recent social policy shifts and medication treatment advances have contributed to the rising numbers of HIV-positive women pursuing new opportunities. Welfare reform's emphasis on work and the Social Security Administration's narrower definition of "disability," which makes it more difficult to qualify for benefits, combined with the increasing number of women initiating and adhering to combination antiretroviral therapies (Cohen *et al*., 2004), have created an environment where more women are looking for educational and employment opportunities, and seeking new opportunities for brighter futures. Yet, the transition from disability-related unemployment to employment is difficult for women living with HIV/AIDS.

An analysis of our data reveals:

- Twenty-seven women in our study (19%) indicated that they are currently working (*See* Figure 7: Currently Employed).
- Of the 31 current TANF recipients, 6 (19%) are working now.
- Of the 59 current SSI recipients, 12 (20%) respondents are currently working.
- Ninety-eight women (81% of respondents) indicated they would like additional information on job training and educational programs.
- Seventy-five women (61% of respondents) expect to work over the next 12 months (*See* Figure 8: Expect to Work).

Figure 7: Currently Employed

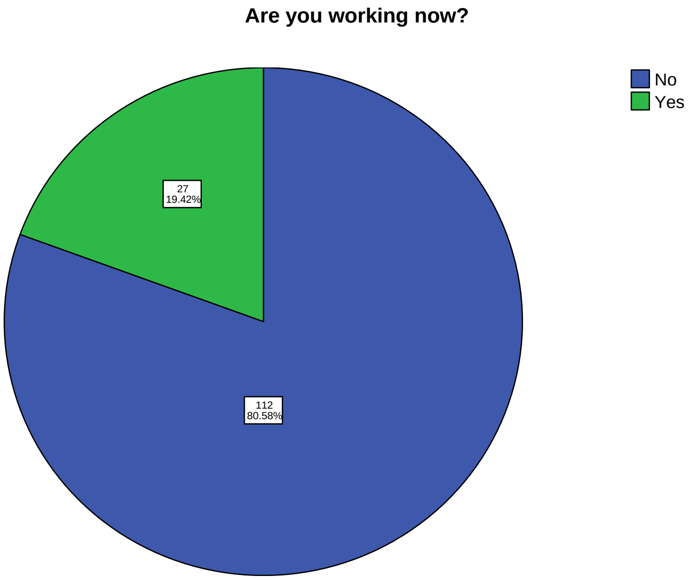
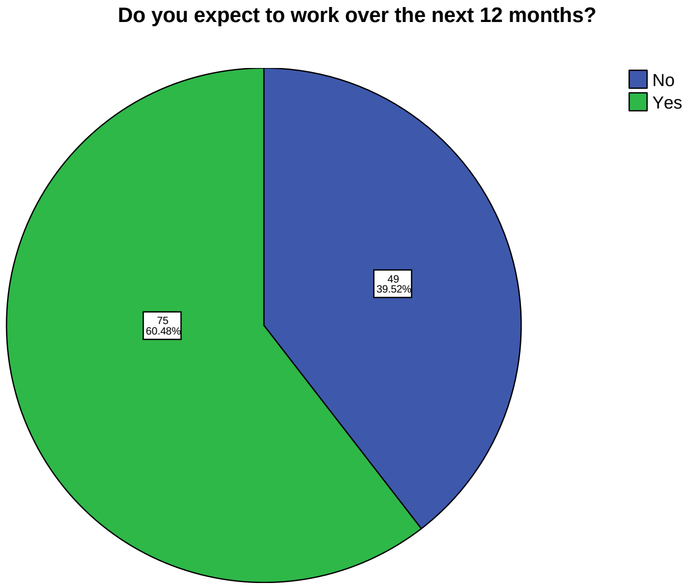


Figure 8: Expect to Work



Yet, most of the women in our study acknowledged that limited educational attainment, a lack of work experience, family responsibilities, unpredictable health challenges, and medication side effects might pose barriers to employment and educational pursuits. More than 50% of the women in our sample had not attained a high school diploma or GED. The statements of respondents offer insight into their hopes and expectations.

"I have been doing peer education for 15 years. I work 10 hours a month. It's an HIV agency. I have had problems finding a job because I don't have the education. Every time I try to go for my education something comes up with my family. I don't apply for training programs because I don't have the education," said a 48-year-old married Hispanic woman with an 8th grade education.

* * *

"When you look at me I look fine, but the medication gave me diarrhea. It made me vomit. I don't have the same energy like before," a Latina, who had worked for 18 years before her AIDS diagnosis and has since attempted to re-enter the workforce.

* * *

"It's hard as head of household [to enroll in a training program]. *I have to care for everyone. I'm also scared because of my lack of education,"* explained a 48-year-old Hispanic woman from the Bronx.

* * *

2. Nutrition

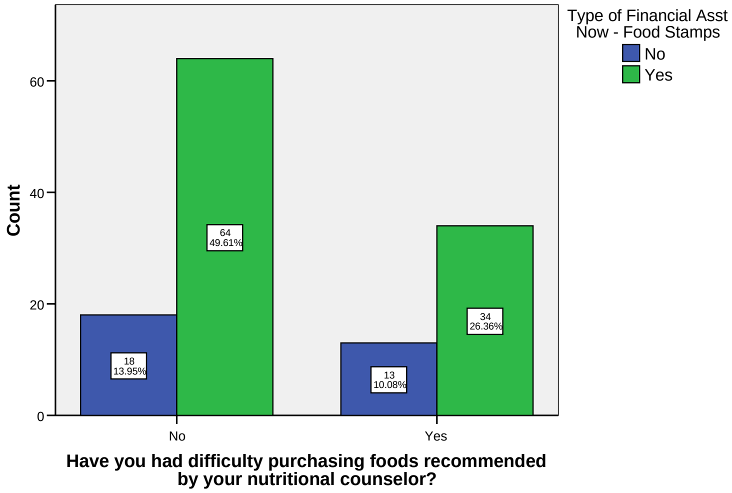
"I struggle. There are places to get food, but because I'm diabetic, I can't eat it. I also don't have the money to get there," commented a 41-year-old grandmother.

* * *

Women living with the virus are encouraged to follow a prescribed nutritional regimen. Failure to maintain healthy eating habits may negatively impact immune functioning and consequently increase disease progression (Mackle, 2001). Low-income HIV-positive women who reside in inner city areas face numerous obstacles to obtaining reasonably-priced healthy foods. Quality supermarkets are less likely to be located in inner city neighborhoods, and fast food restaurants more likely (Pothukuchi, 2005; Moland *et al*, 2002). Poor women often lack the ability to travel to stores with higher quality foods. Our findings suggest:

- Twenty-nine respondents (21%) did not receive nutritional counseling.
- Thirty-three respondents (24%) did not have enough food for themselves and their families to eat.
- Of the 47 women in our sample who stated that they have had difficulty purchasing foods recommended by their nutritional counselor, 34 (72%) are Food Stamp recipients (*See* Figure 9: Difficulty Purchasing Foods by Food Stamp Recipient).

Figure 9: Difficulty Purchasing Foods by Food Stamp Recipient



To access nutritious foods, 38 women (28%) stated that they receive food from their agency, while 46 women (33%) look to food pantries. The women in our study commented:

"Eating well keeps the disease at bay. I would like a pantry for healthy food, also classes about how to make healthy food," a Puerto Rican widow from the Bronx

said. “*They should have a place for people who are positive that gives healthy food and* [teaches us] *how to eat right.”*

* * *

“I’m anemic. I need meat. It’s expensive,” said a single thirty-something woman. *“People with the virus need more vegetables. They should be able to give us coupons—not only for people with children. I don’t always have enough to eat.”*

* * *

3. Housing

"I have moved ten times in the last two years," lamented a 21-year-old Brooklyn mother. *"I'm unsatisfied . . . . There's lead paint, the tub is rusty,* [the] *sink fell, the ceiling is falling, the neighborhood is dirty. I was in the shelter* [system]. *The shelter is better. There's no lead."*

* * *

Adequate housing in safe environments is essential to the well-being of HIV-positive women and their families. Homelessness and unstable housing are related to increased drug-use, sex work, mental illness (Robertson *et al*., 2004), unsafe sexual practices (Aidala *et al*., 2006), and higher rates of physical violence (Tucker *et al*., 2004). Stable quality housing, conversely, is linked to enhanced quality of life, improved adherence to medication, reduced mental and emotional stresses (Grube, 2000; Gutheil & Chernesky, 1999), and improved health outcomes (Wechsberg *et al*., 2004). Securing decent housing is challenging for many poor sero-positive women who have limited affordable housing options. They also are stigmatized for their lifestyle and HIV status, and discriminated against for racial/ethnic profiles.

Our findings suggest:

- Almost three out of four respondents reside in permanent rental housing (*See* Figure 10: Housing).
- Ninety percent of respondents (110 women) informed us that they receive assistance from a government agency to pay their rent or mortgage (e.g., public housing, Section 8, HASA services) (*See* Figure 11: Assistance with Rent or Mortgage).
- While 45 women (33% of respondents) indicated that the quality of their housing or living arrangement had improved in the last year, 60 women (44%) reported no change, and 33 women (24%) revealed that their housing or living arrangement had worsened.
- Of the 33 women who indicated that their housing/living arrangement had worsened, 18 (55%) stated that the quality of their housing/living arrangement was unsatisfactory.

Figure 10: Housing

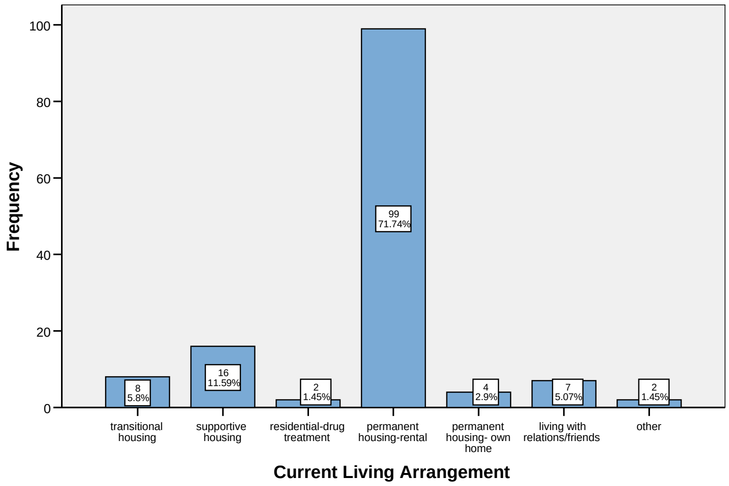
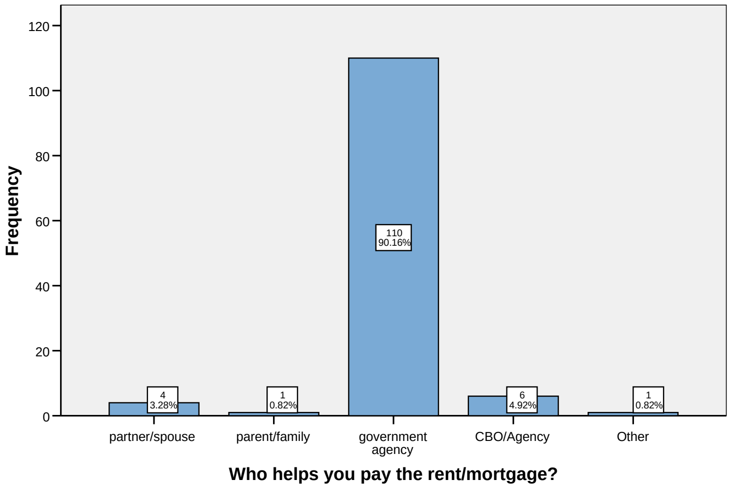


Figure 11: Assistance with Rent or Mortgage



Further analysis reveals:

- Over half of study respondents (77 women) had not moved in the last two years.
- Sixty-six women (51%) informed us that they are looking for another place to live in the upcoming year.
- Three women (2%) indicated that they were currently homeless.[23]

The women in our sample discussed their housing challenges:

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[23] One woman resided with friends/relatives, and two women lived in transitional housing.

"Before diagnosis, I wasn't able to afford an apartment because the rents were high. I only could afford to live in the projects," stated a 43-year-old Bronx mother and HASA recipient.

*   *   *

"Landlords have told me, you live off my tax money. You're not supposed to live good. They feel that you are going to die anyway, [so] *why do you need to live good . . . . You deserve the worse . . . ,"* reported a divorced Bronx mother whose children and grandchildren reside with her.

*   *   *

"I live like a gypsy. I want anything [type of housing]. *I don't meet the qualifications for housing applications. I can't afford the rent, and if I could, then nothing would be left for anything else. It's hard to make ends meet . . . . I need something suitable for the kids in an area that I don't have to worry about the kids getting shot. I'm not asking for a white picket fence,"* lamented a 27-year-old Bronx mother.

*   *   *

C. THE IMPORTANCE OF GOVERNMENT ASSISTANCE

> *"Since they cut the food stamps, what happens is, two of the weeks out of the month, I end up spending $30 a week out of my own money to buy food. It's a big cut to take $90 out of somebody's food stamps. That's a lot of food stamps,"* remarked a Haitian woman who is a single mother.

* * *

While women of all economic backgrounds are HIV-positive, poor women are disproportionately infected. Recent studies highlight the burden carried by poor women (Barkan *et al*., 1998) and gender disparities among HIV-positive individuals (Bozzette *et al*., 1998; Joint United Nations Program on HIV/AIDS and World Health Organization, 2003). Most women infected with HIV are unemployed, members of households with incomes less than $10,000 per year, not married, and black or Latina. Many live alone and about half are responsible for at least one child under the age of 15 (Barkan *et al*., 1998). Compared to HIV-positive men, a larger percentage of infected women are African American, unemployed, live in households with incomes below $5,000 per year, and are without health coverage (Bozzette *et al*., 1998).

For many poor and low-income HIV-positive women, government support serves as a stabilizing force in their lives, helping them meet economic, social, medical, and housing needs (*See* Table 2: Forms of Government Assistance Women Received Before and After HIV Diagnosis). Yet, securing governmental support is becoming increasingly difficult in an environment of welfare reform and reduced funding for social welfare programs.

Table 2: Forms of Government Assistance

Women Received Before and After HIV Diagnosis

Forms of Government Assistance	Received ***Before*** HIV Diagnosis		Received ***After*** HIV Diagnosis	
	N = 139	**Percent**	**N = 139**	**Percent**
Food Stamps	78	56.1	105	75.5
Medicaid	75	54.0	105	75.5
PA/TANF	68	48.9	31	22.3
Rent Supplement	29	20.9	25	18.0
SSI	12	8.6	59	42.4
SSD	6	4.3	20	14.4
DAS/HASA	0	0	87	62.6
Medicare	1	0.7	11	7.9
AIDS Health Insurance	0	0	5	3.6
AIDS Drug Assistance	0	0	1	0.7

An analysis of our data reveals:

- Roughly half of the women indicated they received Food Stamps, Medicaid, and Temporary Assistance for Needy Families (TANF) before their HIV diagnosis. The number of women relying on governmental support generally increased after discovery of HIV/AIDS.
- Three out of four respondents indicated they became Food Stamp and Medicaid recipients after their diagnosis, reflecting jumps of 26% and 29% respectively.
- After HIV diagnosis, the number of TANF recipients declined by 54%, while SSI recipients jumped 80%, a leap from 12 recipients before HIV diagnosis to 59 after diagnosis.
- One respondent indicated she received Medicare prior to HIV diagnosis. Medicare recipients rose to 11 following HIV diagnosis, a 90% increase.
- After HIV diagnosis, 87 women indicated they received HASA[24] services.
- Forty-two women (43% of respondents) had experienced problems obtaining government assistance.

Study respondents commented on the significance of governmental support in their lives:

> "*You may not be disabled, but if you have the virus, you will get sick mentally and physically. The guidelines [for HASA/DAS] are unrealistic,"* shared a black woman in her 40s.

* * *

> *"I applied for social security.* [I was] *denied for four years,"* a 52-year-old Trinidadian woman explained. "[I qualified] *only after getting pneumonia and my T-cells went down -- only after I got an AIDS diagnosis."*

* * *

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[24] The HIV/AIDS Services Administration (HASA) is the agency of The City of New York, Human Resources Administration charged with delivering services and support to persons living with HIV/AIDS.

D. HIV/AIDS-RELATED SERVICES UTILIZATION

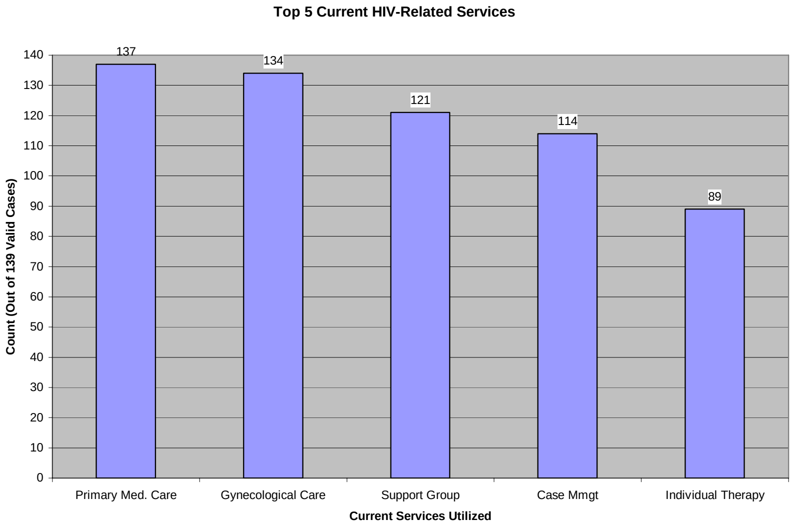
> *"The agency is great. But they need more help and staff, more PLWHA (people living with HIV/AIDS) working in agencies, and stipends for peer educators and trainings,"* said a 45-year-old Bronx woman.

* * *

While studies have found little gender difference in the progression rate of HIV infection, it appears that women progress from AIDS to death more quickly than men (Squires, 2003). The rapid progression to AIDS among women may in part result from the failure of medical practitioners to recognize, make early diagnosis, or treat appropriately the disease in women compared to men (Squires, 2003). Quality primary medical and gynecological care for HIV-positive women is a critical component in meeting their specific health needs.

- An analysis of our results finds that nearly all of the women in our study are currently accessing primary medical care and gynecological care. The top five responses for currently received HIV/AIDS-related services are primary medical care, gynecological care, support groups, case management services, and individual therapy. (*See* Figure 12: Top 5 Current HIV-Related Services.)

Figure 12: Top 5 Current HIV-Related Services



Studies have found that access to supportive and case management services may increase the likelihood that clients seek medical care (Messeri *et al*., 2002; Sherer *et al*., 2002). Coordinated services provided by case managers have proven instrumental in helping clients navigate complex medical care systems and secure resources such as insurance benefits and medical referrals (Messeri *et al*., 2002). Clients who receive services in case management, transportation, mental health, and chemical dependency were more likely to receive higher levels of health care than patients who did not use these supportive services (Sherer *et al*., 2002).

- Our results suggest that black and Hispanic women utilize specialty medical care[25], group therapy, support groups, and other mental health services[26] in different manners. Compared to Latinas, black women are three times more likely to currently use specialty medical care and group therapy. Black women also are four times more likely to take advantage currently of support groups and 11 times more likely to access other mental health services.
- Women with minor child responsibilities are almost five times more likely to access family/parenting and holistic services, and mental health care for services for their children than women without responsibility for a minor child.
- Women who are responsible for minor children are more than eight times as likely to use childcare and after-school services, compared to respondents without minor child responsibility.

"If it wasn't for WSS and support groups, I wouldn't be able to take my granddaughter to different places. I'm grateful. I couldn't afford it. I want it to continue," remarked a 50-year-old Brooklyn grandmother.

* * *

"I can only pray that we continue to get the services that we need because they are cutting everything. Like this program here, it's an excellent program, but they don't have any money to hire the help that they need. There's one case manager here. She's here all alone for all of us. That's not right. You can't burn her out like that. If she gets tired, she'll go somewhere else. They need help," said a 47-year-old black woman.

* * *

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[25] Specialty medical care includes health services related to medication side effects or other medical conditions, such as eye and skin care, diabetic and cancer treatments, and care for digestive and neurological disorders.

[26] Other mental health services are delivered by psychiatrists, psychologists, psychiatric nurses or social workers in a hospital or clinical setting; and not supportive services, such as individual therapy or support groups, offered through local HIV/AIDS service organizations.

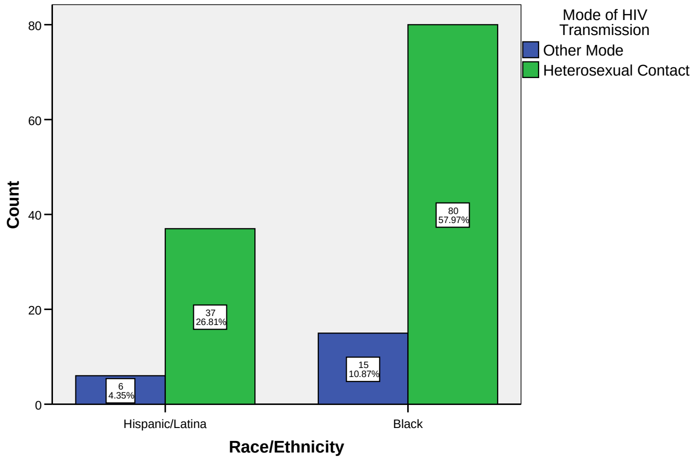
E. HIV/AIDS PREVENTION

> *“Women still have to do what they have to do. Still sleep around to make ends meet. Sometimes it gets hard, and women know they can use their bodies to get something. Like my food stamps will probably run out especially with holidays coming up, so sometimes you sleep with him because he got paid and you need extra* [cash],*”* said a 43-year-old black woman from Brooklyn.

* * *

One of the greatest challenges to prevention is the vulnerability of the women created by personal and structural concerns. Increasingly black women and Latinas are contracting HIV through heterosexual contact, often in long-term intimate heterosexual relationships (El-Bassel *et al*., 2005). Roughly 85% of women in our study indicated they had contracted HIV through heterosexual contact. (*See* Figure 13: Race/Ethnicity by Mode of HIV Transmission).

Figure 13: Race/Ethnicity by Mode of HIV Transmission



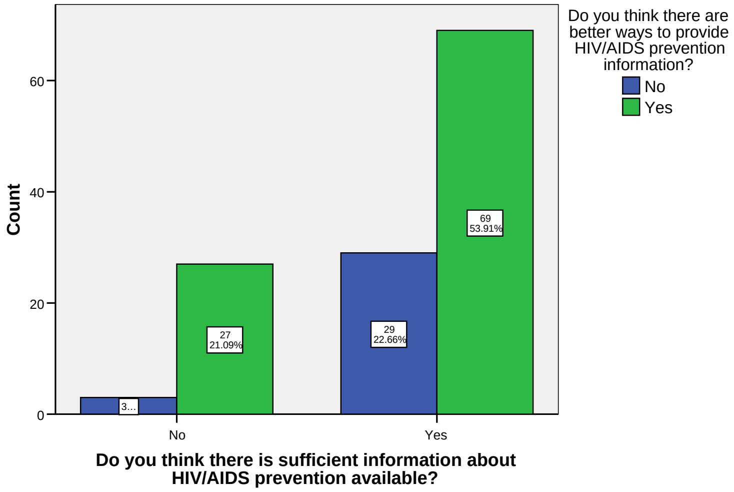
While research indicates that condom use among women is rising (Stark *et al*., 1998), it is not uncommon for some women to engage in behaviors (Ajzen, 1991) or activities (Ajzen & Fishbein, 1977) that place themselves and their partners at greater risk for HIV transmission and reinfection. Studies reveal that some women continue to engage in risky sexual behavior including having sex with multiple partners and periodic or no use of condoms (Sikkema *et al*., 1996; Aral, *et al*., 2004; Aidala *et al*., 2006). Women, along with their partners, use—and do not use—condoms for many reasons. The meanings associated with condom use are complicated and multidimensional (Pivnick, 1993). While some women associate condom use with birth control, HIV/AIDS protection, and love and concern for one’s partner, others associate the use of condoms with the lack of intimacy and suspicion of sexual infidelity, particularly those in long-term relationships.

Women living in poverty often weigh the perception of contracting HIV against other needs and risks that at the time are valued more highly (Mays *et al*., 1988). For instance, disadvantaged women may not use a condom because of fear of partner violence, cultural pressures within the context of marriage, powerlessness during drug-use, need to secure shelter, or desire to obtain financial resources and assistance (May *et al*., 1988). Risky sexual behavior has been associated with anxiety, stress, and social and economic oppression (Diaz *et al*., 2004).

Additionally, beliefs about antiretroviral therapies held by some sero-positive women have led to increased sexual risk taking. Some women report higher levels of unprotected sex following the initiation of HIV/AIDS medications, believing that they are less infectious (Cohen *et al*., 2004). Seventy-eight percent (107 respondents) of the women in our sample indicated that they are taking HIV or antiviral medication.

When asked about HIV prevention information, 84 respondents (64%) indicated that they could have done something to avoid contracting HIV; some wishing they had had adequate information. New approaches to HIV/STI prevention are needed, particularly for heterosexual couples (El-Bassel *et al*., 2005). While slightly more than three out of four women in our sample (98 respondents or 77%) believe that there is sufficient information about HIV/AIDS prevention available, three out of four (96 respondents or 75%) also feel that there are better ways to provide HIV/AIDS prevention information (*See* Figure 14: HIV/AIDS Prevention Information).

Figure 14: HIV/AIDS Prevention Information



Effective HIV/AIDS prevention and intervention initiatives are designed to halt virus transmission, reduce barriers to early diagnosis, and decrease the number of reinfections. Higher levels of education often are associated with an increased ability to process information about health and safety risks (O'Conor *et al*., 1996). Yet, while a lack of basic education and limited health education are major barriers to effective prevention and intervention, they in themselves do not render initiatives ineffective. In addition to competence, the keys to preventive approaches are knowledge of the population, culture, and language, and awareness of individual and group life conditions.

A woman in our sample revealed:

"The information is there. How do you get people to [listen]*? Because, like I said, years ago people were just dying, and now you have these kids that think it's no big deal because you can live with this. They think—oh, they just give you some pills and you'll be fine. It'll be like diabetes. They have no clue. It's not like that. Years ago it was a life and death thing. Right now, this younger generation doesn't see the devastation . . . . Now, it's like so what if I get sick, I'll go to the doctor, and they'll give me medicine . . . ."* said a 46-year-old Latina outreach worker.

* * *

VI. CONCLUSION

Our primary goal in conducting this study has been to give voice to a diverse group of women. This work is significant because it highlights the needs of women of color with HIV/AIDS, a population that has largely been neglected by major segments of the public, elected officials, and the media. This lack of attention is complicated by unwarranted stigmas, vestiges of sexual innuendos about black women and Latinas, and the absence of a well-funded advocacy community. The silence surrounding HIV-positive women is complicated further by women's own reluctance to disclose their status and the absence of research that gives them "voice." Apprehensions about stigmatization, potential violence, and cultural norms often are reasons women refrain from disclosing. Hiding their status, however, limits access to valuable medical care, information, resources, and case management and supportive services. Consequently, underestimations of the number of women living with the virus result, and their need can go unmet until their health deteriorates from late-stage HIV-infections or AIDS.

Each woman in our study presents a unique set of needs and concerns to the service organizations where she seeks support and assistance. Fortunately, for many women residing in New York City, the extent of devastation from HIV/AIDS in their lives has been mitigated in part by the programs and services offered through a network of HIV/AIDS service organizations.

Community-based HIV/AIDS service organizations serve as safe-havens for many HIV-positive women. Yet, service providers face their own unique set of challenges, often defined by the same forces that influence the lives of women they serve. HIV/AIDS service organizations, particularly those serving women of color, struggle to survive themselves in an environment of under-funding, allocation cutbacks, shifting funding priorities, human resource limitations, and diminishing political will and support. While structural changes are needed desperately to eradicate conditions of poverty in communities at risk, service providers must have the human and financial resources to equip and empower HIV-positive women to transform their lives in the midst of the poverty in which they live. With a variety of support systems, it is hoped that poor sero-positive women can become more self-sufficient and advocates of change in their own lives, families, and communities.

The women in our study commented on their concern for their agencies:

> *"We need more funding for more outreach. The agency's funding is being cut. We're fundraising,"* said a 48-year-old Latina.

* * *

> *"If the agency gives us training, you get out of the house, and you could start to feel better about yourself, you'll take better care of yourself, and you'll be helping someone else. It's not a hard thing to do, but the monies have to be there,"* a Bronx Latina stated.

* * *

> *"We need support groups in my native language. Family members don't understand the condition. We don't get enough help. Need more services for Hispanic women to help us to disclose,"* shared a 47-year-old Puerto Rican from Manhattan.

* * *

This work points to the tremendous service and program needs of HIV-positive women and their families. We have highlighted met, unmet, and emerging needs. We also have discussed how these needs are shaped by social, economic, cultural, and political contexts and manifested through personal and structural concerns. The study documents the interwoven relationship between the feminization of poverty and the feminization of HIV/AIDS and supports prior research that links poverty with increases in the likelihood of HIV infection among poor women of color. The study also suggests that black and Hispanic women who were economically self-sufficient prior to their HIV/AIDS diagnosis are likely to sink into poverty after receiving a positive diagnosis.

Our findings, however, should be interpreted in light of the study's limitations. The non-probability sample contributes to selection bias and limits generalizability beyond accessible black and Hispanic clients who receive services through WFI-participating agencies. Women in our sample look to agency staff to assist them in accessing and utilizing services. This report does not address the degree to which service providers have steered participants to some services and programs over others. Self-reported data makes results subject to recall and reporting bias. The use of cross-sectional surveys for data collection limits our ability to imply directional causal associations. Additionally, the fact that women in our sample and the WFI population reside in New York City, the epicenter for women with HIV/AIDS, may limit generalizability of findings outside major metropolitan areas.

Despite study limitations, it is evident poor and low-income women bear a disproportionate burden of HIV/AIDS, and that their unmet and emerging needs are not solely defined by their HIV/AIDS status. Poverty, racism, classism, sexism, maternal and marital status, as well as accompanying health and mental health conditions and life style choices also contribute to the formation of their needs.

This study presents a wealth of information on the needs of black women and Latinas living with HIV/AIDS. Due to the demographic profile of our sample, we were unable to examine the needs of women from other racial/ethnic groups. Future research is needed on the issues and concerns facing white, Asian, Native American, and multi-racial HIV-positive women. More research also is needed on HIV-positive women born in Puerto Rico and sero-positive women from immigrant populations.

We have sought to elevate the needs of HIV-positive women by giving them voice through the presentation of their own words. Through this work, women in our study have spoken about their present and future needs, and those of their children and partners. It is our hope that somebody is listening to our call to action.

VII. RECOMMENDATIONS

The interplay of racism, sexism, and socioeconomic factors are blamed for much of the health disparity experienced between HIV-positive women of color, men, and white women (Ginty, 2005). Inequality is linked to the rising HIV/AIDS epidemic among women, reflecting alarming gender gaps in resources and power (Joint United Nations Program on HIV/AIDS, 2004). Additionally, compared to white women, black women are 25 times more likely to be HIV-positive (Ginty, 2005). Disparities in employment status, education, household income, medical care and insurance, and social services (Bossette *et al*., 1998; Barkan *et al*.,1998; Pinn, 1992; Clancy and Massion, 1992), combined with the manner in which sexual relations are governed between men and women, leave many women powerless and vulnerable to HIV infection. The interplay of these and other forces together places a tremendously heavy burden on HIV-positive women in New York City.

Thirteen recommendations follow. They address three major areas: service models, emerging needs, and resources.

MODELS OF SERVICE

Recommendation #1: Collaborate with the private sector, non-profit organizations, and governmental social services departments to strengthen HIV/AIDS services and program outreach efforts.

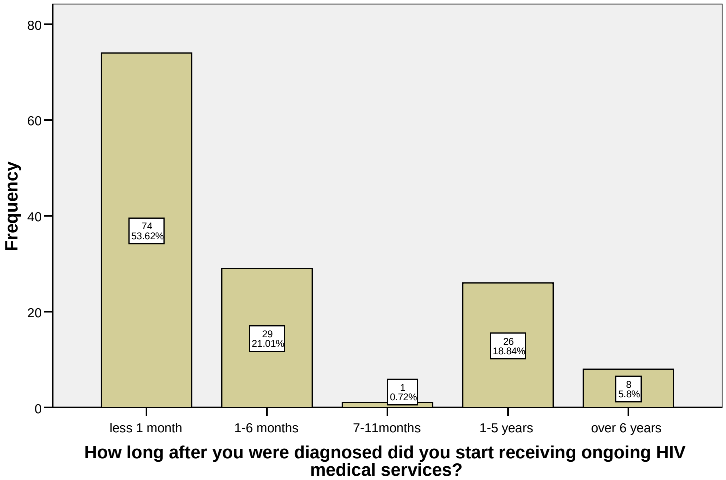
Forty-eight women in our study did not receive governmental financial assistance before discovery of their HIV status. After an HIV diagnosis, the number of women accessing governmental support increased dramatically. Forty-two women (30%) in our sample indicated they have experienced problems obtaining governmental assistance. We recommend the formulation of strategically targeted, multi-source messages (e.g., written materials, video/television promotional pieces, etc.) that feature several local HIV/AIDS service organizations, their services and program offerings, client testimonials, and agency contact information. Outreach efforts should highlight the HIV/AIDS service organizations' ability to help women overcome barriers to services and maneuver fragmented systems.

Additionally, unmet and anticipated service needs mentioned by study participants speak to gaps or disconnections between the perceived needs of study participants and their service providers. In communities where services are already provided, we recommend that outreach initiatives be strengthened to address the perception of service needs among specifically targeted client populations. While some of the women in our sample indicated needs for services presently provided by service organizations and health care providers, their comments suggest that there is a need to increase outreach efforts and develop innovative strategies to eliminate the perception—or misperception—of lack in service availability and accessibility. This study underscores the need to address perceptions held by study participants and the larger HIV/AIDS female client population.

Recommendation #2: Improve coordination and communication across agencies within the HIV/AIDS service networks that focus of the needs of women and families.

While almost 100% of the women in our sample indicated that they currently receive primary medical and gynecological care, a quarter (25%) of respondents informed us that they waited more than a year after notice of their HIV status to begin receiving ongoing HIV medical care (*See* Figure 15: Receipt of HIV Medical Services after HIV-Diagnosis). Additionally, 26 respondents (19%) stated they had experienced problems accessing medical or other health-related assistance. Since research suggests that women are more likely to be diagnosed at a later stage in disease progression than men, and they may progress from AIDS to death more quickly than men (Squire, 2003), improvements should be made in the coordination and communication across agencies, particularly the strengthening of linkages with agencies based on the medical model, to encourage earlier access to medical care and health services among HIV-positive women.

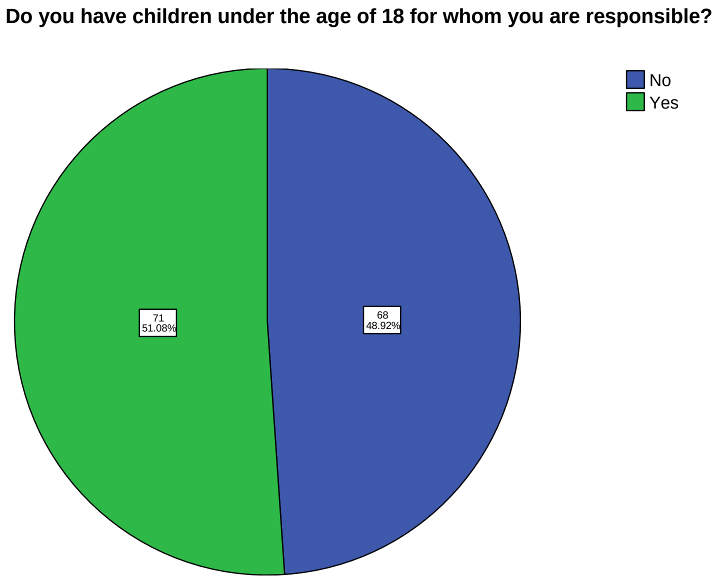
Figure 15: Receipt of HIV Medical Services after HIV-Diagnosis



Recommendation #3: Provide capacity-building resources for agencies to specialize in and expand family-focused services.

Women in our study are patients, mothers, wives, partners, and daughters. Specialized family services should attempt to better serve the family as a unit. Twenty-six percent of the women in our sample are married or living with a partner. Of the women who indicated they had a partner, 32% of the women believe that as a result of their HIV status, their partners will need services to cope. Half of the women also indicated that they have minor child responsibility (*See* Figure 16: Minor Child Responsibility). We recommend the provision of capacity building resources to programs that meet the needs of disabled and HIV-positive family members, lesbians/bisexual partners, substance users, children, heterosexual partners and spouses, and elderly adults residing with women living with HIV/AIDS. For instance, services for adolescent children may include after-school phone-groups, where youth can communicate with peers facing similar challenges in the comfort and safety of their homes, yet feel a connection to a support network (Wiener, 1998). Mothers in our sample indicated that agencies often close around the time children are released from school preventing children from taking advantage of services and programs.

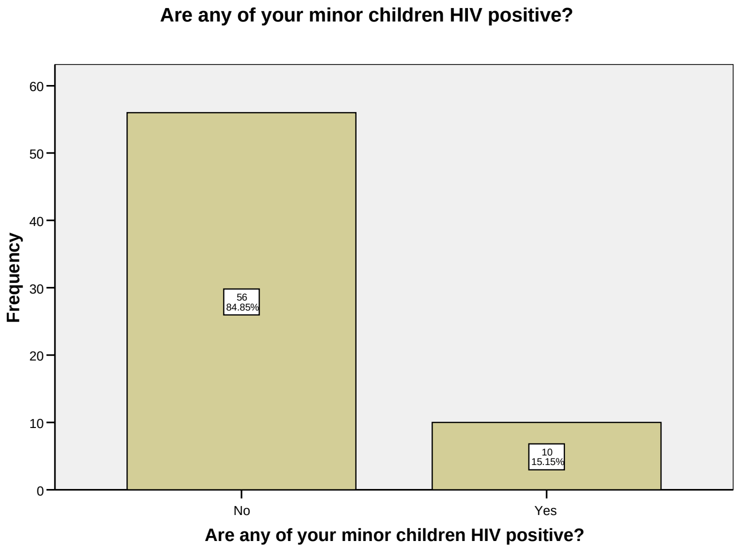
Figure 16: Minor Child Responsibility



Recommendation #4: Enhance and increase the number of programs and services specifically targeting the children of HIV-positive women.

Collaborate with the private sector and governmental agencies to strengthen and increase the programs and services designed to meet the needs of children whose mothers are HIV-positive. Resources should focus on health and mental health, after-school and childcare, and substance abuse, HIV-prevention, and physical and sexual abuse prevention services. Resources also should be channeled into the development of child-inspired and child-focused educational curriculum and materials to serve young and adolescent children with special needs. Ten of the women in our sample indicated having an HIV-positive minor child (*See* Figure 17: HIV-Positive Children).

Figure 17: HIV-Positive Children



EMERGING NEEDS OF WOMEN

Recommendation #5: Increase funding for mental health services and treatments. Encourage and support the development of collaborative efforts among providers to better address the multi-layered complex issues of women and their families.

Numerous studies highlight the impact of depressive symptoms in the lives of HIV-positive women (Squires, 2003; Schuman *et al*., 2001; Ickovics *et al*., 2001; Cook *et al*., 2004). Compared to HIV-positive men, major depression in HIV-positive women is twice as high (Evans *et al*., 2002). Additionally, quality of life and death in sero-positive women have been linked to the presence and level of mental symptoms (Bing *et al*., 2001; Tostes *et al*., 2004).

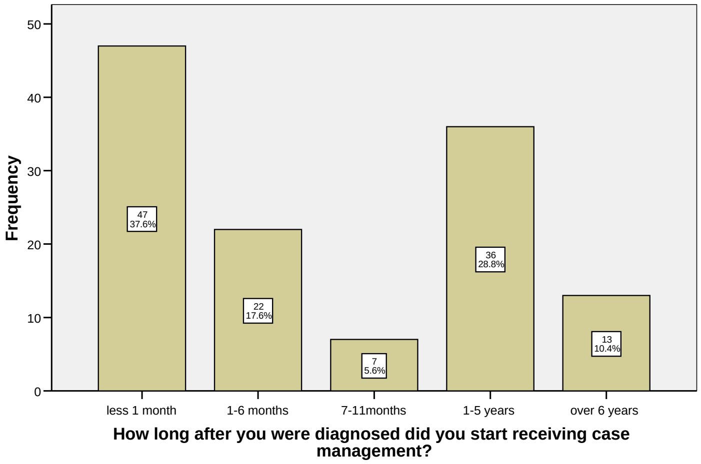
Our study reveals that HIV-positive women are not the only persons in their household in need of mental health services; often children, partners (male and female), and entire families have mental health issues that must be addressed. We recommend the development of new funding streams to agencies, programs, and healthcare service providers with proven track records in serving HIV-positive women with depressive symptoms (Squires, 2003). We also encourage the development of more effective case management for HIV-positive women with depressive symptoms that involves appropriate psychosocial care that also deals with HIV infection and its effects on self-esteem, relationships, reproductive choices, and family care (Squires, 2003).

We also recommend the development and support of collaborative initiatives between primary care practitioners, patients, mental health providers, and case managers. Collaborative efforts must involve substance abuse counselors or domestic violence service providers when appropriate. Such initiatives will be better equipped to address multiple stressors, such as poor mental health, chronic disease diagnosis (cancer, diabetes, etc.), unemployment, drug and alcohol dependency, and sexual, physical, and emotional abuse. Many HIV-infected women have expressed a need for additional forms of psychosocial support, resources, and information, such as those provided through counseling, support groups, and other situations that afford interaction with other HIV-positive patients (Heath & Rodway, 1999).

Recommendation #6: **Work with case management staff to improve service delivery, better meet administrative tasks, and prevent case manager turnover and burnout.**

Forty-nine women (35%) indicated that they waited a year or more after receiving notice of their HIV-status to begin accessing case management services (*See* Figure 18: Receipt of Case Management after HIV-Diagnosis). Reinvigoration of some case management staff through training and incentives may be necessary to improve recruitment efforts among newly diagnosed women who are reluctant to initiate case management services and better serve women comprising current caseloads. Group specific recruitment strategies and vehicles should be developed to attract non-U.S.-born women who are five times more likely to want but not receive case management services than native born women. Non-U.S.-born women may be reluctant to access services because of feelings of denial, guilt, and fear, cultural and language barriers, low-self esteem, or preoccupation with children and family needs.

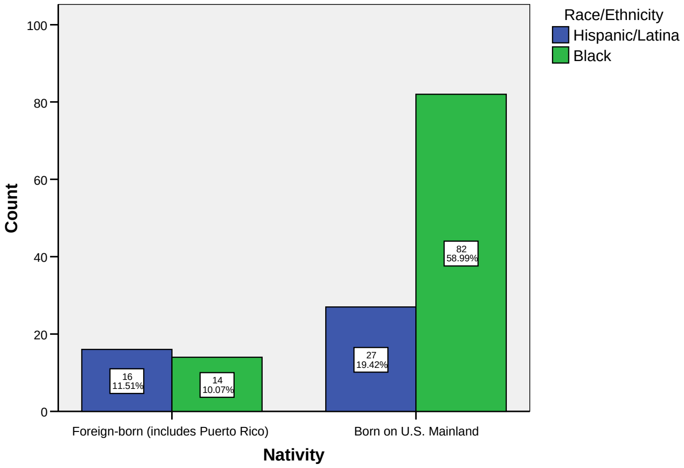
Figure 18: Receipt of Case Management after HIV-Diagnosis



Recommendation #7: Fund and create special programs to identify and serve women in new immigrant communities.

Research reveals that children of Latina women are less likely to be aware of their mothers' HIV status compared to the children of HIV-positive European and African American mothers (Tompkins *et al*., 1999). Analysis of our data reveals significant differences among women of color based on nativity. Our results suggest that U.S.-born women differ significantly from foreign-born women in terms of wanting more support groups, and disclosure and mental health services. Compared to women born on the mainland, foreign-born women are almost three times more likely to receive but want more HIV-related support group services.

Figure 19: Nativity by Race/Ethnicity



We recommend the funding and creation of new outreach initiatives, prevention strategies, and service delivery programs that target documented and undocumented immigrant populations, particularly in New York City where 36% of the population is foreign-born (New York City Mayor's Office to Combat Domestic Violence, http://www.nyc.gov/html/ocdv/html/issues/immigrants.shtml). While the vast majority of black women in our study self-identified as African American (*See* Figure 19: Nativity by Race/Ethnicity), 13% of them indicated their birthplace as Nigeria, Jamaica, Haiti, Trinidad, Barbados, or Guyana. Thirty-one percent (31%) of respondents identified themselves as Latina. Among Latinas, 63% were native-born. Twenty-one percent were born in Puerto Rico, while 16% were born in Peru, Honduras, Dominican Republic, Cuba, or Nicaragua. Eight women (6%) indicated Spanish as their primary language, and 18 (13%) were bilingual.

RESOURCE IDENTIFICATION

Recommendation #8: Increase financial resources to non-profit agencies serving women with HIV/AIDS.

Identify new funding streams to augment and enhance the human and financial resources of community-based organizations serving HIV-positive women and their families. Financial resources should be identified to improve the awareness and quality of non-profit staffing, case management, and supportive service delivery systems. Agencies serving women with HIV/AIDS must be supported in their efforts to provide social and medical services, emergency food, nutritious meals, transportation assistance, and social and psychological services. Supportive service delivery should target specific groups, such as: (1) women in need of home attendants and childcare and after-school services for their children; (2) women with minor child responsibilities who are in need of family/parenting, financial/entitlement, basic living, holistic, and home attendant services; (3) women over fifty who would like more age-specific services; and (4) non-U.S.-born women in need of group therapy, social networks, and holistic and legal/correctional services.

Recommendation #9: Provide funding to HIV/AIDS service organizations to strengthen domestic violence prevention programs and services.

Sixty-five percent of the women in our sample had experienced an abusive relationship. Non-U.S.-born women were twice as likely to have been in an abusive relationship and to have been concerned that someone might physically hurt them when disclosing their HIV status, compared to native-born women. Partnerships with non-profit organizations, corporations, and government agencies must be encouraged to improve domestic violence awareness campaigns and initiatives. We recommend crafting and disseminating culturally appropriate and gender specific prevention messages about HIV/AIDS and abuse.

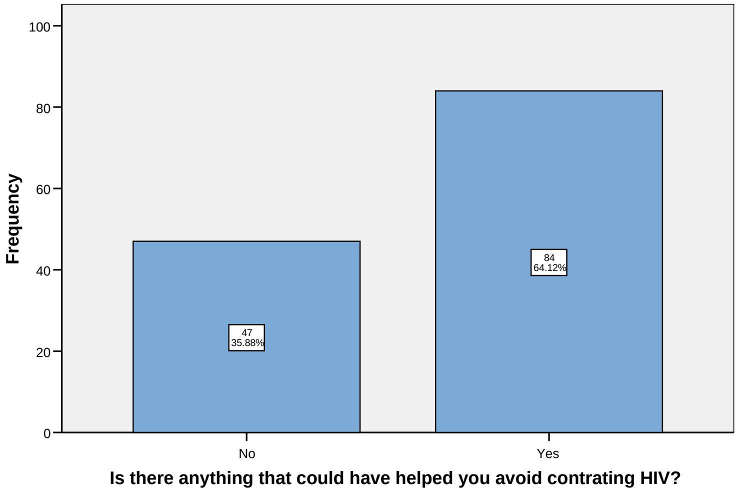
Agencies should embark on active—not passive—dissemination of literature and messages that are informed by the perspectives of women living with the virus. For instance, hand out educational materials at venues frequented by hard to reach populations. Or, sponsor public service announcements to run on English and non-English speaking radio stations that are listened to by women in specific age groups. Almost 20% of study respondents indicated their primary language as Spanish (6%) or bilingual (13%). Development of domestic violence prevention and awareness literature should be written below the fifth grade reading level in languages representative of the diversity within single racial/ethnic groups.

Recommendation #10: Increase funding to HIV/AIDS-risk-reduction interventions that have demonstrated effectiveness in changing behavior and reducing transmission risk.

Risky sexual behavior has been linked to childhood sexual abuse (Wyatt *et al.*, 2005; Cohen *et al.*, 2000), domestic violence (Stanhope, 1996; Cohen, 2000), partner abuse (Wingood & DiClemente, 1997; Saul *et al.*, 2000), anxiety, stress, and depression (Diaz *et al.*, 2004), drug-use (Tucker *et al.*, 2004), homelessness (Sikkema *et al.*, 1996), and social and economic oppression (Diaz *et al.*, 2004). While an unlimited number of successful behavioral modification interventions exists for maladaptive behaviors such as smoking, over-eating, and drug-use, more successful programs are needed to modify risky sexual behaviors engaged in by women (Mays *et al.*, 1988). Research shows that there is limited effectiveness in risk reduction modification strategies in the context of interpersonal relations governed by sexual mores, gender dynamics, power and dependencies, and cultural norms (Mays *et al.*, 1988). Effective HIV/AIDS prevention and intervention initiatives are designed to halt virus transmission, reduce barriers to early diagnosis, and decrease the number of reinfections. Yet, HIV/AIDS prevention and intervention strategies are not always sensitive to the educational levels, ethnic and cultural contexts, socioeconomic backgrounds, gender inequality in relationships, and the intimate dynamics of sexual relations of poor and low-income women of color. HIV/AIDS prevention interventions targeting women of color must offer alternative approaches that enhance skills while empowering women, such as peer education and outreach programs.

We recommend the channeling of financial resources to support, strengthen, and replicate risk-reduction interventions that understand how women of color develop and weigh perceptions of risk. Interventions that have proven track records should serve as reproducible models. These include initiatives that effectively: (1) assist women in behavior modification within their own cultural and interpersonal contexts, (2) help women translate knowledge about HIV risk transmission into effective verbal and non-verbal cues, (3) teach drug-users and sex workers how to successfully use male and female condoms and spermicides, and (4) acknowledge the special issues, such as limited educational attainment, facing poor women of color. Eighty-four women in our study (64% of respondents) indicated that they could have done something to avoid contracting HIV (*See* Figure 20: Avoidance of HIV)—some respondents believe that more adequate HIV/AIDS prevention information would have equipped them with the skills to protect themselves from HIV transmission. New approaches to HIV/STI prevention are needed, particularly for heterosexual couples (El-Bassel *et al.*, 2005). Relationship-based interventions emphasize the creation of supportive environments where partners can learn safer sex practices together. Research indicates that couple interventions are more likely to increase condom use (El-Bassel *et al.*, 2005). Effective behavior modification initiatives and AIDS-risk-reduction interventions can play a role in equipping women with the appropriate awareness, knowledge, and skills to reduce HIV infection and reinfection.

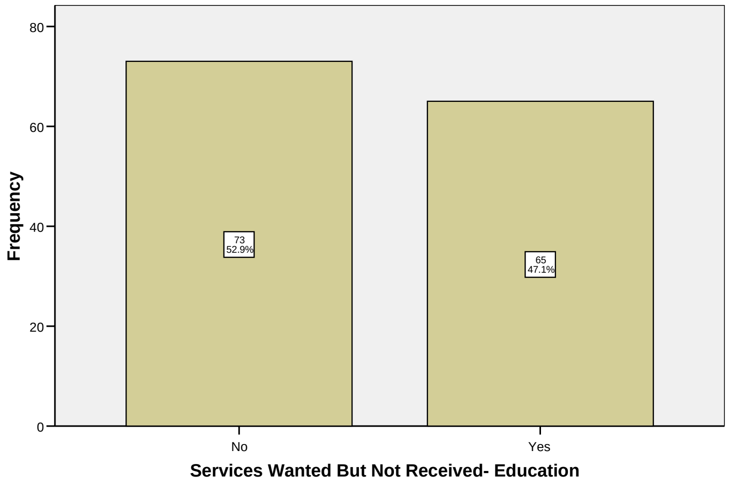
Figure 20: Avoidance of HIV



Recommendation #11: Provide funding to agencies and organizations that educate and train women living with HIV/AIDS who are interested in earning their GED, acquiring life skills experiences, and preparing for employment opportunities.

Research suggests that higher levels of education are associated with higher socioeconomic status (Jencks & Peterson, 1991). Yet, the interplay of behavioral factors and structural forces continues to contribute to educational inequality between minorities and whites (Jencks & Peterson, 1991; Cohn & Fossett, 1995), limiting the advancement of poor women of color. Adult female illiteracy is clearly a problem among women in our sample with over 50% of the women lacking GED's or high school diplomas. Respondents revealed that a variety of barriers prevent them from pursuing educational advancement opportunities. Nevertheless, almost half of the women in our sample wanted educational services but were not receiving them (*See* Figure 21: Educational Services Wanted). Training and educational programs and services are critical to helping women living with HIV/AIDS overcome barriers and access employment opportunities (The Lewin Group, 2000).

Figure 21: Educational Services Wanted

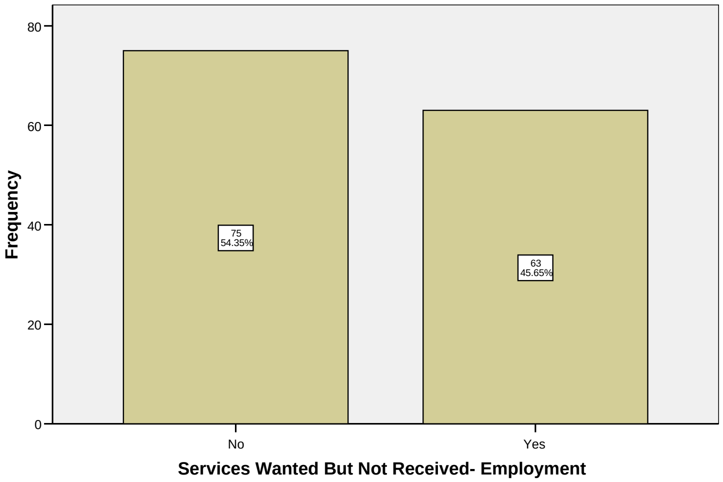


We recommend funding support for agencies and programs that have developed proven strategies and track records for empowering HIV-positive women through education, particularly women who are illiterate, learning English as a second language, caregivers, and disabled. Special focus should be given to the support of agencies and programs that are sensitive to the complex lives of HIV-positive women while providing health literacy, life skills development, GED, vocational training, and college preparation, as well as job placement training and services.

Recommendation #12: Support and collaborate with organizations that are utilizing effective strategies to facilitate and support HIV-positive women's entry, reentry, and advancement in the labor market.

Our society increasingly is viewing work as a viable option for some disabled individuals. While 22 women in our study (29% of respondents) indicated that they were not working because of disability, 75 women expect to work over the next 12 months. Additionally, almost half of the women in our sample were not receiving employment services but wanted them (*See* Figure 22: Employment Services Wanted). Given that many poor HIV-positive women are classified as hard-to-employ (The Lewin Group, 2000), specialized services and programs are required to help transition them to work.

Figure 22: Employment Services Wanted



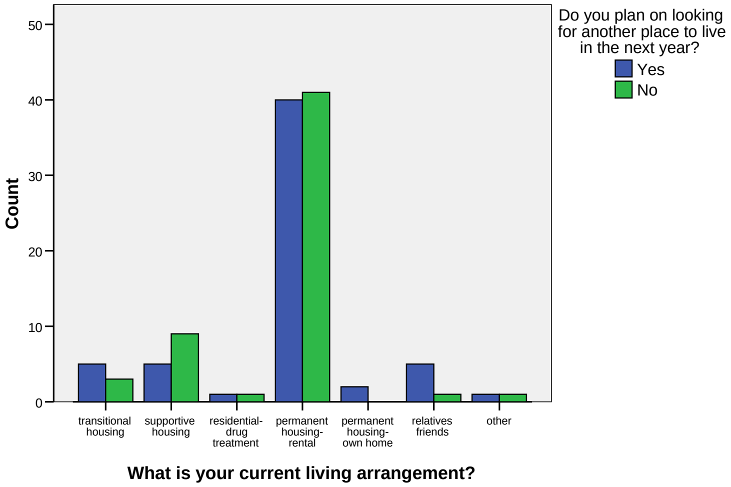
We recommend the identification and support of agencies and programs that are sensitive to the diverse needs of HIV-positive women, yet have developed effective strategies for changing expectations and outlooks of persons with disabilities and encouraging their participation in the labor force (The Lewin Group, 2000). We also recommend channeling resources to organizations with proven track records in training, placing, and providing on-going support (e.g., cash, in-kind, and transitional) to HIV-positive women and their family members to help them remain employed (The Lewin Group, 2000). Finally, collaborate with employers to redefine, develop, and supply employment opportunities for sero-positive women and their family members (The Lewin Group, 2000).

Recommendation #13: Support organizations that build and provide access to affordable housing.

Market forces, public policies, and discriminatory practices have contributed to the concentration and isolation of poor and low income renters in urban cores (The Joint Center for Housing Studies of Harvard University, 2006; Massey & Denton, 1993). The disappearance of low-cost rental stock, the scarcity of decent safe units, and rising rents are placing tremendous burdens on poor and low-wage households (The Joint Center for Housing Studies of Harvard University, 2006). More specifically, poor sero-positive women who are heads of household, elderly, or disabled often are unable to manage rental payments along with the costs of food, transportation, healthcare costs, and other living expenses.

While most women in our sample resided in rental housing, others lived in transitional and supportive housing, drug-treatment facilities, owned their homes, or had arranged living space with friends or relatives. Women in each group indicated that they planned on looking for another place to live in the next year—almost half of the renters planned to relocate (*See* Figure 23: Current Residence by Plans to Move).

Figure 23: Current Residence by Plans to Move



We recommend funding agencies and programs that assist HIV-positive women and their families in meeting their housing needs. We suggests channeling resources to organizations that provide decent affordable emergency and permanent housing, offer emergency rental assistance, and teach women budgeting and financial management skills. We also encourage the support agencies that have proven track records or that are developing innovative ways to link housing service needs with other social and supportive services needs.

APPENDICES

Appendix A: United Hospital Fund (UHF Neighborhoods)[27]

UHF	Neighborhood Name	Zip Code
Bronx		
101	Kingsbridge – Riverdale	10463, 10471
102	Northeast Bronx	10466, 10469, 10470, 10475
103	Fordham - Bronx Park	10458, 10467, 10468
104	Pelham - Throgs Neck	10461, 10462, 10464, 10465, 10472, 10473
105	Crotona – Tremont	10453, 10457, 10460
106	High Bridge – Morrisania	10451, 10452, 10456
107	Hunts Point - Mott Haven	10454, 10455, 10459, 10474
Brooklyn		
201	Greenpoint	11211, 11222
202	Downtown - Heights - Park Slope	11201, 11205, 11215, 11217, 11231
203	Bedford Stuyvesant - Crown Heights	11213, 11212, 11216, 11233, 11238
204	East New York	11207, 11208
205	Sunset Park	11220, 11232
206	Borough Park	11204, 11218, 11219, 11230
207	East Flatbush – Flatbush	11203, 11210, 11225, 11226
208	Canarsie – Flatlands	11234, 11236, 11239
209	Bensonhurst - Bay Ridge	11209, 11214, 11228
210	Coney Island - Sheepshead Bay	11223, 11224, 11229, 11235
211	Williamsburg - Bushwick	11206, 11221, 11237
Manhattan		
301	Washington Heights – Inwood	10031, 10032, 10033, 10034, 10040
302	Central Harlem - Morningside Heights	10026, 10027, 10030, 10037, 10039
303	East Harlem	10029, 10035
304	Upper West Side	10023, 10024, 10025
305	Upper East Side	10021, 10028, 10044, 10128
306	Chelsea - Clinton	10001, 10011, 10018, 10019, 10020, 10036
307	Gramercy Park - Murray Hill	10010, 10016, 10017, 10022
308	Greenwich Village - SoHo	10012, 10013, 10014
309	Union Square - Lower East Side	10002, 10003, 10009
310	Lower Manhattan	10004, 10005, 10006, 10007, 10038, 10280
Queens		
401	Long Island City – Astoria	11101, 11102, 11103, 11104, 11105, 11106
402	West Queens	11368, 11369, 11370, 11372, 11373, 11377, 11378
403	Flushing – Clearview	11354, 11355, 11356, 11357, 11358, 11359, 11360
404	Bayside - Little Neck	11361, 11362, 11363, 11364
405	Ridgewood - Forest Hills	11374, 11375, 11379, 11385
406	Fresh Meadows	11365, 11366, 11367
407	Southwest Queens	11414, 11415, 11416, 11417, 11418, 11419, 11420, 11421
408	Jamaica	11412, 11423, 11432, 11433, 11434, 11435, 11436
409	Southeast Queens	11004, 11005, 11411, 11413, 11422, 11426, 11427, 11428, 11429
410	Rockaway	11691, 11692, 11693, 11694, 11695, 11697
Staten Island		
501	Port Richmond	10302, 10303, 10310
502	Stapleton - St. George	10301, 10304, 10305
503	Willowbrook	10314
504	South Beach - Tottenville	10306, 10307, 10308, 10309, 10312

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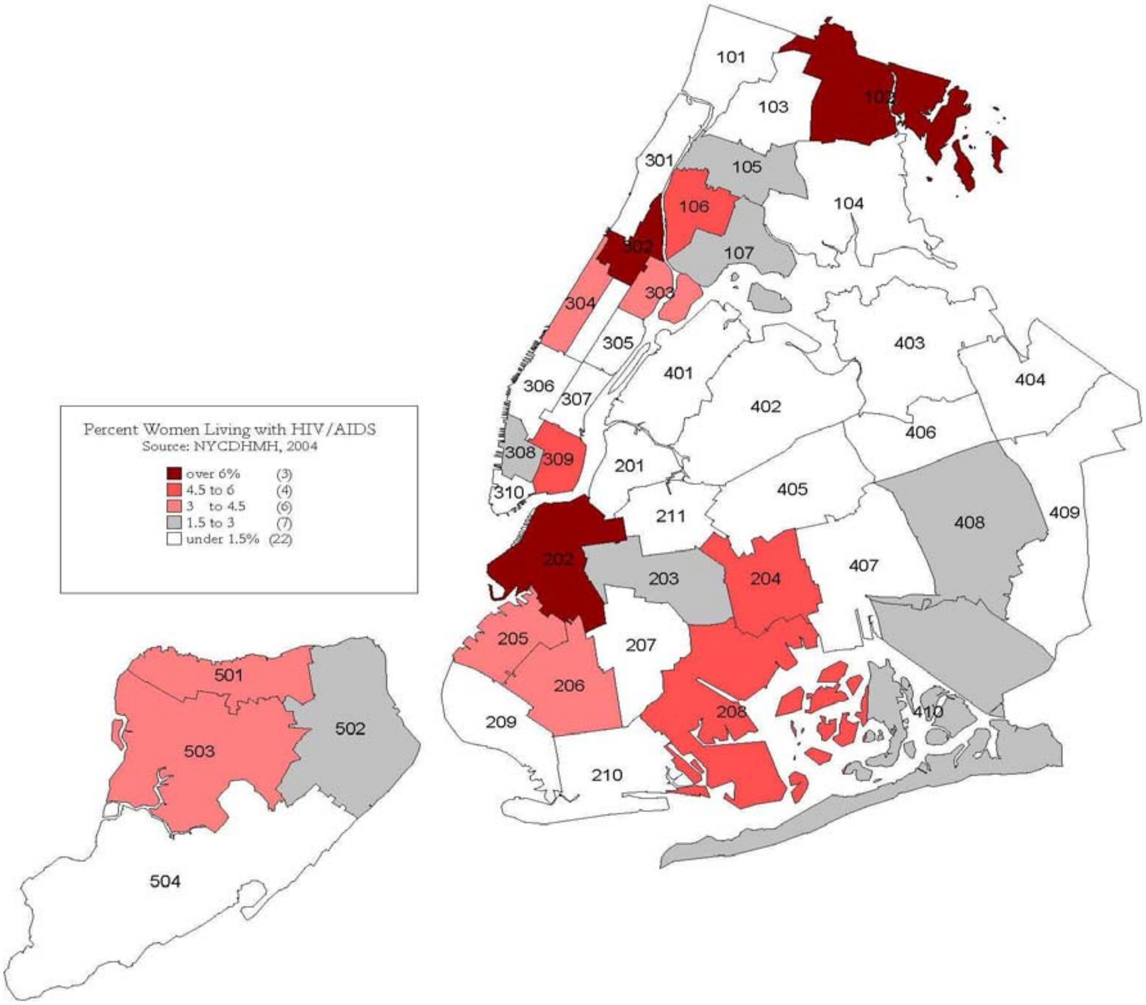
[27] (Source: New York City Department of Health and Mental Hygiene-HIV Epidemiology Program (HEP). UHF neighborhoods "correspond to a geographic area within New York City that is an aggregate of between 1 and 9 zip codes but that is smaller than a borough. UHF neighborhoods reflect catchment areas for certain healthcare facilities." Available online at http://www.nyc.gov/html/doh/html/ah/hivtables2003.shtml.

Appendix B: Map Illustrating the Percentage of Women Living with HIV/AIDS by UHF Neighborhoods through June 2003[28]



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[28] (Source: New York City Department of Health and Mental Hygiene-HIV Epidemiology Program).

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Located at the New York University's, Wagner School of Public Service, The Women of Color Policy Network is dedicated to ending the invisibility of women of color in public policy through policy research, advocacy, public education, and mentoring a new generation of advocate researchers.

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