Nassau-Suffolk EMA Ryan White Part A HIV Health Services Planning Council

'In Care' Women of Color PLWH/A Needs Assessment in the Nassau Suffolk EMA

2009 REPORT OF FINDINGS

Prepared by

COLLABORATIVE RESEARCH

May 2009

UNITED WAY OF LONG ISLAND

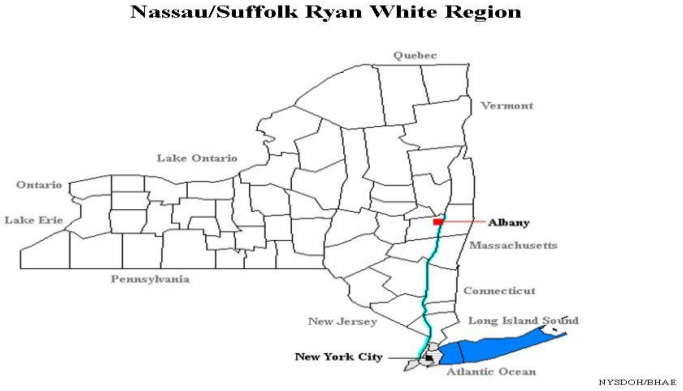
TABLE OF CONTENTS

2009 "In Care" Women of Color PLWH/A Needs Assessment

Nassau-Suffolk EMA HIV Health Services Planning Council *May 2009*

Executive Summary

In the Long Island region, the Eligible Metropolitan Area (EMA) is made up of Nassau and Suffolk Counties. The Nassau-Suffolk region is an island, 100 miles long, an average of 12 miles wide, (287 square miles for Nassau and 911 square miles for Suffolk) with a population of over 2.8 million people. Long Island is the most populous island in the 48 contiguous U.S. states and the most populated of any U.S. state or territory with a population density of 5,470 people per square mile. The eastern end of the EMA splits into two peninsulas, known as the North Fork and the South Fork. The region's link to the mainland is on its western border, through New York City.



The geography of the EMA poses unique problems for delivery of, and access to, services. There is little mass transportation available in either county except the Long Island Railroad, which is primarily designed to serve commuters traveling from the suburbs into New York City. There is one interstate highway, I-495, that goes from New York City to the East End (Eastern Long Island) but does not reach to the end of the EMA. Additionally, there is no north/south mass transportation making it virtually impossible to get from the north side of the island to the south side. Thus, even for persons who do have an automobile, travel within the region is often quite difficult.

The general population for both counties is primarily White (Nassau County 79%; Suffolk County 85%); followed by the Hispanic populations (Nassau County 10%; Suffolk County 11%) and African American populations (Nassau County 10%; Suffolk County 7%). Despite areas of affluence throughout this two-county EMA, there remain pockets of poverty and problems traditionally viewed as urban.

The EMA has an estimated 50,000 homeless persons, many substance users, a large immigrant population and, cumulatively, more persons living with AIDS than any other suburban region in the country.

The Nassau-Suffolk EMA contains approximately **2,815,129 residents** or **38% of the total population** residing on Long Island. As of December 31, 2007, the New York State Department of Health reported a total of 5,753 PLWH/A in the EMA. The region's three NYSDOH Designated AIDS Centers (DACs), located in East Meadow, Manhasset and Stony Brook, provide many valuable services, such as outpatient care, mental health services, and HIV/AIDS specialty services. Unfortunately, the challenges with transportation make it difficult for individuals to access and maintain these services.

Relevance of the 2008 "In Care" Women of Color PLWH/A Needs Assessment Study

The disproportionate impact of HIV infection on racial and ethnic minorities is a health crisis and has affected communities like the Nassau-Suffolk EMA, already struggling with many social and economic challenges, such as poverty, substance abuse, homelessness, and unequal access to health care. Although the epidemic is disproportionately affecting all racial and ethnic minorities, within these minority populations women are particularly affected. Between 2000 and 2004, AIDS cases in the United States increased by 9.9% in women as compared with 7.1% in men *(USDHHS, 2006),* and women now account for 27% of AIDS diagnoses *(Kaiser Family Foundation, 2007a).*Women of color—especially African American and Hispanic women—are disproportionately affected by HIV, and women with HIV are more likely than their male counterparts to be poor *(Kaiser Family Foundation, 2007a). (L. Bradley-Springer, Women and HIV. JANAC, Vol. 19:1, January 2008)*

Women tend to become infected at younger ages than men and to know less about HIV infection, including modes of transmission, methods of prevention, and ways to access care *(USDHHS, 2004).* And, whereas United States HIV death rates declined between 2000 and 2004 by 10.3% for men, they remained the same for HIV-infected women. *(USDHHS, 2006) (L. Bradley-Springer, Women and HIV. JANAC, Vol. 19:1, January 2008)*

The care and management of racial and ethnic minority women who have HIV infection has been complicated by the unequal access to health care and the many co-morbid conditions that affect the delivery of care to minority female patients living with HIV infection. These complicating factors include but are not limited to depression, substance and alcohol abuse, and post-traumatic stress disorders. *(VA Cargill, VE Stone. Med Clin North Am. 2005 Jul; 89(4):895-912).* The intersection of race, poverty, and gender-based power inequalities make young women of color particularly vulnerable to HIV infection.

In 2006, a total of 3,488 persons were reported as living with AIDS and 1,898 persons were reported as living with HIV for a total of 5,386 PLWH/A (NYSDOH, 2007). In 2007, the EMA reports a total of 3,714 PLWA and 2,039 PLWH, for a grand total of 5,753, ***yielding an increase of 7 % and 367 additional PLWH/A in the EMA.*** This number does not include incarcerated PLWH/A (n=165).

The Nassau-Suffolk EMA has a total PLWH/A population of 5,753 individuals, of which 3,804 (66%) are males and 1,949 (34%) are females. Table 1 below represents the HIV/AIDS incidence and prevalence within the EMA, by gender as of 12/31/07:

TABLE 1: GENDER COMPOSITION

Gender	New AIDS Cases		New HIV Cases		PLWH		PLWA	
	Total #	% of New AIDS	Total #	% of New HIV	Total #	% of PLWH	Total #	% of PLWA
Male	266	68.91	307	68.07	1251	61.35	2553	68.74
Female	**120**	**31.09**	**144**	**31.93**	**788**	**38.65**	**1161**	**31.26**
Total	**386**	**100%**	**451**	**100%**	**2039**	**100%**	**3714**	**100%**

Source: New York State Department of Health, 2007

Data provided by the New York State Department of Health (NYSDOH) for the period ending December 31, 2007 illustrates the significant impact the epidemic has on the populations within the Nassau-Suffolk EMA. Clearly, the EMA's minority populations are disproportionately impacted representing 62% of all PLWH/A as of December 31, 2007 in the EMA**.**

*African Americans comprise 10% and 7% of Nassau and Suffolk counties' general populations, respectively, yet represents **38.6% of PLWH/A, with a prevalence rate of 856 per 100,000 population.** Hispanics comprise 10% and 11% of the general populations for Nassau and Suffolk counties, respectively, and yet represent almost **20% of the living cases of HIV/AIDS, with a prevalence rate of 333 per 100,000**.*

The following table represents the HIV/AIDS incidence and prevalence by racial/ethnic categories for the EMA as of 12/31/07. *Minorities carry a heavy and disproportionate burden of the HIV/AIDS incidence and prevalence when compared with their proportion of the general population in the Nassau-Suffolk EMA:*

TABLE 2: DISPROPORTIONATE IMPACT BY RACIAL/ETHNIC GROUP

Race/Ethnicity	Nassau County	Suffolk County	EMA HIV/AIDS	Percent PLWH/A	Prevalence Rate
White	79.3%	84.6%	2,178	37.9%	94.3
African American	10%	7%	**2,185**	**38.6%**	**855.6**
Hispanic	10%	11%	**1,130**	**19.6**	**332.7**
American Indian/Alaskan	1.6%	2.7%	4	0.07	75.53
Asian/Pacific Islander	4.8%	6.1%	40	0.7	18.5
Multi-Race	2.1%	3.7%	206	3.6	Not Available
TOTAL	100%	100%	5,753	100%	187.2

Source: New York State Department of Health, December 31, 2007

The table on the following page represents the HIV/AIDS incidence and prevalence by racial/ethnic categories for the EMA as of 12/31/07.

TABLE 3: RACE/ETHNIC GROUP DISTRIBUTION

Race/ Ethnic Group	New AIDS Cases		New HIV Cases		PLWH		PLWA	
	#	%	#	%	#	%	#	%
White, not Hispanic	101	26.17	131	29.05	810	39.73	1368	36.83
African American, not Hispanic	140	**36.27**	149	**33.04**	742	**36.39**	1443	**38.85**
Hispanic	108	**27.98**	134	**29.71**	403	**19.76**	727	**19.57**
Asian/ Pacific Islander	6	1.55	11	2.44	20	.98	20	.54
American Indian/ Native American	-	-	-	-	1	.05	3	.08
Multi-race	31	8.03	26	5.76	55	2.7	151	4.07
Other					8	.39	2	.05
Total	**386**	**100%**	**451**	**100%**	**2039**	**100%**	**3714**	**100%**

Source: New York State Department of Health, 2007

Persons of color comprised 71% of the emergent HIV and a staggering 74% of the new AIDS cases in 2007. African Americans and Hispanics carry the greatest proportion of the HIV/AIDS disease burden in the EMA. ***African Americans*** *represent 36.3% of the newly diagnosed PLWA and 33% of emergent HIV cases. The HIV/AIDS prevalence rate is roughly 8 times as high among Blacks as Whites in the EMA.* African Americans comprise 10% of the general Nassau population and 7% of the general Suffolk population, yet account for cases and 38% of all PLWH/A . African Americans comprise 31% of the concurrent HIV/AIDS (AIDS diagnosis within one year of HIV diagnosis)—the late to care fraction in the EMA. In 2007, African Americans comprised 30% of all Part A funded clients. ***Hispanics*** comprise 10% of the general Nassau population and 11% of the general Suffolk population, yet account for almost 30% of the new HIV cases and 27.9% of emergent AIDS cases. Hispanics comprise 38.65% of all PLWH/A and 32.4% of the concurrent HIV/AIDS cases, evidencing the greatest proportion of the 'late to testing and care' pattern among the Severe Need Groups in the EMA**.** Hispanics comprised 15% of the Part A client base in 2007.

Women of Color: Women are disproportionately impacted by HIV/AIDS in the EMA. Females accounted for 31.9% of new HIV cases in 2007 and 31% of new AIDS cases. Women comprise 38.65% of the living HIV cases and make up 31.3% of the living AIDS cases reported in the EMA. *(NYSDOH, 2007) Women of color, and particularly African American and Hispanic females, are disproportionately impacted by HIV/AIDS in the EMA.* Women of color made up 26% of the Part A clients served in 2007.

The 2008 Nassau-Suffolk EMA Planning Council has commissioned this 2009 special Needs Assessment Study for the special population of Women of Color, to determine the service needs, gaps and barriers to care for this special population, the results of which will be used in the Planning Council's 2010 Priority Setting and Resource Allocation (PSRA) process.

Overview of 2009 Women of Color PLWH/A 'In Care' Study Findings

A total of 114 'In Care' female PLWH/A participated in the 2009 Women of Color needs assessment process. Overall, the Women of Color respondents are highly impoverished, with the

majority poorly educated; have multiple medical, mental health and substance abuse co-morbidities; and must deal with multiple competing life challenges.

By race/ethnicity, 58% were African American; 26% Hispanic; 11% multi-racial; and 5% American Indian. The largest proportion of women reported their ages in the 45-54 age group (37%); 28% reported their age in the 55-64 age range; 21% in the 35-44 age band; 7% in the 13-24 age range; and 3.5%, respectively, reported their ages in the 25-34 and 65+ age ranges.

The Women of Color (WOC) survey respondents reported multiple risk exposure modes, but predominantly reported Heterosexual sex (79%) and IDU (23%). The majority of the women report living with HIV-not AIDS (70%) and 30% reported living with AIDS. Overall, the 2009 WOC survey respondents report a fairly strong 'In Care' presence, with 95% evidencing an ideal or satisfactory primary medical care presence, and only 5% evidencing a 'fragile or erratic In Care' presence.

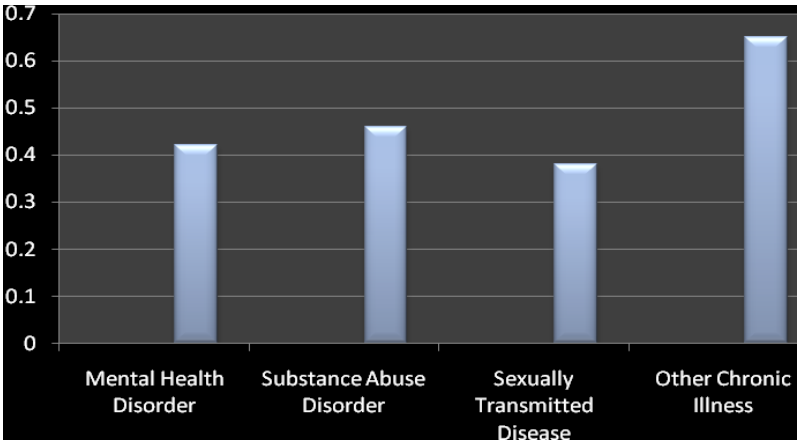
Over 33% of the WOC survey participants report current or previous homelessness. Only 29% report current employment, and 43% have only some high school or grade school level education. The WOC respondent group I a highly impoverished one, with almost ¾ reporting their incomes at or below $9,999 per year, with 93% living with incomes at or below $19,999 per year.

The 2009 survey findings among Women of Color living with HIV or AIDS in the Nassau-Suffolk EMA reveal a high level of co-morbidities, overall:

- 42% report the previous diagnosis and/or treatment for a mental health disorder;
- 46% report treatment for a substance abuse disorder;
- 38% report a previous STD, other than HIV;
- 65%, report diagnosis and/or treatment for another chronic illness, in addition to HIV disease.

Figure 1 below provides a graphic summary of the degree of these co-morbid conditions among the 2009 WOC survey respondent group.

FIGURE 1. CO-MORBIDITIES AMONG 2009 WOC PLWH/A RESPONDENTS



Overview of Women of Color 'In Care' Respondents' Services Needs, Uses, Gaps and Barriers

TABLE 4: 2009 'IN CARE' WOMEN OF COLOR NEED, USE, GAP, & BARRIER MATRIX

SERVICE CATEGORY	Need Rank	Use Rank	Gap Rank	Barrier Rank
Housing Assistance	1	8 tie	1 tie	2
Food Bank/Nutrition Services	2	8 tie	1 tie	3
Primary Medical care	3	2	NR	NR
Medications	4	5	NR	6 tie
Medical Transportation	5	1	4 tie	1
Mental Health Counseling	6	4	5 tie	6 tie
Emergency Financial/Utility Assistance	7	9 tie	4 tie	4 tie
Psychosocial Support/Support Groups	8	6	NR	NR
Health Insurance/Health Benefits Assistance	9 tie	7	5 tie	7 tie
Employment Assistance	9 tie		3	4 tie
Health Information/HIV Education & Info about Services	10 tie	10 tie	2	5
Substance Abuse Counseling	10 tie	9 tie	NR	7 tie
Case Management	NR	3	NR	NR
Oral Health Care	NR	8 tie	NR	NR
Peer Advocate	NR	10 tie	NR	NR
Legal Services/Immigration	NR	NR	5 tie	7 tie

Top Ranking WOC PLWH/A Service Needs

1. Housing Assistance
2. Food bank/Nutrition Services
3. Primary Medical Care
4. Medications
5. Medical Transportation
6. Mental Health Counseling
7. Emergency Financial Assistance/Utility Assistance
8. Psychosocial Support/Support Groups
9. Health Insurance/Co-pay Assistance (including obtaining Medicare and Medicaid benefits) tied with Employment Assistance
10. Health Information/HIV Education (including for more information about available services) tied with Substance Abuse Counseling

Top Ranking WOC PLWH/A Service Uses

1. Medical Transportation
2. Primary Medical Care
3. Case Management
4. Mental Health Counseling
5. Medications
6. Psychosocial Support/Support Groups
7. Health Insurance/Co-pay Assistance (including Medicare and Medicaid)
8. Housing Assistance tied with Food Bank/Nutrition Services tied with Oral Health Care
9. Emergency Financial Assistance/Utility Assistance tied with Substance Abuse Counseling
10. Health Information/HIV Education/Information about Services tied with Peer Advocate

Top Ranking WOC PLWH/A Service Gaps

1. Housing Assistance tied with Food Bank/Nutrition Services
2. Health Information/HIV Education/Information about Services
3. Employment Assistance
4. Medical Transportation tied with Emergency Financial Assistance/Utility Assistance
5. Mental Health Counseling tied with Health Insurance Assistance (including Medicaid/Medicare) and Legal/Immigration Services

2009 Women of Color PLWH/A Overall Reasons for Service Gaps

Women of Color Reasons for Service Gaps
Not well run
Lack of funding for these
Don't know - I'm new at this
Limited services - aren't realistic
They say because Section 8 and my area I don't qualify for much.
Can't use one service if you have used another
No services available
Legal status and because not available
Not legal - immigrant, not available in my area
Because it's difficult to get
Because I don't qualify
Illegal status and area where I live

(See TABLE 5: 2009 WOMEN OF COLOR PLWH/A SERVICE-SPECIFIC GAP REASONS, on the following page)

TABLE 5. 2009 WOMEN OF COLOR PLWH/A SERVICE-SPECIFIC GAP REASONS

SERVICE CATEGORY	Need Rank	Gap Rank	GAP REASONS
Housing Assistance	1	**1 tie**	Housing – For my family, say I am making too much - looking for subsidy. housing with my small pet dog
Food Bank/Nutrition Services	2	**1 tie**	I went to WACC for food pantry and they have waiting list - I have just had decrease in food stamps. I went to closer food pantry but can only go once every 6 months. Can't get Healthy food. Can't get food stamps.
Primary Medical care	3	**NR**	NA
Medications	4	**NR**	NA
Medical Transportation	5	**4 tie**	I'm still trying to get half fare but even when all forms are filled out by me and doctor, still haven't heard. Transportation - really hard for me right now
Mental Health Counseling	6	**5 tie**	Need MH Counseling & Transportation to get there
Emergency Financial/Utility Assistance	7	**4 tie**	Financial help. Telephone. Furniture - I need to get some other than the hospital bed and chair I have.
Psychosocial Support/Support Groups	8	**NR**	
Health Insurance/Medicaid/ Medicare Assistance	9 tie	**5 tie**	Can't get the red, white, and blue card. Battery operated chair to get around - my walking is not good but hard to get out of house - can take care of myself but need extra
Employment Assistance	9 tie	**3**	Better jobs
Health Information/HIV Education & Info about Services	10 tie	**2**	Information - I research on my own but don't know it always.
Substance Abuse Counseling	10 tie	**NR**	NA
Case Management	NR	**NR**	NA
Oral Health Care	NR	**NR**	NA
Peer Advocate	NR	**NR**	NA
Legal Services/Immigration	NR	5 tie	Illegal status

Top Ranking WOC PLWH/A Service Barriers

1. Medical transportation
2. Housing Assistance
3. Food Bank/Nutrition Services
4. Emergency Financial Assistance tied with Employment Assistance
5. Health Information/HIV Education/Information about Services
6. Mental Health Counseling tied with Medications
7. Health Insurance Assistance tied with Substance Abuse Counseling tied with Legal/immigration Services

2009 Women of Color PLWH/A Overall Reasons for Service Barriers

Women of Color Reasons for Service Barriers
Money
Limits and funds
Money and services changed about transportation
Budget cuts
Because of being illegal immigrant, language barrier, no services available
Legal status and because not available
Because of my legal status and not available in my area
No income
I don't qualify
No services available in my area.
Too many requirements
Because I don't have good transportation. Hard to get out but I can have food delivered if over $50.
Some of the agencies might be only worried about their service. I only get 2 round trips and have many more appointments than that per month.

TABLE 6. 2009 WOMEN OF COLOR PLWH/A SERVICE-SPECIFIC BARRIER REASONS

SERVICE CATEGORY	Need Rank	Barrier Rank	Barrier Reasons
Housing Assistance	1	**2**	Housing - the lottery for housing is a problem. Housing is the hardest! Section 8 housing - so long a time. Housing help - I have a room now that I pay $550 a month. Need help with rent. HUD won't go out to Suffolk, but my family is in Suffolk and I am limited to Nassau with my HUD help.
Food Bank/Nutrition Services	2	**3**	Nutrition - Last year it was hard to get a food voucher, shelter and transportation. Nutritious food. Need help with food.
Primary Medical Care	3	**NR**	Sometimes hard to get medical care - especially with transportation limits
Medications	4	**6 tie**	Sometimes medication is hard to get/pay for. Money for meds
Medical Transportation	5	**1**	I don't have a car so transportation can be hard. Transportation - big problem! Can only get 1 time per month so changed clinic to be closer to home and do not feel this one is as good as the other clinic I had been going to. CAB - used to take cab through RW but they suck! You call to confirm, they get to you late and then you have to wait for them to get to you. Then they treat you like crap. Now I take the bus. Transportation - I have lots of doctors appointments and without transportation, it's hard.
Mental Health Counseling	6	**6 tie**	Getting right counselor to whom you can talk - took me almost 20 years before I could really talk about it. Counseling about my grief
Emergency Financial/Utility Assistance	7	**4 tie**	Finances - I need more with SSI and SSD - I get less than $800. Emergency funds are hard to get. Need help with telephone.
Psychosocial Support	8	**NR**	NA
Health Insurance/ Assistance	9 tie	**7 tie**	I want to be on the blue and white card—(Medicare)
Employment Assistance	9 tie	**4 tie**	Need job, and job training. Need employment help. Help with getting a job
Health Information/HIV Education & Service Info	10 tie	**5**	Hard to get education. More understanding of what happens - people just don't talk about it anymore. I don't know what's out there.
Substance Abuse Counseling	10 tie	**7 tie**	Getting into a program to stay clean is really hard and discouraging me
Legal Services/Immigration	NR	**7 tie**	Hard to get papers/hard to find legal help. Legal status is big barrier.

Chapter 1: Introduction

Annual Needs Assessments are "snapshot" studies in time conducted to determine the priority service needs, barriers, and gaps in the continuum of care for People Living with HIV/AIDS (PLWH/A). Results of this client-centered activity are used to establish service priorities, document the need for specific services, determine barriers to accessing care, provide baseline data for comprehensive planning including capacity building, and help providers improve the accessibility, acceptability and quality of services delivered, especially to the designated 'Severe Need Groups/Special Populations'.

A comprehensive assessment of the service needs, gaps and barriers of "In Care" [1] Women of Color PLWH/A within the Nassau-Suffolk EMA was conducted in the spring of 2009. This assessment of need included an "In Care" survey questionnaire of this marginalized group of PLWH/A utilizing the In Care Needs Assessment Client Survey (NACS) tool.

Relevance of the Part A Comprehensive "In Care" Women of Color PLWH/A Needs Assessment

HIV infection among racial and ethnic minorities is an ongoing health crisis. The disproportionate impact of HIV infection on racial and ethnic minorities has affected communities like Nassau-Suffolk EMA, already struggling with many social and economic challenges, such as poverty, substance abuse, homelessness, unequal access to health care, and unequal treatment once in the health care system. In addition to these challenges is HIV infection, the transmission of which is facilitated by many of these factors. Although the epidemic is disproportionately affecting all racial and ethnic minorities, within these minority populations women are particularly affected. *(HIV/AIDS: A Minority Health Issue, Med Clin North AM, 2005, Jul; 89(4) 895-912).* The intersection of race, poverty and power-based gender inequality makes young women of color especially vulnerable to HIV infection.

New York is home for 16% of all cases of HIV and AIDS nationwide and continues to be the most disproportionately affected state in the nation with the highest per capita AIDS case rate: 28.5/100,000 as compared with 12.9/100,000 nationwide, as of 2006. Women in New York State are heavily and disproportionately affected by AIDS. Female PLWA represent a larger proportion as compared to those living with AIDS in the United States –30% vs. 23%. As highlighted by recently released CDC statistics, New York continues to lead the nation in the number of persons impacted by this disease. The new incidence estimate shows that 72 of every 100,000 of New Yorkers were newly infected in 2006, compared to 23 per 100,000 nationally. *(Report to the Legislature: The Continuing HIV/AIDS Crisis in New York: A Course of Action to Advance and Foster HIV/AIDS Research Tailored to the Needs of New Yorkers, 2008)*

The targeted Women of Color have emerged as a major focus of study for the Nassau-Suffolk planning area. The Planning Council is continuously challenged in identifying the changing

[1] 1) **CD4 – CD4 (T4) or CD4 + CELL COUNT and PERCENT**.
2) **VIRAL LOAD TEST** - Test that measures the quantity of HIV RNA in the blood.
3) **ANTIRETROVIRAL DRUGS** - Substances used to interfere with replication or inhibit the multiplication of retroviruses such as HIV.

needs of the PLWH/A community in order to best facilitate access, engagement and retention in care for all those living with HIV/AIDS in the service area.

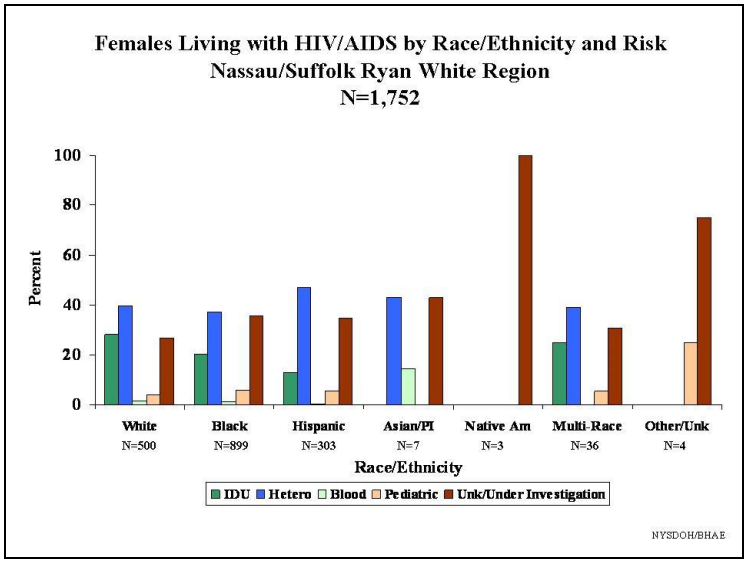
Based upon their highly disproportionate impact within the EMA, as evidenced in the table below, the 'In Care' needs assessment survey process and resulting report highlights the differing needs, uses, gaps and barriers to HIV primary medical care and support services experienced by the 'In Care' Women of Color PLWH/A within the Nassau-Suffolk EMA.

TABLE 7. POPULATIONS OF PLWH/A UNDERREPRESENTED IN RW FUNDED CARE SYSTEM

SEVERE NEED GROUP	Percent PLWH/A	Percent in Core Medical Care	Percent in Supportive Care	Percent in any Part A Care
AFRICAN AMERICANS	**38%**	**30%**	**63%**	**40%**
HISPANICS	**20%**	**15%**	17%	15%
MSM	**29%**	**21%**	16%	19%
WOMEN OF COLOR	**N/A per NYSDOH**	**19%**	**42%**	**26%**
IDU	**19%**	**13%**	18%	15%
45+/AGED	**58%**	**46%**	**68%**	**53%**

As evidenced in the table above, there are consistent disparities noted for each of the severe needs populations, when their relative proportion in the local epidemic is compared to their relative proportion in Part A funded core medical care services. Also evident are the striking differences between participation in core medical services versus use of supportive services, particularly among the African American, Women of Color and Aged PLWH/A populations, whose level of supportive services utilization far outweighs their relative participation in core medical services for the 2007 project year.

FIGURE 2. FEMALE PLWH/A BY RACE/ETHNICITY AND RISK



(***Source: NYSDOH, Area Profile of Nassau-Suffolk Ryan White Region of New York State, 2005***

When the population of Women of Color living with HIV/AIDS is examined by race and risk in the Nassau-Suffolk service delivery area, it is evident that Heterosexual sex is the most commonly reported 'known' risk category for Hispanic women, followed by Asian/Pacific

Islander women, then White women, and then African American women. IDU is most commonly reported among White women, then Black women, then Hispanic women. Unknown risk is reported most frequently among Native American women, followed by Asian Pacific Islander women, then by Black, Hispanic and White women. Reports of 'Unknown' risk are substantial among female PLWH/A in the EMA, with the highest levels of 'unknown' risk reported among Native American women, followed by Asian/Pacific Islander women, then by Black women, followed closely by Hispanic women and women of multi-racial background, and reported least among white women

The rate of poverty is greatly magnified when examined in the context of race/ethnicity within the EMA, and disproportionately impacts Blacks and Hispanics, and particularly women of color, who most frequently possess less education, have lower paying jobs, and live in greater poverty than their male counterparts. African Americans and Hispanics bear three times the rates of poverty in the EMA (3.1 and 3.2, respectively), as compared to rates for non-Hispanic Asians and Whites (1.5), as reported by Boston University School of Public Health, Analysis of Census data. *(diversitydata.org.)* It is estimated that 16% of all Long Islanders are uninsured. However, the rates of un-insurance are disproportionately born by Blacks and Hispanics in the EMA. *Diversitydata.org* reports that the proportion of uninsured Blacks in the EMA is 21.3% and for Hispanics it is 26.9%, far exceeding the average uninsured proportion among Whites residing in the EMA (8.7%) Women of Color are typically more disproportionately un-insured than men of color, and generally bear a far greater level of un-insurance than their white female counterparts. *(Harvard School of Public Health, 2007).*

Project Design for the 'In Care' Women of Color PLWH/A Needs Assessment Study

The objective of the 2009 Women of Color PLWH/A Needs Assessment Study was to identify the extent and types of service Needs, Gaps, Uses and Barriers among "In Care" Women of Color in the Nassau-Suffolk EMA service area. The term 'Women of Color' refers to women of all races/ethnicities other than Caucasian race, and primarily refers to African and Hispanic women in the Nassau-Suffolk Ryan White funded service delivery system.

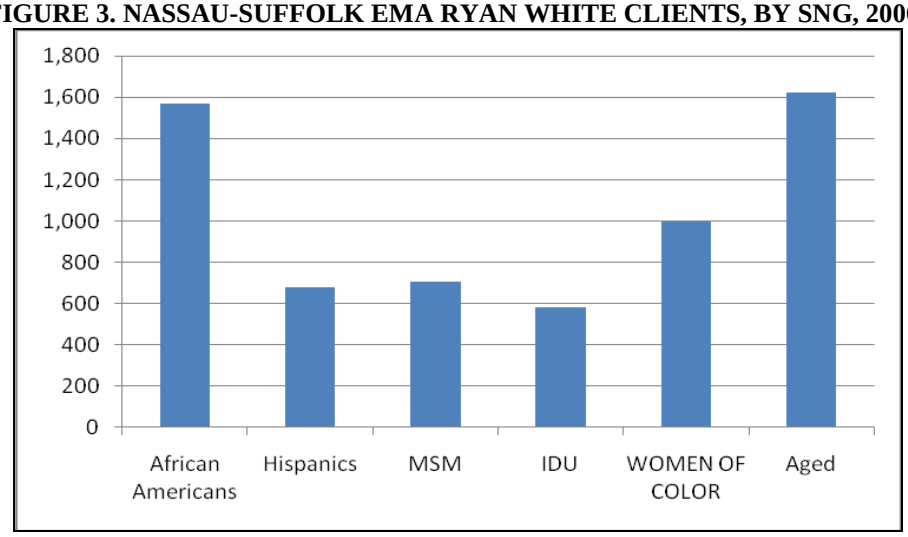
The sample for surveying the 'In Care' Women of Color population was first determined by establishing a 10% participation rate for a representative sampling of the estimated number of PLWH/A 'In Care' in the Nassau-Suffolk EMA (N=997).

TABLE 8. RYAN WHITE IN CARE POPULATION BY SNG

EMERGING POPULATION	# RW clients served in '06
African Americans	1,567
Hispanics	681
MSM	706
IDU	581
WOMEN OF COLOR	**997**
Aged	1,624
TOTAL	**3,368**

The survey process was designed to target as high level participation as possible among this disproportionately impacted population of PLWH/A (N=100). The actual 2009 survey participation rate for the 'In Care' population of WOC PLWH/A totaled 114 respondents.

FIGURE 3. NASSAU-SUFFOLK EMA RYAN WHITE CLIENTS, BY SNG, 2006



Literature Review: Nationally today, women account for more than one quarter of all new HIV/AIDS diagnoses. Women of color are especially affected by HIV infection and AIDS. In 2005, women accounted for 26 percent of the estimated 37,163 new diagnoses of HIV/AIDS in adults and adolescents, up from 8 percent in 1985. 70 percent of American women with HIV were infected with the virus through sexual contact with men, and another 27 percent became infected through injection drug use.

In 2005, HIV was the fifth leading cause of death among all U.S. women aged 34–44, and the sixth leading cause of death among all U.S. women aged 25–34. *(AmfAR Fact Sheet, Women and HIV/AIDS, 2008)* The only diseases causing more deaths of women were cancer and heart disease. *(CDC, August 2008)*

U.S. Women of Color are disproportionately affected by HIV/AIDS:

- In 2005, African-American and Latina women represented 24 percent of all U.S. women, but accounted for 82 percent of the total AIDS diagnoses that year
- In 2004, HIV infection was the leading cause of death for African-American women ages 25–34 years.
- African-American women are 23 times more likely than Caucasian women to be diagnosed with AIDS. The AIDS diagnosis rate for Latinas is four times that of Caucasian women. *(Office of Minority Health and U.S. census Bureau, 2005)*

NY State Women of Color are disproportionately affected by HIV/AIDS

- New York State continues to lead the nation in the number of women living with AIDS. Black and Hispanic women account for only 29% of the New York female population. However, together they represent 86% of New York women living with HIV/AIDS.

- Female teens and young women represent nearly half of newly diagnosed HIV cases in their age groups. The increased impact of HIV on young women and teens may be an indicator of the epidemic's future course: a trend toward equalization of male and female cases. *(Women in Peril--HIV/AIDS: The Rising Toll on Women of Color, A Report of the New York State AIDS Advisory Council, 2005)*

A recent study conducted by the New York State AIDS Advisory Council explored the societal, biological and cultural factors that put women at risk for infection and limit women's access to HIV prevention, health care and support services. The results of this study include the following:

- In New York, females now account for 48% of new HIV infections among teens ages 13-19, and 43% of new infections among young adults, ages 20 to 24. An increasing number of HIV/AIDS cases are also being seen in women >50 years of age.
- The concentration of the HIV epidemic among women of color is striking. ***The rate of HIV infection among African American women in New York is more than 27 times higher than that of white women; the rate for Hispanic women is 13 times higher than white women.*** Also at increased risk for HIV infection are Asian/Pacific Islander women, Native American women and immigrant women from regions where HIV is endemic, including Africa, Haiti and the Dominican Republic.
- Many of the women at greatest risk for HIV are also struggling with drug and alcohol use, mental illness, low educational levels, poor nutrition, sexually transmitted diseases, teen pregnancy and lack of culturally appropriate and accessible health and social services. Many are homeless, incarcerated, and mentally ill or engaged in prostitution to meet subsistence needs for themselves and their families. *(Women in Peril--HIV/AIDS: The Rising Toll on Women of Color, A Report of the New York State AIDS Advisory Council, 2005)*

Many HIV-positive women report no risk factors for HIV infection. It is likely that these women were infected through sexual contact with a partner they did not know to be HIV positive. **(***Women and HIV/AIDS Fact Sheet, The Foundation for AIDS Research, 2008)* For women of color, as for all women, heterosexual transmission overtook injection drug use as the primary risk factor for HIV/AIDS years ago. Today, the greatest risk factor for American women, including women of color, is the sexual and drug using behaviors of their male sexual partners.

Women living in AIDS epicenters—as many women of color do in the Nassau-Suffolk EMA—are at greater risk of HIV infection because there is a higher chance that their sexual partners will be infected with HIV. Many women are completely unaware that a partner engages in high-risk behavior, such as male-to-male sex or injection drug use. *(AIDS Action, Policy Facts, Communities of Color and HIV/AIDS, January 2002)*

The HIV burden among women in the US is not distributed equally across age, race, or socio-economic class. Poor women of color are disproportionately infected with HIV: in 2005, over 66% of the women diagnosed with HIV in the U.S. were Black, and fully 64% of the women living with HIV had annual incomes below $10,000 *(Centers for Disease Control and Prevention, 2007; Kaiser Family Foundation, 2008)*

Effects of Stigma, Poverty, Violence

Male dominance and power – expressed through violence and coercion – also play a critical role in increasing the risk of HIV infection to women. Many HIV-infected women have a history of childhood sexual abuse, rape, incest and domestic violence from adult male partners. Power imbalance deters many women from attempting to negotiate safer sex or to resist unprotected sex with a high-risk partner. Women may also face violence as a result of being HIV positive. In addition to domestic violence, abusive partners may threaten to reveal the woman's status to family, friends and employers, or use her HIV status as grounds for paternal custody. *(Women in Peril--HIV/AIDS: The Rising Toll on Women of Color, A Report of the New York State AIDS Advisory Council, 2005)*

Stigma against women living with HIV acts as a major obstacle to prevention and treatment of HIV/AIDS. Stigma leads to the marginalization and social and gender inequalities, such as poverty and unequal educational and occupational opportunities, force women to rely on male partners for financial support, making it more difficult for them to insist on interventions that reduce their risk of acquiring HIV. *(S. Blumenthal, MD, Pervasive Stigma Surrounds Women Living with HIV/AIDS, The Huffington Post, 4/1/08).*

Because women often have lower incomes than men or work lower paying jobs with minimal benefits, women have less access to HIV care and affordable medical insurance. Women are more likely to postpone health care due to illness or lack of transportation than are men. Women assume more family care responsibilities and are more likely to sacrifice their own health care in order to care for their family, especially their children *(Women and HIV, About.com, 7/31/08)*

Chapter 2: "In Care" Women of Color Survey Findings[2]

The 2009 HIV/AIDS Needs Assessment provides a "snapshot" of the 'In Care' Women of Color community service needs, usage, barriers, and gaps as expressed by consumers of HIV related services. The goal of the 'In Care' survey process was to achieve a 10% level of participation by the 'In Care/In System' female clients of non-Caucasian race (including African Americans and Hispanics) hereafter referred to as 'Women of Color In Care' population (N=100). The actual 'In Care' participation rate was 114'survey respondents, which provides a sound representative sample of this emerging population for comparison to historical and future needs assessment findings of need among Women of Color PLWH/A in the EMA.

Overview of the "In Care" Women of Color (WOC) Survey Results

The 'In Care' Women of Color client surveys were scheduled over a two-month period in the winter/spring of 2009. The tables below indicate the age, race, risk and sexual orientation of the 'In Care' Women of Color survey population.

Demographic and Health Profile of ''In Care'' Women of Color Survey Respondents
The majority of the WOC survey respondents (58%) reported their race as African American, 26% as Hispanic, 5% as American Indian and 11% as multiracial. None of the respondents reported Caucasian or Asian/Pacific Islander.

TABLE 9. RACE/ETHNICITY OF WOC PLWH/A RESPONDENTS

Do you consider yourself?		
Answer Options	**Frequency**	**Count**
African American	57.9%	66
American Indian	5.3%	6
Hispanic/Latino	26.3%	30
Multi-Racial	10.5%	12
answered question		114

Thirty two percent (32%) of the Women of Color respondents reported ages 13-44 years, and 68% reported their age as 45+ years.

TABLE 10. AGE RANGE OF WOC PLWH/A RESPONDENTS

What year were you born?		
Answer Options	**Frequency**	**Count**
13-24 years	7.0%	8
25-34 years	3.5%	4
35-44 years	21.1%	24
45-54 years	36.8%	42
55-64 years	28.1%	32
65+	3.5%	4
answered question		114

[2] In Care – defined by HRSA as receiving one or more of the following services 1) Viral Load test 2) CD4 Cell Count and/or 3) Antiretroviral drugs within the past 12 months

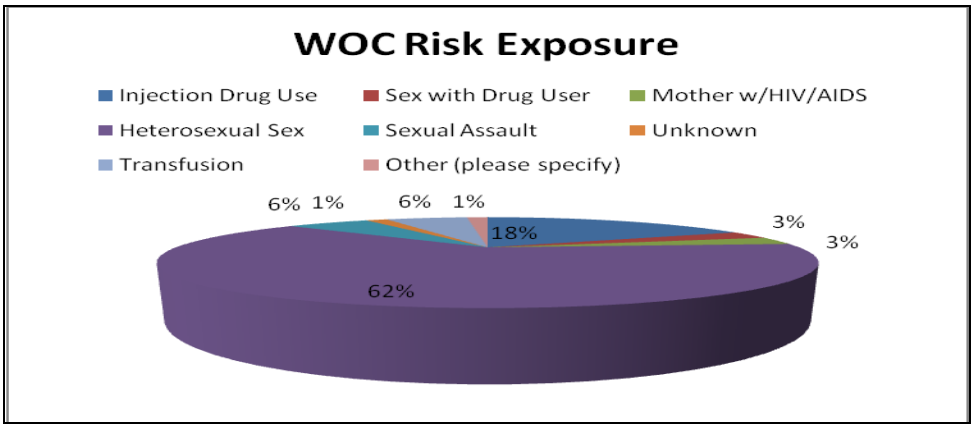
The largest age band among the WOC respondent group (37%) reports their age between 45 and 54 years. The second largest age band (28%) reports their age in the range of 55-64 years. The third largest proportion of the Women of Color respondents reported their age in the 35-44 age range. The vast majority of the Women of Color reports a 'straight' or heterosexual orientation. Only one woman reported her sexual orientation as 'gay' and several preferred not to answer.

As evidenced below, the vast majority of the Women of Color survey respondents report their risk exposure mode as heterosexual sex (79%), followed by IDU (23%). Almost 4% report 'sex with a rug user' and four Women of Color report 'Mother with HIV' as transmission mode. Seven percent (7%) cite 'sexual assault' as their risk exposure mode and another 7% report they acquired HIV from a transfusion.

TABLE 11. RISK EXPOSURE MODE

Do you know how you may have acquired HIV/AIDS? (please check all that apply)?		
Answer Options	**Frequency**	**Count**
Injection Drug Use	22.8%	26
Sex with Drug User	3.5%	4
Mother w/HIV/AIDS	3.5%	4
Heterosexual Sex	78.9%	90
Sexual Assault	7.0%	8
Unknown	1.8%	2
Transfusion	7.0%	8
Other (please specify): Needle-stick; PNTA	1.8%	2
answered question		114

FIGURE 4. RISK EXPOSURE MODES REPORTED BY WOC RESPONDENTS



Residence and Living Arrangements

A total of 74 (almost 65%) of the 114''In Care'' Women of Color PLWH/A survey participants reported their residence in one of 10 zip codes in the Nassau-Suffolk EMA. Almost 1/3 of all WOC respondents reports their residence in two zip codes (zip code 11550—reported by 26 women and zip code 11950—reported by 10 women). A total of 31 different zip codes were reported by the 2009 Women of Color PLWH/A respondents. (See Table 12 below)

TABLE 12: TOP 10 ZIP CODES OF RESIDENCE

ZIP CODE	COUNTY		Number WOC Respondents
11413	Queens,	New York	4
11510	Baldwin,	Nassau	4
11550	Hempstead,	Nassau	26
11570	Rockville Centre,	Nassau	4
11717	Brentwood,	Suffolk	6
11720	Centereach,	Suffolk	4
11755	Lake Grove,	Suffolk	4
11779	Ronkonkoma,	Suffolk	4
11772	Patchogue,	Suffolk	8
11950	Mastic,	Suffolk	10
TOTAL			**74**

HIV/AIDS Status and Year of Diagnosis

Over two-thirds (70%) of the Women of Color report living with HIV and only 30% report an AIDS diagnosis. The range of years from initial HIV diagnosis spans from 1981 to 2008, and for those reporting an AIDS diagnosis, diagnosis dates ranged from 1990 to 2007.

TABLE 13. YEAR OF HIV/AIDS DIAGNOSIS

Year HIV Diagnosis	Frequency	Count	Year of AIDS Diagnosis	Frequency	Count
1981	2.0%	2	1981	0.0%	0
1982	2.0%	2	1982	0.0%	0
1983	2.0%	2	1983	0.0%	0
1985	2.0%	2	1985	0.0%	0
1987	2.0%	2	1987	0.0%	0
1988	2.0%	2	1988	0.0%	0
1990	2.0%	2	1990	5.9%	2
1991	7.8%	8	1991	0.0%	0
1992	9.8%	10	1992	0.0%	0
1993	2.0%	2	1993	0.0%	0
1994	2.0%	2	1994	5.9%	2
1995	5.9%	6	1995	11.8%	4
1996	2.0%	2	1996	0.0%	0
1997	7.8%	8	1997	5.9%	2
1998	7.8%	8	1998	5.9%	2
1999	5.9%	6	1999	0.0%	0
2000	5.9%	6	2000	11.8%	4
2001	3.9%	4	2001	17.6%	6
2002	2.0%	2	2002	17.6%	6
2003	5.9%	6	2003	0.0%	0
2004	2.0%	2	2004	11.8%	4
2005	3.9%	4	2005	0.0%	0
2006	5.9%	6	2006	0.0%	0
2007	0.0%	0	2007	5.9%	2
2008	5.9%	6	2008	0.0%	0
2009	0.0%	0	2009	0.0%	0
	answered question	**102**			**34**

Approximately 36% of the Women of Color report the initial receipt of their first HIV diagnosis prior to 1994, with the majority (64%) reporting that they learned their HIV status since 1995. Among the women reporting an AIDS diagnosis (N=34), 35% report learning their AIDS status in the years spanning 1990-1999, with the majority--65%--reporting a more recent diagnosis, rendered between 2000 and 2007.

The vast majority of the Women of Color respondents (97%) reports receiving their HIV diagnosis in the State of New York, with only three women learning their HIV status in another state, including Pennsylvania and New Jersey. One woman reported receiving her first positive HIV test in the NY City jail and another "on the streets".

Health Insurance Coverage

Over two-thirds (70%) of the WOC respondents reported Medicaid benefits; another 26% reports Medicare and another 7% reports private insurance. None of the 2009 respondents reported VA benefits. Almost 18% report 'ADAP' as their primary form of health insurance. The 'other' benefits were reported as AARP, Oxford, United Health, and Health First.

Only two female respondents reported no insurance, though a total of 22 or approximately 19% report a lack of health insurance coverage, citing either ADAP or 'none' for health benefits

TABLE 14. CURRENT HEALTH INSURANCE COVERAGE

Do you currently have health insurance?		
Answer Options	**Frequency**	**Count**
Private Health Insurance (Humana, Aetna, etc)	7.0%	8
Medicare	26.3%	30
Medicaid	70.2%	80
ADAP	17.5%	20
None	1.8%	2
Other (please specify): AARP, Oxford, United Health, Health First	8.8%	10
answered question		**114**

Last Physician Visit and CD4 and Viral Load Monitoring Visits

Overall, this ''In Care'' Women of Color respondent group evidences a strong primary medical care presence, with the vast majority evidencing an ideal or satisfactory HIV primary medical care visit pattern. As noted below, there were only six of the 2009 Women of Color PLWH/A (5%) who could be categorized as 'erratically' In Care and none of the female PLWH/A had a technically 'Out of Care' status per their reports of their most recent HIV Primary Care Physician (PCP) visit. Two women reported their last PCP visit in March of 2008, indicating a less than desirable 'In Care' status (and verging on becoming technically 'Out of Care').

Overall, lab monitoring visit patterns reflect the same strong connection to care as for the PCP visit patterns, with the exception of the two female PLWH/A who are verging on an OOC status, reporting their last lab monitoring visits in March of 2008. *(See Table 15 on the following page)*

A total of 84% of the Women of Color PLWH/A respondent group reports the current active receipt of antiretroviral therapy.

TABLE 15: PATTERN OF MOST RECENT PCP, CD4 AND VIRAL LOAD MONITORING VISITS

VISIT TIME FRAME	DOCTOR	CD4	VIRAL LOAD
Past 3-4 Months **1/09-3/09 (Ideal "In Care" Status)**	58	48	48
Past 4-6 Months 10/08-12/08 **(Satisfactory "In Care" Status)**	50	58	56
Past 7-9 Months 7/08-9/08 **(Erratically "In Care" Status)**	4	5	5
Past 10-12 Months 3/08-6/08 **(Erratically "In Care" Status- At risk of Unmet Need)**	2	2	2
TOTAL "In Care"	***114***	***113***	***113***
'Out of Care' > One Year (OOC Since 2007 or before)	0	0	0
Did not answer	0	1	1
TOTAL 'Out of Care'	***0***	***0***	***0***
GRAND TOTAL	**114**	**114**	**114**

The Women of Color respondent group reports the receipt of their HIV primary medical care from North Shore Clinic (approximately 32%); Stony Brook (18%); and Nassau University Medical Center (30%). 'Other' HIV primary care clinics reported by the Women of Color respondent group included Brentwood Health Center, Brookhaven Health Center, David E. Rogers Center, Elmhurst Clinic, Franklin Medical Center, Martin Luther King Center, Patchogue Clinic, Shirley Health Care, and South Brookhaven. None of the women report a private physician.

TABLE 16. CLINIC/DOCTOR LOCATION

What clinic/doctor's office do you go to for your HIV?		
Answer Options	**Frequency**	**Count**
SUNY-Stony brook	17.5%	20
North Shore	31.6%	36
Nassau University Medical Center (NUMC)	29.8%	34
Other (please specify)	21.1%	24
answered question		**114**

The majority of the Women of Color group of respondents reports the location of their HIV primary care physician in Nassau County (62%), while approximately 35% report the receipt of

their HIV primary medical care in Suffolk County. Only two female respondents report New York City as the location of their HIV primary care physician.

TABLE 17. COUNTY LOCATION OF PCP

In what County is this doctor located?		
Answer Options	**Frequency**	**Count**
Nassau	61.8%	68
Suffolk	34.5%	38
New York City	1.8%	2
Other (please specify): Don't know what county it is in	1.8%	1
answered question		109

History of Mental Illness and/or Substance Abuse

Over 42% of the Women of Color survey respondents report the previous diagnosis and/or treatment for a mental health disorder.

TABLE 18. HISTORY OF DIAGNOSIS/TREATMENT FOR MENTAL ILLNESS

Have you ever been diagnosed with or treated for a mental illness?		
Answer Options	**Frequency**	**Count**
Yes	42.1%	48
No	57.9%	66
answered question		114

An even higher percentage (46%) of the Women of Color respondents reports having been previously diagnosed with and/or treated for a substance abuse disorder.

TABLE 19. DIAGNOSIS OF OR TREATMENT FOR SUBSTANCE ABUSE DISORDER

Have you ever been diagnosed with or treated for substance abuse?		
Answer Options	**Frequency**	**Count**
Yes	45.6%	52
No	54.4%	62
answered question		114

History of Diagnosis and/or Treatment for STDs and Diseases Other than HIV

Over 1/3 (38%) of the Women of Color PLWH/A respondents report the previous diagnosis and/or treatment for STDs other than HIV. Women of Color also report an exceptionally high proportion of other chronic illness, second only to the Aging PLWH/A, at 65%. (See Table 21 on the following page)

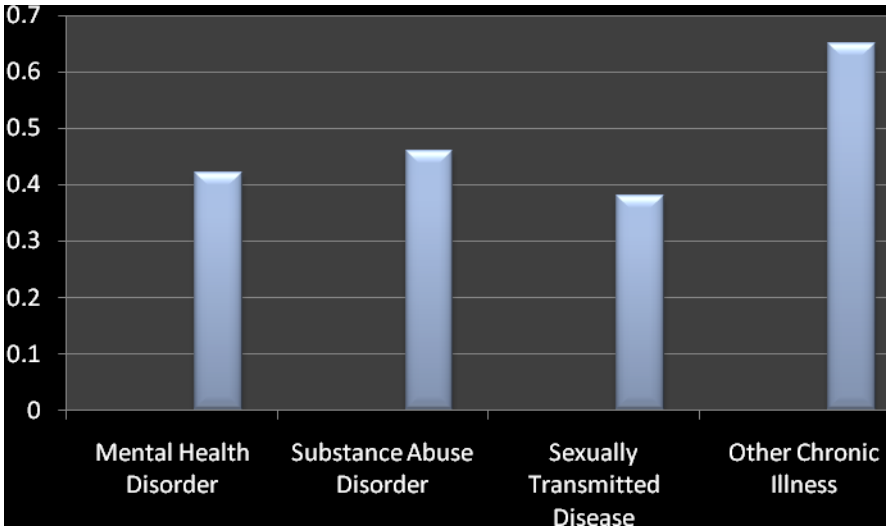
TABLE 20. DIAGNOSIS AND TREATMENT OF STDs

Have you ever been diagnosed with or treated for STDs?		
Answer Options	**Frequency**	**Count**
Yes	37.5%	42
No	62.5%	70
answered question		112

TABLE 21. DIAGNOSIS AND TREATMENT OF DISEASES OTHER THAN HIV

Have you ever been diagnosed with or treated for diseases other than HIV?		
Answer Options	**Frequency**	**Count**
Yes	64.9%	74
No	31.6%	36
Don't know	3.5%	2
	answered question	**114**

FIGURE 5. SUMMARY OF CO-MORBIDITIES AMONG 2009 WOMEN OF COLOR



History of Homelessness and Jail/Prison Stay

While less than 4% of the Women of Color survey participants reports current homelessness, 30% of the respondents reports a period of previous homelessness, in the recent and distant past.

Only 3.5 % of the WOC PLWH/A survey participants reported a recent jail or prison stay in the past six months.

TABLE 22. CURRENT OR PREVIOUS HOMELESSNESS

Are you now or have you ever been homeless?		
Answer Options	**Frequency**	**Count**
Never	66.7%	76
Currently homeless	3.5%	4
Been homeless in past 2 years, but not now	12.3%	14
Been homeless longer than past 2 years, not now	17.5%	20
	answered question	**114**

The 2009 Women of Color respondents ranked Housing Assistance as their top #1 Service Need and #1 Service Gap. This level of overall housing instability supports housing assistance as a top priority service need for this special population.

Current Living Arrangements

The vast majority of the Women of Color respondents reports renting their living space, and only a fraction (5%) reports owning their home. A total of 7% of the 2009 respondents reports being temporarily housed, staying with friends or relatives. Another 4% reports transitional housing and/or housing via a residential mental health facility. Over 5% of the Women of Color PLWH/A survey participants reports current homelessness, currently staying in a shelter.

TABLE 23. CURRENT LIVING ARRANGEMENTS/PLACE OF RESIDENCE

Do you currently?		
Answer Options	**Frequency**	**Count**
Own your home	5.3%	6
Rent	78.9%	90
Live with a Friend/Relative	7.0%	8
Stay in a Shelter	5.3%	6
Other (please specify):Transitional housing for HIV+ women; Residential Mental Health facility	3.5%	4
answered question		**114**

Over 55% of the Women of Color respondents report the receipt of some form of housing assistance/rent assistance.

Employment, Education and Income Levels

Only 29% of the Women of Color PLWH/A respondent group reports current employment. The need for a job and the desire for employment assistance were frequently mentioned in the women's comments to the survey questionnaire and were scored as a top ranking Need by the 2009 WOC respondent group. *The overall educational level of the Women of Color respondent group is exceptionally low, as compared to other special populations in the EMA.*

Forty-three percent (43%) of Women of Color respondents reports only some high school or grade school or less. Almost 29% have acquired a H.S. diploma or GED, and 25% have some college. Less than 4% of the female respondents report some a graduate level degree.

TABLE 24. HIGHEST LEVEL OF EDUCATION

What is your highest level of education?		
Answer Options	**Frequency**	**Count**
Grade school	3.6%	4
Some high school	39.3%	44
High School degree/GED	28.6%	32
Some college	25.0%	28
College degree	0.0%	0
Some graduate school	0.0%	0
Graduate school degree	3.6%	4
answered question		**112**

TABLE 25. ANNUAL INCOME LEVEL

What is your approximate yearly income?		
Answer Options	**Frequency**	**Count**
$0-$9,999	73.7%	84
$10,000 - $19,999	19.3%	22
$20,000-$29,999	3.5%	4
$30,000 - $30,999	1.8%	2
$40,000-$49,999	1.8%	2
Over $50,000	0.0%	0
	answered question	**114**

As evidenced in the above table, the 2009 Women of Color respondent group is highly impoverished, with almost ¾ or 74% reporting annual incomes at or below $9,999 and fully 93% reporting their total income at or below 200-250% of the federal poverty level.

'2009 'In Care' Women of Color Needs Assessment Survey Results

The ''In Care'' Women of Color PLWH/A Needs Assessment Survey results are discussed in order by the frequency and rankings of expressed service needs, service usage, service gaps and service barriers based upon the following definitions:

NEED	Number of ''In Care'' client survey respondents who stated "I currently need this service."
USE	Number of ''In Care'' client survey respondents who indicated service use in the past year
BARRIER	Number of ''In Care'' client survey respondents who indicated that a needed service is 'Hard to Get'.
GAP	Sum of ''In Care'' client survey respondents who indicated a needed service is unavailable ("Cannot get")

(See TABLE 26: 2009 'In Care' Women of Color NEED, USE, GAP, & BARRIER MATRIX, on the following page)

Overview of Women of Color PLWH/A 'In Care' Respondents' Services Needs, Uses, Gaps and Barriers

TABLE 26: 2009 'IN CARE' WOMEN OF COLOR NEED, USE, GAP, & BARRIER MATRIX

SERVICE CATEGORY	Need Rank	Use Rank	Gap Rank	Barrier Rank
Housing Assistance	1	8 tie	1 tie	2
Food Bank/Nutrition Services	2	8 tie	1 tie	3
Primary Medical care	3	2	NR	NR
Medications	4	5	NR	6 tie
Medical Transportation	5	1	4 tie	1
Mental Health Counseling	6	4	5 tie	6 tie
Emergency Financial/Utility Assistance	7	9 tie	4 tie	4 tie
Psychosocial Support/Support Groups	8	6	NR	NR
Health Insurance/Medicaid/Medicare Assistance	9 tie	7	5 tie	7 tie
Employment Assistance	9 tie	NR	3	4 tie
Health Information/HIV Education & Info about Services	10 tie	10 tie	2	5
Substance Abuse Counseling	10 tie	9 tie	NR	7 tie
Case Management	NR	3	NR	NR
Oral Health Care	NR	8 tie	NR	NR
Peer Advocate	NR	10 tie	NR	NR
Legal Services/Immigration	NR	NR	5 tie	7 tie

Top Ranking WOC PLWH/A Service Needs

1. Housing Assistance
2. Food Bank/Nutrition Services
3. Primary Medical Care
4. Medications
5. Medical Transportation
6. Mental Health Counseling
7. Emergency Financial Assistance/Utility Assistance
8. Psychosocial Support/Support Groups
9. Health Insurance/Co-pay Assistance (including obtaining Medicare and Medicaid benefits) tied with Employment Assistance
10. Health Information/HIV Education (including specific requests for more information about available services) tied with Substance Abuse Counseling

Top Ranking WOC PLWH/A Service Uses

1. Medical Transportation
2. Primary Medical Care
3. Case Management
4. Mental Health Counseling
5. Medications
6. Psychosocial Support/Support Groups
7. Health Insurance/Co-pay Assistance (including Medicare and Medicaid)
8. Housing Assistance tied with Food Bank/Nutrition Services tied with Oral Health Care
9. Emergency Financial Assistance/Utility Assistance tied with Substance Abuse Counseling
10. Health Information/HIV Education/Information about Services tied with Peer Advocate

Top Ranking WOC PLWH/A Service Gaps

1. Housing Assistance tied with Food Bank/Nutrition Services
2. Health Information/HIV Education/Information about Services
3. Employment Assistance
4. Medical Transportation tied with Emergency Financial Assistance/Utility Assistance
5. Mental Health Counseling tied with Health Insurance Assistance (including Medicaid/Medicare) and Legal/Immigration Assistance Services

Overall Reasons for Service Gaps

WOC Reasons for Service Gaps
Not well run
Lack of funding for these services
Don't know - I'm new at this
Limited services - aren't realistic
They say because Section 8 is not in my area I don't qualify for much.
Can't use one service if you have used another
No services available
Legal status and because not available
Not legal - immigrant, not available in my area
Because it's difficult to get
Because I don't qualify
Illegal status and area where I live

(See Table 27 on the following page for Women of Color Service-Specific Gap Reasons)

TABLE 27. WOMEN OF COLOR SERVICE-SPECIFIC SERVICE GAP REASONS

SERVICE CATEGORY	Need Rank	Gap Rank	Gap Reasons
Housing Assistance	1	1 tie	Housing – For my family, say I am making too much - looking for subsidy. housing with my small pet dog
Food Bank/Nutrition Services	2	1 tie	I went to WACC for food pantry and they have waiting list - I have just had decrease in food stamps. I went to closer food pantry but can only go once every 6 months. Can't get Healthy food. Can't get food stamps.
Primary Medical care	3	NR	NA
Medications	4	NR	NA
Medical Transportation	5	4 tie	I'm still trying to get half fare but even when all forms are filled out by me and doctor, still haven't heard. Transportation - really hard for me right now
Mental Health Counseling	6	5 tie	Need MH Counseling & Transportation to get there
Emergency Financial/Utility Assistance	7	4 tie	Financial help. Telephone. Furniture - I need to get some other than the hospital bed and chair I have.
Psychosocial Support/Support Groups	8	NR	
Health Insurance/Medicaid/Medicare Assistance	9 tie	5 tie	Can't get the red, white, and blue card. Battery operated chair to get around - my walking is not good but hard to get out of house - can take care of myself but need extra
Employment Assistance	9 tie	3	Better jobs
Health Information/HIV Education & Info about Services	10 tie	2	Information - I research on my own but don't know it always.
Substance Abuse Counseling	10 tie	NR	NA
Case Management	NR	NR	NA
Oral Health Care	NR	NR	NA
Peer Advocate	NR	NR	NA
Legal Services/Immigration	NR	5 tie	NA

Top Ranking WOC PLWH/A Service Barriers

1. Medical Transportation
2. Housing Assistance
3. Food Bank/Nutrition Services
4. Emergency Financial Assistance tied with Employment Assistance
5. Health Information/HIV Education/Information about Services
6. Mental Health Counseling tied with Medications
7. Health Insurance Assistance tied with Substance Abuse Counseling tied with Legal/immigration Assistance Services

Overall Women of Color PLWH/A Reasons for Service Barriers

Barrier Reasons
Money
Limits and funds
When I ask, I am told funding
services take too long
Money and services changed about transportation
Budget cuts
Because of being illegal immigrant, language barrier, no services available
Legal status and because not available
Because of my legal status and not available in my area
No income
I don't qualify
No services available in my area.
Too many requirements
Because I don't have good transportation and I'm just recovering from bad flu. Hard to get out but I can have food delivered if over $50.
Some of the agencies are not concerned; they might be only worried about their service. I only get 2 round trips and have many more appointments than that per month.

TABLE 28. 2009 WOMEN OF COLOR PLWH/A SERVICE-SPECIFIC SERVICE BARRIER REASONS

SERVICE CATEGORY	Need Rank	Barrier Rank	Barrier Reasons
Housing Assistance	1	**2**	Housing - the lottery for housing is a problem. Housing - the hardest! Section 8 housing - so long a time. - I have a room now that I pay $550 a month. Need help with rent. Housing - HUD won't go out to Suffolk, but my family is in Suffolk and I am limited to Nassau with my HUD help.
Food Bank/Nutrition Services	2	**3**	Nutrition - Last year it was hard to get a food voucher, shelter and transportation. Nutritious food. Need help with food.
Primary Medical Care	3	**NR**	Sometimes hard to get medical care - especially with transportation limits
Medications	4	**6 tie**	Sometimes medication is hard to get/pay for. Money for meds
Medical Transportation	5	**1**	I don't have a car so transportation can be hard. Can only get 1 time per month so changed clinic to be closer to home and do not feel this one is as good as the other clinic. Used to take cab through RW -You call to confirm, they get to you late and then you have to wait for them to get to you. Then they treat you badly. Now I take the bus. Transportation - I have lots of doctors appointments and without transportation, it's hard.
Mental Health Counseling	6	**6 tie**	Getting right counselor to whom you can talk - took me almost 20 years before I could really talk about it. Counseling about my grief
Emergency Financial/ Utility Assistance	7	**4 tie**	Finances - I need more with SSI and SSD - I get less than $800. Emergency funds are hard to get. Need help with telephone.
Psychosocial Support/ Support Groups	8	**NR**	NA
Health Insurance/ Health Benefit Assistance	9 tie	**7 tie**	I want to be on the blue and white card—(Medicare)
Employment Assistance	9 tie	**4 tie**	Need job, and job training. Need employment help. Help with getting a job
Health Information/HIV Education & Information about Services	10 tie	**5**	Hard to get education. More understanding of what happens - people just don't talk about it anymore. I don't know what's out there.
Substance Abuse Counseling	10 tie	**7 tie**	Getting into a program to stay clean is really hard and discouraging me
Legal Services/Immigration	NR	**7 tie**	Hard to get papers/hard to find legal help. Legal status is big barrier.

CHAPTER 3: Recommendations for Comprehensive Strategic Plan

Special Strategies Directed toward Optimizing Access and Retention in Care

In response to the comprehensive needs assessment study findings, the following general recommended strategies may be employed by the Nassau-Suffolk HIV Health Services Planning Council to further strengthen the service delivery system in the Nassau-Suffolk EMA:

Recommended Priority Strategies to Enhance Linkage, Engagement & Retention in Care for Women of Color PLWH/A:

1) Ensure that an up-to-date and comprehensive Ryan White Service Guide is provided to newly entering PLWH/A, to facilitate knowledge of how to access and maximally use all available services in the EMA.
2) Ensure 'point of entry' agency and staff awareness of all available Ryan White and other resources to ensure timely referrals and linkages with care and services for newly diagnosed and out of care PLWH/A.
3) Ensure Medical and Social Case Management provider awareness and use of all Ryan White and other local funding sources available for meeting the comprehensive service needs expressed by WOC PLWH/A.
4) Ensure consistent mental health and substance abuse screenings of WOC PLWH/A on Intake and aggressively refer those who evidence anxiety, depression and/or other mental health/substance abuse co-morbidities, (which contribute to fragile engagement and/or care deterrence); and ensure strong linking mechanisms and co-locate to the extent possible increased levels of on-site Mental Health and Substance Abuse treatment services to address the high degree of these co-morbid conditions within the WOC PLWH/A population.
5) Strengthen the "minority and women friendly" provider settings to encourage engagement and retention in care for the WOC subpopulations of PLWH/A.
6) Ensure that Women's programs include components on access to and retention in primary medical care, access to gynecological care, address family and parenting and child care concerns, emphasize treatment adherence and management of side effects, address mental health and substance abuse co-morbidities, and incorporate the impact of poverty, domestic violence, and homelessness.
7) Increase client linkages to care by assessing and addressing the multiple and complex social, emotional and physical needs upon entry to care; targeting those deemed at high risk for erratic care use and/or disengagement from care; and strongly engaging them in care during the first year of primary medical care participation.
8) Expand/seek additional funding to support the unmet transportation, housing, food, EFA, health information, employment assistance, mental health counseling, health insurance assistance and other service needs reported as Gaps by the surveyed WOC PLWH/A.
9) Ensure optimal collaboration among core medical, medical specialty (especially gynecologic services) and other supportive services providers, co-locating to the extent possible all priority services to meet the priority needs of WOC PLWH/A.
10) Market the benefits of treatment and availability of simpler and improved treatment regimens, which possess fewer side effects.
11) Strive to reduce the stigma surrounding HIV disease in the service area. HIV-related stigma acts as a barrier to testing and care among Women of Color and prevents disclosure of HIV

status, which acts as a serious impediment to preventing/reducing further transmission of HIV disease among PLWH/A in the service area.

II. Address Women of Color's Top Ranking Service Gaps

Top Ranking WOC PLWH/A Service Gaps

1. Housing Assistance tied with Food Bank/Nutrition Services
2. Health Information/HIV Education/Information about Services
3. Employment Assistance
4. Medical Transportation tied with Emergency Financial Assistance/Utility Assistance
5. Mental Health Counseling tied with Health Insurance Assistance (including Medicaid/Medicare) and Legal/Immigration Assistance Services

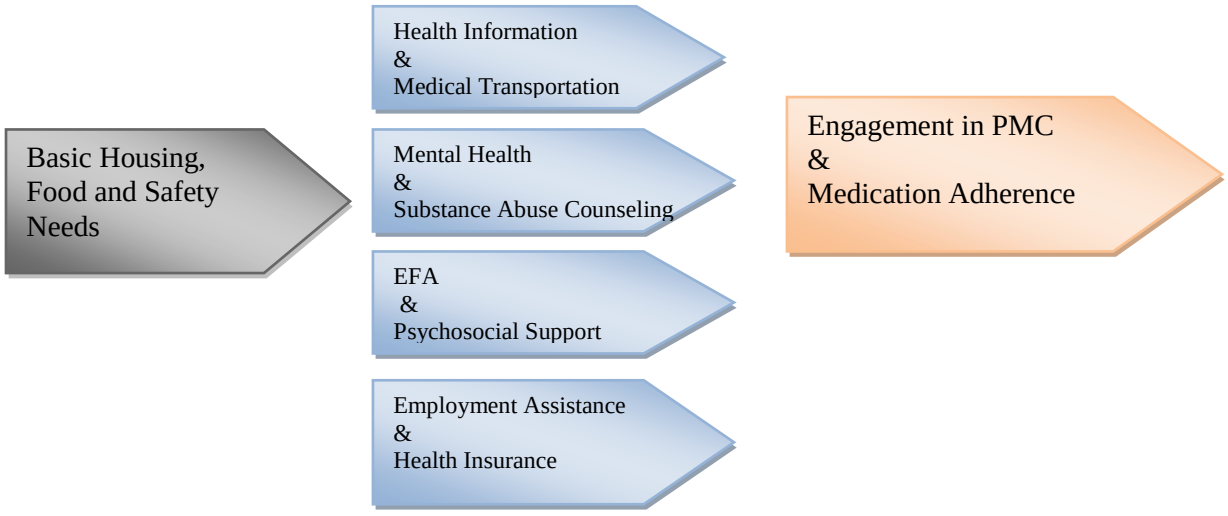
III. Address Women of Color's Top Ranking Service Barriers

Top Ranking WOC PLWH/A Service Barriers

1. Medical Transportation
2. Housing Assistance
3. Food Bank/Nutrition Services
4. Emergency Financial Assistance tied with Employment Assistance
5. Health Information/HIV Education/Information about Services
6. Mental Health Counseling tied with Medications
7. Health Insurance Assistance tied with Substance Abuse Counseling tied with Legal/immigration Assistance Services

Care Trajectory for Women of Color in the Nassau-Suffolk EMA

Basic Health & Safety/Information & Advocacy/ Stabilization/Entry & Retention in Care



APPENDIX

'In Care' PLWH/A Survey Instrument

This survey is confidential, not anonymous. Individual responses will not be shared. The information you provide will be used to provide overall trend information. If you have any questions, please ask the survey facilitator.

1. What is your date of birth?_____

2. What is your Zip Code? _____

3. Are you HIV positive or has your HIV progressed to AIDS? ☐ HIV ☐ AIDS ☐ Don't Know

4. What Year were you diagnosed with HIV:____ ____ ____ ____ ☐ unknown

5. What Year were you diagnosed with AIDS:____ ____ ____ ____ ☐ unknown

6. Do you know how you may have acquired HIV/AIDS? (please check all that apply)

☐ Male sex w/male	☐ Injection Drug Use	☐ Health Care Worker
☐ Female sex w/female	☐ Sex with Drug User	☐ Mother w/HIV/AIDS
☐ Heterosexual Sex	☐ Sexual Assault	☐ Unknown
☐ Prison	☐ Transfusion	☐ Other

7. Do you currently have health insurance?

☐ Private Health Insurance (Humana, Aetna, etc) ☐ Medicare ☐ Medicaid ☐ VA ☐ None
☐ Other _____

8. When was the last time you saw a doctor to treat your HIV?_____
Month, Year

9. When was the last time you had a CD4 (T-cell) Count? _____
Month, Year

10. When was the last time you had a Viral Load test?_____
Month, Year

11. Are you currently taking ART (HIV) medications? ☐ Yes ☐ No ☐ Don't know

12. Have you ever been diagnosed with or treated for a mental illness? ☐ Yes ☐ No

13. Have you ever been diagnosed with or treated for substance abuse? ☐ Yes ☐ No

14. Have you ever been diagnosed with or treated for sexually transmitted diseases (STD)?
☐ Yes ☐ No ☐ Don't know ☐ RTA

15. Have you ever been diagnosed with or treated for diseases other than HIV?
☐ Yes ☐ No ☐ Don't know ☐ RTA

16. Are you now or have you ever been homeless? ☐ Never ☐ Currently homeless
☐ Been homeless in past 2 years, but not now
☐ Been homeless longer than past 2 years, but not now

17. Do you currently? ☐ Own your home ☐ Rent ☐ Live with a Friend/Relative ☐ Stay in a Shelter
☐ Other _____

18. Do you get help with your rent? ☐ Yes ☐ No

19. Are you currently employed? ☐ Yes ☐ No

20. What is your approximate yearly income? ☐ $0-$9,999 ☐ $10,000 - $19,999 ☐ $20,000-$29,999 ☐ $30,000 - $30,999 ☐ $40,000-$49,999 ☐ Over $50,000

21. What is your highest level of education? ☐ Grade school ☐ Some high school ☐ High School degree/GED ☐ Some college ☐ College degree ☐ Some graduate school ☐ Graduate school degree

22. What is your sexual orientation? ☐ Gay ☐ Bisexual ☐ Straight ☐ Prefer not to Answer ☐ Other

23. Have you been in jail or prison in the past 6 months? ☐ Yes ☐ No

24. **In what city and state were you FIRST diagnosed with HIV or AIDS?** _____
city and state

25. Are you? ☐ Male ☐ Female ☐ Transgender ☐ Other _____

29. Do you consider yourself? ☐ African American ☐ American Indian ☐ Asian/Pacific Islander ☐ Caucasian ☐ Hispanic/Latino ☐ Multi-Racial ☐ Other_____

30. Who is your HIV Doctor? _____

31. What clinic/doctor's office do you go to for your HIV?
☐ SUNY-Stonybrook ☐ Northshore
☐ Nassau University Medical Center (NUMC) ☐ VA
☐ Health Unit (Prison) ☐ Other_____

32) **Need:** As a person living with HIV/AIDS, what are the 5 most important **needs?**

1._____
2._____
3._____
4._____
5._____

33. **Use:** List the top 5 services that you **use** to stay in care for HIV

1._____
2._____
3._____
4._____
5._____

34. **Barrier:** List the top 5 services that you need for HIV that are **hard to get**

1._____
2._____
3._____
4._____
5._____

35. **Why are these services hard to get?**

36. List the top 5 services that you need for HIV that you ***can't get***

1._____
2._____
3._____
4._____
5._____

37. **Why can't you get these services?**

Thank you for your time in completing this survey. Your confidential responses will be valuable information for the Nassau/Suffolk HIV Planning Council. If you would like information on how to participate with the Nassau/Suffolk HIV Planning Council, please ask the survey facilitator.