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

African American 'In Care' PLWHA Needs Assessment in the Nassau Suffolk EMA

2008 REPORT OF FINDINGS

Prepared by

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Nassau-Suffolk EMA HIV Health Services Planning Council *May 2008*

Executive Summary

Overview of Nassau-Suffolk EMA: 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" African American Needs Assessment Study

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).

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 74% of the emergent AIDS and 71% of new HIV cases for the period of 1/1/06 through 12/31/07.

African Americans comprise 10% and 7% of Nassau and Suffolk counties' general populations, respectively, yet represents 36.3% of the newly diagnosed PLWA and 33% of emergent HIV cases. *Hispanics comprise 10% and 11% of the general populations for Nassau and Suffolk counties, respectively, and yet represent 28 % of the newly diagnosed PLWA and 30% of emergent HIV cases*. Additionally, Whites represent approximately 26% of emergent AIDS and 29% of the HIV incidence, and 37.9% of the HIV/AIDS prevalence for the EMA (1/1/06 through 12/31/07). The following table represents the HIV/AIDS incidence and prevalence by racial/ethnic categories for the EMA as of 12/31/07:

Table 1: 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

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. The following table represents the HIV/AIDS incidence and prevalence within the EMA, by gender as of 12/31/07:

TABLE 2: 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

The table below represents the EMA's PLWH/A distribution by age as of 12/31/07. While the 20 to 44 age group comprises 39.42% of all prevalent cases, persons ages 45 years or more are

heavily and disproportionately impacted by HIV/AIDS in the EMA, comprising 57.6% of all PLWH/A and 64% of all prevalent AIDS cases in the EMA.

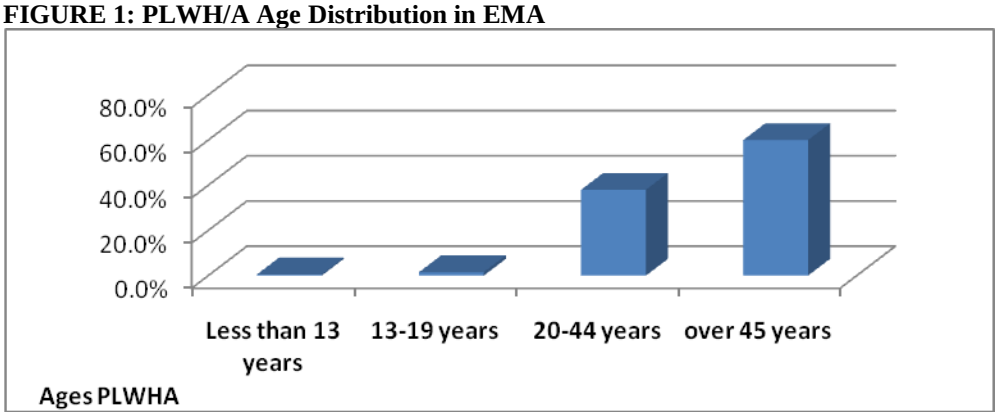
TABLE 3: AGE GROUP DISTRIBUTION (New AIDS and HIV, PLWH/A), 2007

Age Group (years)	New AIDS Cases		New HIV Cases		PLWH		PLWA	
	Total number	% of New AIDS	Total #	% of New HIV	Total #	% of PLWA	Total #	% of PLWH
< 13	--	--	1	.2	50	2.46	5	.13
13-19	19	4.92	15	3.33	63	3.1	45	1.21
20-44	224	58.03	318	70.51	974	47.89	1294	34.84
Over 45	143	37.05	117	25.94	947	46.5	2370	63.81
Total	**386**	**100%**	**451**	**100%**	**2039**	**100%**	**3714**	**100%**

Source: New York State Department of Health; 2007

The epidemiologic data clearly reflects that the largest proportion of PLWH/A within the EMA as of 12/31/07 is over 45 years of age (57.66%). The following graph provides a visual representation of the number of PLWH/A in the EMA who are 45 years or greater in age.

FIGURE 1: PLWH/A Age Distribution in EMA



The table below depicts the numbers of PLWH/A by risk transmission category, and evidences the disproportionate share of MSM and IDU in the EMA.

TABLE 4: TRANSMISSION RISK BY PLWH/A IN NASSAU-SUFFOLK EMA, 2007

Transmission Risk	Number of PLWH/A	Percentage of PLWH/A
	#	%
MSM	1669	28.1
IDU History	1101	18.5
Heterosexual	996	16.8
MSM/IDU	194	3.3
Other/Unknown	1557	26.2
Blood transfusion/components	199	3.4
Pediatric Risk	189	3.2

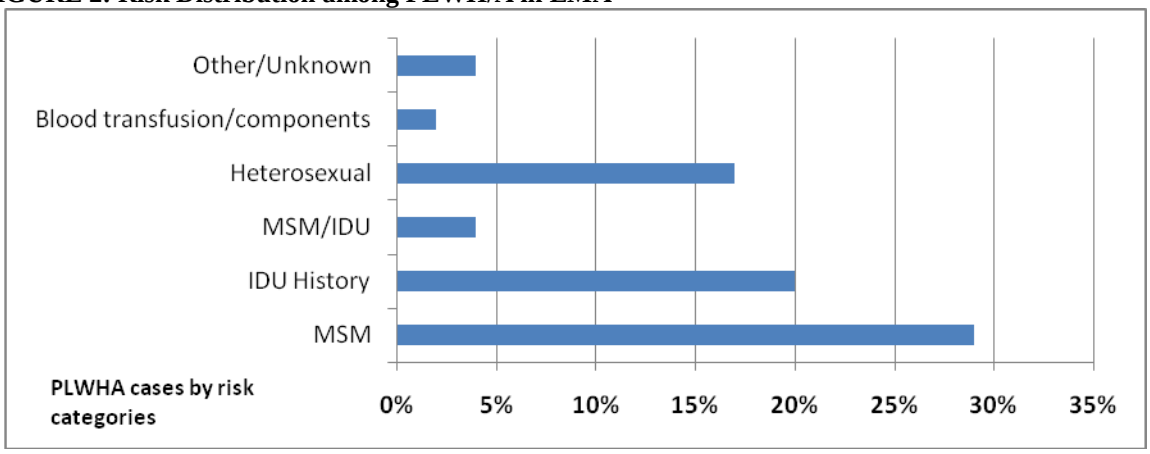
Source: New York State Department of Health, 2007

Men Who Have Sex with Men (MSM) account for over 28% of the total living cases within the Nassau-Suffolk EMA. The second largest behavioral risk group includes those PLWH/A who

have a history of intravenous drug use (18.5%). High risk heterosexual behavior accounts for an additional 16.8% of the PLWH/A populations within the region.

The following graph provides a visual demonstration of the distribution of HIV/AIDS cases by risk behavior. Clearly, those persons with "any" MSM behavior are at greatest risk for HIV/AIDS, comprising 32.38% of all PLWH/A, followed by those persons with "any" IDU risk behavior, who account for 22.5% of all PLWH/A in the EMA.

FIGURE 2: Risk Distribution among PLWH/A in EMA



Disproportionate Impact among Racial/Ethnic Populations

Minorities carry a heavy and disproportionate burden of the HIV/AIDS incidence and prevalence in the Nassau-Suffolk EMA, as evidenced in the table below.

TABLE 5: 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	NA
TOTAL			5,753	100%	187.2

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

Persons of color comprised 71% of the emergent HIV and a staggering 74% of the new AIDS cases. Persons of color make up 62% of all PLWH/A as of December 31, 2007 in the EMA. **African Americans and Hispanics carry the greatest proportion of the HIV/AIDS disease burden in the EMA. When combined with data discussed elsewhere describing racial/ethnic disparities it is clearly evident why certain racial/ethnic groups were selected as populations with demonstrated need.**

African Americans: ***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 33% of emergent HIV, 36% of new AIDS 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. Based on these statistics, in 2008 the Nassau-Suffolk EMA Planning Council commissioned this special Needs Assessment Study for the African American "In Care" population, to determine the service needs, gaps and barriers to care for this special population. The results of this study were used in the Planning Council's 2009 Priority Setting and Resource Allocation (PSRA) process.

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, 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 a 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.

Disproportionate Impact among Other Special Populations

TABLE 6: Populations of PLWH/A Underrepresented in CARE Act Funded Medical Care

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%**

Men who have Sex with Men: MSM are estimated to comprise approximately 10% of the general population in the EMA, yet account for 35.7% of emergent HIV and 28.5% of emergent AIDS in the EMA. MSM demonstrate a high late to testing and care pattern, with 31.1% of concurrent HIV/AIDS case (AIDS diagnosis within one year of HIV diagnosis). MSM comprise 29% of the PLWH/A population and 29.5% of the cumulative AIDS cases.

When "any" MSM risk behavior is considered (including MSM/IDU) MSM account for 32.38% of all PLWH/A in the EMA in 2007. *(NYSDOH, 2007) MSM comprised 21% of all Part A clients served during 2007.*

IDU: IDU comprise 2.66% of emergent HIV cases and 8% of emergent AIDS cases, but account for 18.5% of all PLWH/A and 34.1% of the cumulative AIDS cases in the EMA.

(NYSDOH, 2007) When "any" IDU risk behavior is considered, (including MSM/IDU) IDU comprised 22.5% of all PLWH/A in the EMA in 2007. IDU accounted for 13% of all Part A clients in 2007.

Aged/45+: PLWH/A, ages 45 years or greater, comprise almost 58% of the total living HIV/AIDS population in the EMA, evidencing substantial disparity. The aged make up 26% of emergent HIV cases, 37% of emergent AIDS cases and 46% of all Part A clients served during 2007. *(NYSDOH, 2007)*

As evidenced in the table above, there are consistent disparities noted for each of the severe need populations, when their relative proportion in the local epidemic is compared to their relative proportion in Part A funded core medical care services. For example, African Americans comprise 38% of the PLWH/A, but represent only 30% of those Part A core medical clients during 2007. 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.

Service Delivery Challenges for PLWH/A in the EMA

Lack of Public Transportation*:** Of particular concern in this EMA is the need for funds to provide transportation; this EMA has a limited mass transit system that is difficult to navigate even for healthy people. The need for funds to provide non-third-party-reimbursable trips to access primary care, other core medical services, and supportive services, cannot be overstated. From the eastern portion of Suffolk County to the County's Designated AIDS Center (DAC), a ***one way trip is 71.4 miles taking up to three hours. Without these funds, PLWH/A cannot be retained in care. For those who know their status but are not in care, outreach efforts are not effective, if PLWH/A cannot access services. While the system of care in this region provides high quality care, the lack of transportation provides barriers to entry into the system. Further compounding this issue is the limited number of medical clinics that offer HIV specific services in the EMA. Clients, who know their status but do not wish to access services close to where they live due to a fear of disclosure and other confidentiality issues, have few alternatives. Without the mass transit system that allows them easy access to other sites, they may choose to remain out of care and not access services.

ECONOMIC OPPORTUNITIES: Share of Households Without Access to a Vehicle by Race/Ethnicity, 2004	Nassau-Suffolk Metro Area
Black	10.2%
Asian	3.1%
Non-Hispanic White	4.6%
Hispanic	10.5%

Definition: Share of Households Without Access to a Vehicle
Source: U.S. Census Bureau, ***Diversitydata.org of the Harvard School of Public Health, 2007***

According to the Census 2000 Profile of Selected Housing Characteristics in the Nassau-Suffolk PMSA, 6.5% of the entire population (or 59,815 persons) have no vehicle available. According

to the DiversityData.org website of the Harvard School of Public Health, 5.6% of the EMA's residents do not have a vehicle. Much higher proportions of the EMA's Black and Hispanic residents lack a vehicle, tremendously impacting minority PLWH/A access to services.

***Large Immigrant Population*:** More than one of every three New Yorkers was born outside the U.S., compared with 11% of residents nationwide. Half of the foreign-born are from Latin America. Almost 4 out of 5 Asian New Yorkers were born outside the U.S. The foreign-born immigrants have higher risks for and rates of disease, for example, in New York immigrants disproportionately bear the heaviest burden of Tuberculosis *(Health Disparities in New York, 2005) In the Nassau-Suffolk EMA, a total of 14.4% of the general population is foreign-born, and 6.8% are undocumented citizens (U.S. Census 2000: Profile of Selected Social Characteristics, Nassau-Suffolk PMSA).*

Substance Abuse: An estimated 218,948 individuals within the Nassau-Suffolk EMA use judgment impairing substances, such as alcohol, methamphetamines, cocaine, heroin, other opiates, and inhalants. According to the *2006 Edition of Community Need Index,* Nassau County documented 163/100,000 cocaine discharges in 2006 and Suffolk County documented 148/100,000 cocaine discharges during the same time period, as compared to the 50th percentile median rate of 112/100,000 in the state. Opioid discharge rates for both of the EMA's Counties were even higher, at 224/100,000 and 223/100,000, for Nassau and Suffolk Counties, respectively (compared to the 50th percentile median rate of 194/100,000. *(NYSDOH, 2007)*

According to the 2008 African American PLWH/A survey results, co-morbidity with substance abuse is high, with 55%, reporting a history of diagnosis and/or treatment for a substance abuse disorder. Problems with adherence to treatment regimens, compliance with appointment schedules, and overall health status make this population more difficult to treat. Intensive case management and additional support services are required, increasing the costs to provide care. Substance use and abuse acts as a serious deterrent to both entry into and retention in HIV primary medical care as evidenced by the Nassau-Suffolk EMA 'Out of Care' survey respondent reports. Sixty percent (60%) of the OOC survey respondents admit to regularly using alcohol and/or drugs not prescribed by a physician on a relatively frequent basis, and 27% admit to previous IDU.

Mental Illness: It has been estimated that nearly 30,000 people in the general population suffer from severe chronic mental health disorders. Compliance with treatment regimens and the continuity of care can easily be compromised. Studies reported in *JAIDS* and the *American Journal of Medicine* demonstrate that medical care adherence is lower for HIV-infected women with depression, while death rates are higher. An intense effort at maintaining such individuals in the system of care results in higher costs. Those persons with the lowest incomes in New York are 2 to 6 times more likely to experience serious emotional distress than those with highest incomes. Among racial/ethnic groups, Hispanic New Yorkers report the highest levels of emotional distress *(Health Disparities in New York, 2005).*

Within the Nassau-Suffolk EMA, there are serious mental health issues within the PLWH/A population. A chart audit performed at Part A Outpatient Ambulatory Medical Care provider

sites demonstrated that approximately 32% of the PLWH/A present with or report mental health issues. The following table illustrates the results of the audit:

Mental Health Issue Identified	Depression	Seriously Mentally Ill
	23%	9%

Source: Chart Audit conducted @ Outpatient Ambulatory Medical Providers; 2007. N=79

According to the 2008 African American PLWH/A needs assessment survey results, co-morbidity with mental illness is high, with 44% reporting a history of diagnosis and/or treatment of mental illness. An even greater proportion of the 2008 Hispanic PLWH/A survey respondents report diagnosis or treatment for mental health disorders (57%).

Homelessness: Homelessness is an important factor that affects PLWH/A in the EMA. The Nassau-Suffolk Coalition for the Homeless estimates that there are 50,000 homeless persons present in Nassau and Suffolk Counties. Further, the Coalition estimated that in 2005, based on the most recent point in time count, there were approximately 3,943 persons present in the EMA that were either sheltered or unsheltered. Of this number, 20.6% (n=813) were known to be persons living with HIV/AIDS. During the third quarter of 2004, the National Association of Home Builders compiled a list, ranking the affordability of 162 Metropolitan areas. The Nassau-Suffolk region was one of the 15 **least affordable** in the country. Contributing to this lack of affordability are high housing costs, costs for child care, health care, food, and transportation.

The U.S. Department of Housing and Urban Development (HUD) reports that in order to afford the fair market rent for a two-bedroom apartment, an EMA resident would need to earn $50,000 annually. The Rauch Foundation and the Center for Housing Policy have reported similar results about the high cost of housing in this EMA. Finally, *Newsday*, the region's daily newspaper, has reported that there are about 500 homeless families on any given night, seeking shelter from one of the two counties. This underestimates the homelessness of families, some of whom may sleep in cars, friends' homes, or other places without securing help from the counties. With specific respect to PLWH/A, homelessness dramatically affects the cost and complexity of providing care in the EMA. Homeless persons are frequently in poorer health overall, and face each day with the need to find a place to stay, as well as to find food. Issues related to health care are unlikely to receive attention in light of these other more pressing needs. Further, it is difficult for homeless PLWH/A to access medical and support services, since there is no mailing address or telephone number available to maintain continuity of contact between the client and provider organizations. The homeless population is significantly impacted by **serious mental illness, at an estimated 1/3 of all homeless adults,** and is largely non-adherent to either HIV or mental health regimens. Their adherence rate is the lowest of any severe need group at 12-15% nationally (compared to active Injection Drug Users at 17-20% adherence).

Almost half of the 2008 African American "In Care" needs assessment survey respondents reported current or previous homelessness (47%) compared to 24% of the 2008 Hispanic PLWH/A survey respondents. ***An extremely high percentage of the 2008 Out of Care survey respondent group (54%) reported current or previous homelessness,*** obviously acting as a major variable contributing to the high level of unmet need.

Poverty and Lack of Insurance: Major predisposing factors that contribute to the health disparities are the result of poverty and no insurance. Poverty frequently co-exists with homelessness and a lack of health insurance, resulting in lack of access to quality health care and an increased need to rely upon an array of support services. This not only increases cost, but also makes management of care more complex and increases the importance of medical case management in order to assure access to medical care. It is estimated that 14.9% of the Nassau-Suffolk population, a total of 410,333 people, are living below 300% of the Federal poverty level. While the proportion of Long Island residents living at or below 100% FPL is approximately 5%, according to the *Health Disparities Report*, 20-32% of Hispanics and African Americans are living in poverty *(NYDHMH, 2005)* A report by Adelphi University on the social health of the EMA indicated that there was a 40% increase in food stamp recipients in Nassau and a 24% increase in Suffolk from 2000 to 2005, above the overall increase of 22% in the state. As payer of last resort, the levels of poverty and un-insurance seen within the EMA directly impact the expenditures of Ryan White Part A funds.

TABLE 7: Impoverished, Unemployed and Uninsured in Nassau-Suffolk EMA

Category	Nassau County	Suffolk County	Totals for general population
Total population	1,339,641	1,475,488	2,815,129
Proportion of Pop. living in poverty	5.4%	5%	5.2%
Proportion of population unemployed	4%	4.2%	4.1%
Proportion of population uninsured	16%	16%	16%

Source: New York State Department of Health, 2006

The rate of poverty is greatly magnified when examined in the context of race/ethnicity within the EMA, and disproportionately impacts Blacks and Hispanics:

ECONOMIC OPPORTUNITIES: 100% FPL by Race/Ethnicity, 2000-N-S Metro Area	
Asian	5.7%
Black	12.2%
Hispanic	12.6%
Non-Hispanic White	3.9%

Source: 2000 Census Summary File 3, Diversity Data, Harvard School of Public Health

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 for the Nassau-Suffolk EMA by Boston University School of Public Health, Analysis of Census data. (Boston University School of Public Health, Analysis of Census data. *diversitydata.org.)*

ECONOMIC OPPORTUNITIES: Racial Income Inequality -- Poverty Ratios by Race/Ethnicity, 2000	Nassau-Suffolk Metro Area
Non-Hispanic Black/Non-Hispanic White	3.1
Non-Hispanic Asian/Non-Hispanic White	1.5
Hispanic/Non-Hispanic White	3.2

Definition: Poverty ratios between 2 racial groups are an indicator of relative income inequality. A ratio with numbers larger than 1 indicates that a larger proportion of minorities are in poverty, compared to whites

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%) *(Harvard School of Public Health, 2007).*

The 2008 Needs Assessments among African American "In Care" PLWH/A evidence high levels of poverty and un-insurance/underinsurance. The majority of African American "In Care" survey respondents (65%) reported incomes between $0 and $9,999. Only 20% of the African American PLWH/A survey respondents reported current employment. The vast majority of the African American "In Care" respondents cite Medicaid or Medicare (76%) as their primary health benefit resource (perhaps attributable to their undocumented status).

Incarcerated and Recently Released (IRR) PLWH/A Populations: According to AIDS Action Recommendations, incarcerated populations are 5 times more likely to be living with AIDS and 8 to 10 times more likely to be HIV-infected than the general population ("*HIV Prevention and Care for the Incarcerated Populations*"). The report further states that **20% of PLWA and 13-19% of PLWH** in the general public **have been incarcerated** at some time. As of 12/31/06, NYSDOH reports 165 PLWH/A incarcerated within the EMA. Incarcerated males tend to **under-utilize healthcare services and neglect their personal health**. The lack of confidentiality among inmates is one reason incarcerated PLWH/A do not access care within the prison system. Upon release from a correctional facility, PLWH/A IRR do not access care because this population tends to be under-insured or uninsured, as well as unaware of community resources that are available for free or at reduced and affordable rates. Additionally, many inmates may not have had access to care prior to incarceration due to unemployment or limited availability to any entitlement programs. The following is a list of the major barriers to care reported by recently released PLWH/A within the EMA. **Barrier information** was collected by the EMA's Ryan White Part A Medical Case Management program which provides pre-release planning to incarcerated PLWH/A:

- Ability to secure employment;
- Dual stigma related to incarceration and HIV diagnosis;
- Financial/economic security; and
- Educational barriers to advancement.

Most of these individuals return to their respective communities with similar vulnerabilities that initially caused them to commit crimes, with no or weak support systems that allow them to re-establish stable lives. Lack of educational attainment, little or no job training and inadequate support structures are now compounded by the added stigma of a criminal record. Barriers to employment, further education, access to children or family (custody issues) and probable substance abuse and/or mental health issues represent gaps to securing affordable housing.

The targeted minority groups, their sub-populations and the EMA's severe needs groups remain a major focus of study for the planning area. The Planning Council is continuously challenged in identifying the changing 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 Table 8 below, the 'In Care' needs assessment survey process and resulting report highlights the differing needs, uses, and barriers to HIV primary medical care experienced by the severe need group of 'In Care' African American PLWH/A residing within the Nassau- Suffolk EMA.

Disproportionate Impact of HIV/AIDS on Special Disproportionate Impact of HIV/AIDS on Special Populations

The Nassau-Suffolk EMA contains approximately **2,815,129 residents** or **38% of the total population** residing on Long Island. The following table demonstrates the comparison among race/ethnicity categories for both Counties compared to those categories within the EMA's HIV/AIDS populations:

TABLE 8: Portrait of Groups Disproportionately Impacted by HIV/AIDS:

Race/Ethnicity	Nassau County	Suffolk County	EMA HIV/AIDS (combined) population
White	79.3%	84.6%	38%
African American	**10%**	**7%**	**39%**
Hispanic	**10%**	**11%**	**19%**
Native Indian/Alaskan	1.6%	2.7%	<1%
Asian/Pacific Islander	4.8%	6.1%	<1%
Other	2.1%	3.7%	3%

Overview of 'In Care' Needs Assessment of African American PLWH/A and their sub-populations in the EMA

The special characteristics of the Severe Needs Groups especially targeted for participation in the 2008 'In Care' needs assessment process in the EMA are described below**.**

The six (6) emerging populations with special needs for the Nassau-Suffolk EMA are:

1. African Americans
2. Hispanics
3. MSM
4. IDU
5. Women of color
6. Aged

Characteristics of African American PLWH/A in the EMA

African Americans comprise a total of ***39% of the total PLWH/A*** prevalent cases within the EMA. African Americans represent a higher percentage of the uninsured and under-insured populations; an estimated *uninsured rate that is 1.5 times that of the white population* (Kaiser

Family Foundation Survey). Uninsured African Americans are three times more likely to lack a usual source of care (estimated @ 20%); compared to those with private or publicly-funded insurance. Primary barriers to accessing healthcare within this population include, but are not limited to, a *mistrust* of the medical community as a whole, *stigma* related to both socioeconomic status and the diagnosis of HIV/AIDS, lower education and literacy levels, and a lack of sufficient support systems as a result of homelessness and poverty. African Americans are more likely to be tested later in the course of the disease process than whites. Late entry into care is known to create a need for more complex and costly care. ***HIV is the 6th leading cause of death*** for young **African American men *(KFF, 2008)***.

Characteristics of the Sub-population of MSM PLWH/A in the EMA: MSM as a risk behavior represents ***28% of the HIV/AIDS prevalent cases*** reported within the EMA. MSM generally present with higher rates of STDs. In addition, the use of alcohol and illicit drugs remains prevalent among this population, leading to an increase in risky sexual behaviors. With the introduction of highly active antiretroviral therapies (HAART), the MSM population is living longer. Some MSM are under the misconception that HAART can prevent their partners from becoming infected with HIV. In light that many MSMs remain sexually active after learning of their HIV diagnosis, prevention education and counseling are essential, especially when developing a 'prevention for positives' campaign. In addition, some studies have shown increased rates of mental health problems, such as mood disorders, among the MSM population.

Characteristics of the Sub-population of IDU PLWH/A in the EMA: Injection drug use accounts for ***19% of the PLWH/A prevalent cases*** within the EMA. In addition, the risk factor of MSM with IDU accounts for an ***additional 4% of the population***; for a total of 24%. Injection drug users tend to come from lower socio-economic classes, an indicator of the increased potential for illnesses associated with poor hygiene and nutrition. Some studies show that the IDU population has 10-20 times higher rates of illness and death than the non- IDU population. In addition, IDU can cause significant and serious medical problems, such as hypertension, cardiomyopathy, abscesses from dirty needles, neurologic disorders, renal problems, psychiatric issues, and most commonly, hepatitis C.

Characteristics of the Sub-population of Women of Color PLWH/A in the EMA: Research indicates female PLWH/A tend to seek out health care services at a higher rate than men. In general, this is not true for women of color. Family and children come first over their own health and well-being. Women of color tend to have higher rates of family violence and issues with fear of HIV disclosure. Hence, women of color tend to be diagnosed later and may only present when they feel sick. In addition, women of color often present with higher rates of asthma, diabetes, cardiovascular disease, and hypertension.

Characteristics of the Sub-population of Aged PLWH/A: *Individuals who are 45 years of age or older account for an overwhelming 55% of the PLWH/A cases within the Nassau-Suffolk EMA.* The treatment and care of aged PLWH/A is more costly and complex than their younger counterparts because of increased co morbidities such as declines in cognitive function, increased rates of cardiovascular related events, and susceptibility to and morbidity from infections. Other common co-morbid conditions include lipodystrophy, osteopenia/osteoporosis,

diabetes, liver disease, and dementia, further complicating the treatment and care of HIV/AIDS within the EMA's aged population.

To further explore the care patterns and care complications for the African American population, the Nassau-Suffolk HIV Health Services Planning Council conducted the African American 'In Care' Needs Assessment. The study data was used for the 2009 Priority Setting and Resource Allocation process.

Overview of African American 'In Care' Study Findings

- 128 African American 'In Care' survey respondents participated in the 2008 Needs Assessment process
- The African American respondent group as a whole is an aging group of PLWH/A, with majority of respondents reporting ages in the 45-54 age range. The majority are highly impoverished and largely unemployed.
- Modes of transmission are predominantly heterosexual and IVDU.
- Co-morbidities with mental illness and substance abuse are high, with 44% and 55%, reporting a history of diagnosis and/or treatment of mental illness/substance abuse disorders, respectively.
- STD co-morbidity is relatively high at 39%, and the reported presence of other chronic diseases is quite high at 55%
- An extremely high proportion of the African American 'In Care' respondents reports current or previous homelessness (47%).
- The majority of the African American respondents have acquired Medicaid or Medicare benefits (76%), and a very low percentage report current employment (20%).
- The African American respondents report a desire to work but fear that working will lead to a loss of benefits. Many have struggled to reach base-line stability and fear doing anything to jeopardize stable benefits.
- The African American 'In Care' survey respondents evidence a greater delay since their last physician/laboratory monitoring visit than the Hispanic ''In Care' respondents, indicating a somewhat fragile 'In Care' status.
- The unavailability of transportation assistance impedes ready access to available services. The need for transportation exceeds the monthly rides available, leaving inadequate transportation for pharmacy, food pantry, grocery stores or other medical appointments outside of primary medical, dental or mental health service visits.

Overview of African American 'In Care' Respondents' Services Needs, Uses, Gaps and Barriers

TABLE 9: 2008 'In Care' NEED, USE, GAP, & BARRIER MATRIX

Service Category	Need Rank	Use Rank	Gap Rank	Barrier Rank	Gap Reasons	Barrier Reasons
Housing	1	7	1	2	Problems covering 1st month's rent when relocating from out of area or prison; no assistance for non-homeless or working PLWH/A is frustrating: "I'd receive more assistance if I wasn't working. I shouldn't lose assistance for trying to be independent"; "Options and Section 8 saved my life!"; available housing tends to be in dangerous areas; perceived no independent living options for single women or gay men; "I've heard stories about people being harassed at AIDS housing facilities"	"I moved to Suffolk County because could get Section 8 there in 2 years instead of 10"; long waiting lists for DSS or Section 8 assistance; need rent assistance or rent control for HIV+ residents; rent sometimes exceeds assistance (SSI, disability, Section 8, DSS, Veterans) & leaves little left-over; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean independent living options; need assistance for working PLWH/A; difficult to document "homelessness".
Quality Food - Meals and Food Boxes; Food Stamps	2 tie	9	4 tie	3	Food stamps & vouchers limited or unavailable; "qualify for food assistance by no way to get there"; some agencies refuse services like food vouchers to "selective users" (need food but not case management" or people enrolled with multiple agencies; 'Ensure' coverage removed and deemed non-medically necessary.	Food boxes should include toiletries; Need nutritionally sound foods- options- need food program designed to boost the immune system; no transportation to grocery store or food pantry; no incentive to get job because will lose food stamp coverage; "it would be a good idea to give out nutritional meals at medical appointments"
Transportation	2 tie	2	2 tie	1	Medical transportation service is unreliable; need help to find a car; limited # and range of rides- monthly medical appointments often exceed max # of rides (especially with additional diseases), no rides to grocery store, food pantry or pharmacy; no rides across county lines limits choice of providers; discounts should be available on bus and train for PLWH/A; "I live in Port Washington but prefer services in Hempstead- like EAC Food Pantry, pharmacies, support groups and clinics. I have to rely on family or a bus, but times are limited and I live far from the bus stop."	Unreliable services, ordeal to schedule; "suspended Driver's License limits my travel"; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; "I moved to Suffolk County to get Section 8, but now I can't get a ride to my doctor just across the county line"; no transportation available other than bus in some Eastern parts of Suffolk Co.; "I'm hesitant to use medical transportation because my neighbors will find out & start talking. It would be better if anyone needing a ride could have one, then people don't know why you're being picked-up"
Financial Assistance / Stability (including rental	4	NR	2 tie	4	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about $s and #s,	Rent takes up most assistance, leaving little funds for groceries, toiletries, cleaning supplies, utilities, house repairs, Medicaid spend-down and medical co-

assistance)					not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give me food vouchers if I came to other programs and used their case mangt"); public assistance barely covering basic needs	payments; "I'd love to live beyond just surviving"; would like to work but would lose eligibility for financial assistance; parking, travel and food vouchers needed desperately; laundry vouchers would be good idea- especially for families; expressed need for credit resolutions / forbearance; food stamps don't stretch for healthy foods; extreme expressed need for rent assistance
Medicine	5	3	7 tie	13 tie	Limited transportation to doctor, no transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication; need new, more tolerable & affordable meds; many medications not covered (such as migraine medication); "sometimes I have to sacrifice my meds and health to make sure needs are met for my girls"	Need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, high blood pressure, heart problems); paperwork onerous; Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "trying to use online pharmacy (momspharmacy.com) to have my meds delivered".
Primary Medical Care	6 tie	1	4 tie	8 tie	"Many people are living with HIV but not going to the doctor. We need outreach to people who are scared or on the down-low."; high turnover in staff is discouraging; some staff not compassionate (especially in early days of epidemic); transportation is an issue (limited # per month, limited range (ex = won't cross Nassau/Suffolk county lines); hard to obtain emergency appointments; need more after-hour availability for those who work	Hard to get appointment in emergencies; convenient when several services in one location (ex = NUMC, Catholic Charities, Riverhead Health Center); lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation
Education/ Information & Referral	6 tie	NR	9	7	Programs to help obtain GED would be helpful; was receiving POZ magazine but subscription stopped- was great way to stay updated & in-touch with community; need workshops; need better info for newly diagnosed; clients still face discrimination & ignorance in the workplace, in the community, and even in health care facilities; "We're abuot to have an explosion of HIV cases and we're not prepared. Migrant workers and young African Americans and Latinos are increasingly moving to the area and testing positive. We need to be informed & prepared"	Education for PLWH/A (how to live with the disease, adjusting to physical & lifestyle changes, information on new meds and labs); education in elementary schools and society; need outreach campaigns against ignorance and promoting tolerance, prevention & testing
Group support & Day	6 tie	11	NR	6 tie	Support groups lacking attendance because of funding cuts and shifting	Need more socially-oriented co-ed support groups; use Hispanic Counseling Center, FEGS &

Programs					interests/needs	Catholic Charities; need groups focusing on living with the disease and navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Social Support	9	12	NR	8 tie	Support groups lacking attendance because of funding cuts and shifting interests/needs; "FEGS groups give me a great way to meet other people in my situation"	Need more socially-oriented co-ed support groups, focusing on living with the disease and enjoying mature range of activities (arts, socials, sports)
Employment / Skills Training	10 tie	NR	7 tie	5	"Would like skills training and job, but afraid I will lose assistance if I begin working again"; housing crisis affects working poor with HIV, who work in construction & household repair industries; "I want to work but my family and Case Manager discourage it because my budget has finally "stabilized""	Need list or ideas for part-time, suitable employment options for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin working again".
Research-Advocacy-prioritization	10 tie	NR	NR	13 tie	"National priorities focused on war and helping international HIV, but not PLWH/A here"; lack of advocates = funding cuts; need targeted outreach campaigns & PSA's geared towards specific demographics (ex = young gays)	Lack of advocates means funding is not priority and needs are not met; priority shift needed back to provision and away from profit
Life / health / Healthy environment	10 tie	NR	NR	NR		No comment
Mental Health	13	10	6	8 tie	Use FEGS, Hispanic Counseling Center; no outreach efforts educating public on benefits of mental health care; still stigma attached with care	"Waiting lists unless you are referred through an agency"; "many people need mental health support but are not aware of availability or its benefits"; needed for long-term survivors who did not plan to see later phases of life
Health insurance/ Social Security (including ADAP & Disability)	14	6	16	6 tie	"Social Services treats HIV Patients like 5th rate citizens that deserve to be in their situation"; no life insurance available for PLWH/A; reports of extreme run-around and cold, demoralizing treatment (esp DSS); "I worked for 20+ years and now that I need help I can't get it!"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go"	Assistance not available for working poor; "get run-around and very little explanation…not worth it and makes me want to go do drugs again"; need more logical & understandable system; Medicaid spend-down is confusing; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Community Tolerance / Understanding	15 tie	NR	NR	NR		Still face bigotry and fear in community
Case Managers / Social Workers	15 tie	4	16	8 tie	"There seems to be a conflict of interest between the intention of case management and the	"My Case Manager at 5 Towns helped me become independent- she taught me how to fish instead of giving me

					"quotas" of services and patients"; "need agencies to coordinate efforts rather than act as competitors; they are unwilling to help unless you are at the bottom of the barrel"; clients report high levels of run-around (especially with DSS), denials for case management and services (ex = seeking EOC housing assistance made LIACC stop helping with other needs), heavy reliance upon case management; "I don't need handholding...I just want assistance without the run-around"; "high staff turnover rates lead to frustration & distrust in system and movement towards "Out of Care"	the fish. I was thankfully able to cut back on case management because I've become more functional on my own"; some have multiple case managers (HIV + insurance CM); high turnover and inexperience are too common; heavy reliance on case managers for information and regiment management (appointments, coordination of care); cases being closed because clients using multiple agencies or not taking advantage of enough agency services; clients report run-around for services (ex = food vouchers) for "selective user" clients
Legal Services	NR	NR	11	NR	"I was fired from my job and it has led to a downward spiral. I'm trying to sue them, work and raise my son who is also HIV+. We're about to be evicted and I've been denied for all assistance. We don't believe anyone is out there to help us"	
More extensive services	NR	NR	11	NR	"No job/skills training programs available, especially in my area (Glen Cove)"; services being cut due to funding cuts; services need to evolve with changing population (focus on skills training, social group outing/activities, education)	
Alternative Therapies	NR	NR	11	NR	More holistic approach needed to treating PLWH/A-coverage and services only seem available for traditional "medical-only" needs	
Finding Help & Information	NR	NR	11	NR	Need list of special programs available for those in need (ex = Burlington Coat Factory offer, Christmas gifts for children in affected families); need better info for newly diagnosed; often receive run-around while obtaining services; Thursday's Child was one of only sources for "real" information but they are also threatened by funding cuts; "Now that I've finally found a place for help it's closing down [Catholic Charities]. It's hard to know where to go in this area"	
Dentist; dental care	NR	5	11	NR	Transportation limited in # and geographic range; difficult to get dental coverage once lose it (ex = lost Delta Dental, stuck in run-around trying to get coverage)	

Family support	NR	NR	17	NR	No voice representing the needs of "affected" families; system of care designed to support single people with HIV/AIDS	
Clinics	NR	8	NR	NR	Lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; hard to obtain emergency appointments; need more after-hour availability for those who work	

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 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] African American PLWH/A within the Nassau-Suffolk EMA was conducted in the spring of 2008. This assessment of need included an "In Care" survey questionnaire of African American PLWH/A utilizing the In Care Needs Assessment Client Survey (NACS) tool.

Relevance of the Part A Comprehensive "In Care" African American Needs Assessments

The targeted minority groups, their sub-populations and the EMA's severe needs groups remain a major focus of study for the planning area. The Planning Council is continuously challenged in identifying the changing 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 experienced by the 'In Care' severe need group of African American PLWH/A within the Nassau-Suffolk EMA.

Disproportionate Impact of HIV/AIDS on Special Disproportionate Impact of HIV/AIDS on Special Populations

TABLE 10: Portrait of groups disproportionately impacted by HIV/AIDS:

Race/Ethnicity	Nassau County	Suffolk County	EMA HIV/AIDS (combined) population
White	79.3%	84.6%	38%
African American	**10%**	**7%**	**39%**
Hispanic	**10%**	**11%**	**19%**
Native Indian/Alaskan	1.6%	2.7%	<1%
Asian/Pacific Islander	4.8%	6.1%	<1%
Other	2.1%	3.7%	3%

[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.

Characteristics of <u>African American</u> PLWH/A in the EMA

African Americans comprise a total of ***39% of the total PLWH/A*** prevalent cases within the EMA. African Americans represent a higher percentage of the uninsured and under-insured populations; an estimated *uninsured rate that is 1.5 times that of the white population* (Kaiser Family Foundation Survey). Uninsured African Americans are three times more likely to lack a usual source of care (estimated @ 20%); compared to those with private or publicly-funded insurance. Primary barriers to accessing healthcare within this population include, but are not limited to, a *mistrust* of the medical community as a whole, *stigma* related to both socioeconomic status and the diagnosis of HIV/AIDS, lower education and literacy levels, and a lack of sufficient support systems as a result of homelessness and poverty. African Americans are more likely to be tested later in the course of the disease process than whites. Late entry into care is known to create a need for more complex and costly care.

HIV is the 6th leading cause of death for young **African American men**. To further explore the care patterns and care complications for the African American population, the Nassau-Suffolk HIV Health Services Planning Council commissioned an African American Needs Assessment of this special need population. The study data will be used for the 2009 Priority Setting and Resource Allocation process.

Project Design for the 'In Care' African American PLWH/A Needs Assessment Studies

The objective of the comprehensive 'In Care' Needs Assessment Study was:

1) To identify the extent and types of service Needs, Gaps and Barriers among African American "In Care" PLWH/A in the Nassau-Suffolk EMA service area.

The sample for surveying the 'In Care' population was first determined by establishing a 95% confidence interval (CI) for a representative sampling of the estimated number of PLWH/A with unmet need in the Nassau-Suffolk EMA. The survey process was designed to target as high level participation as possible among the key severe need group of African Americans (N=100-150). The actual participation rates for 'In Care' African Americans totaled 128 survey participants in the 2008 Needs Assessment process.

Chapter 2: "In Care" African American Survey Findings

Overview of the "In Care" Survey Results

The 'In Care' client surveys were scheduled over a two-month period in the winter of 2008. The tables below indicate the age, gender, and sexual orientation of the African American 'In Care' survey population.

Age

The greatest proportion of the African American 'In Care' survey participants (72%) report ages in the 35-54 age range. A substantial minority--(17%)--report their ages in the 55-64 age range, representing an aging group of PLWH/A, overall. Less than 10% percent of respondents report their ages between 25 and 34 years of age. Two participants reported their age as <24 years.

Table 11. Ages of African American Respondents

Age Range	#	%
0-13	1	1%
13-24	1	1%
25-34	11	9%
35-44	26	20%
45-54	67	52%
55-64	22	17%
65-74		0%
TOTAL	**128**	**100%**

Gender

Slightly more than half of the survey respondents were male (53%); 47% were female, and none of the respondents identified as transgender.

Table 12. Gender of African American Respondents

GENDER	#	%
Male	68	53%
Female	60	47%
TOTAL	**128**	**100%**

Sexual Orientation

The greatest proportion of the African American survey respondents identify as heterosexual or 'straight' (83%). Eleven percent (11%) of all respondents identify as 'gay' and 4% identify as bisexual. Two preferred not to answer, and one respondent reported 'other' without explanation.

Table 13. Sexual Orientation of 'In Care' Respondents

Sexual Orientation	#	%
Gay	14	11%
Bisexual	5	4%
Straight	106	83%
Other	1	1%
Prefer not to Answer	2	2%
TOTAL	**128**	**100%**

Zip Code of Residence

Almost three quarters (74%) of the 'African American In Care' survey respondents reported their current residence in the following sixteen zip codes, in rank order from greatest to least:11550 (32); 11520 (11); 11901 (7); 11722 (7); 11575 (7); 11003 (5); 11758 (4);11717 (4);. 11706 (3);11701 (3);11798 (2)11772 (2);11720 (2);11533 (2);11207 (2);11030 (2); The remainder of the sample reported a wide variation in zip code of residence. The range and clustering of Zip Codes points towards people living in all parts of Long Island, including many remote and rural areas not serviced effectively by current public transportation options; and suggests "pockets of poverty" with areas with extreme poverty.

Table 14. Zip Code of Residence

ZIP	#	%
11550	32	25%
11520	11	9%
11575	7	5%
11722	7	5%
11901	7	5%
11003	5	4%
11717	4	3%
11758	4	3%
11701	3	2%
11706	3	2%
11030	2	2%
11207	2	2%
11553	2	2%
11720	2	2%
11772	2	2%
11798	2	2%
11001	1	1%
11096	1	1%
11218	1	1%
11361	1	1%
11429	1	1%
11510	1	1%
11518	1	1%
11542	1	1%
11552	1	1%
11561	1	1%
11563	1	1%
11570	1	1%
11704	1	1%
11713	1	1%
11726	1	1%
11727	1	1%
11729	1	1%
11735	1	1%
11735	1	1%

11746	1	1%
11752	1	1%
11755	1	1%
11757	1	1%
11762	1	1%
11763	1	1%
11780	1	1%
11787	1	1%
11801	1	1%
11804	1	1%
11932	1	1%
11953	1	1%
11967	1	1%
11968	1	1%
Grand Total	**128**	**100%**

The Zip Codes with 4 or more respondents are located in the following clusters: 1) 11003 (Alden Manor / Elmont), 11550 (Hempstead), 11575 (Roosevelt): All of these zip codes are in Eastern Nassau County near Nassau University Medical Center, the Clinics, and Hempstead / Freeport-based Service Providers, 2) 11717 (Brentwood), 11758 (Massapequa), 11722 (Central Islip): All of these zip codes are within Central / Southern Suffolk cities near Nassau / Suffolk County Border; 3) 11901 (Riverhead): North Western / Central Suffolk County, is located near medical centers, the correctional facility, and contains the largest city near rural migrant populations.

Income and Location of Residence

The African American 'In Care' survey respondents represent a highly impoverished group overall, with 92% of all survey respondents reporting annual incomes equal to or less than 250% of the federal poverty level: with 65% reporting incomes between $0 and $9,999; followed by an additional 18% reporting incomes between $10-$19,999 per year, and only 5% reporting incomes between $20-29,999.

Table 15. Annual Income by Zip Code of Residence

ZIP Code	0-9,999	10,000-19,999	20,000-29,999	30,000-39,999	40,000-49,999	Over 50,000	Blank	Grand Total	%
11575	4		1	**1**			**1**	7	5%
11553	2							2	2%
11755				1				1	1%
11706	3							3	2%
11552	1							1	1%
11361	1							1	1%
11570		1						1	1%
11798	2							2	2%
11003	2	2	1					5	4%
11550	23	5	1	2				31	24%
11762	1							1	1%

11520	5	4	1	1				11	9%
11727	1							1	1%
11780	1							1	1%
11726	1							1	1%
11735	2							2	2%
11717	3						1	4	3%
11713			1					1	1%
11758	3	1						4	3%
11752	1							1	1%
11518		1						1	1%
11953		1						1	1%
11968	1							1	1%
11932	1							1	1%
11901	4	1		1				6	5%
11746		1						1	1%
11096	1							1	1%
11429	1							1	1%
11704		1						1	1%
11001	1							1	1%
11510	1							1	1%
11720	2							2	2%
11722	6						1	7	5%
11701		1		1		1		3	2%
11218							1	1	1%
11967			1					1	1%
11729		1						1	1%
11804		1						1	1%
11207	1			1				2	2%
11801		1						1	1%
11030	2							2	2%
11757	1							1	1%
11561	1							1	1%
11542		1						1	1%
11563	1							1	1%
11763							1	1	1%
11787	1							1	1%
11779							1	1	1%
11772	2					1		3	2%
Totals	**83**	**23**	**6**	**8**	**0**	**2**	**6**	**128**	**100%**
	65%	**18%**	**5%**	**6%**	**0%**	**2%**	**5%**	**100%**	

HIV/AIDS Status

The majority of "African American In Care" survey respondents (59%) report a diagnosis of HIV and 41% report a current AIDS diagnosis, representing a more recently diagnosed group of PLWH/A, overall.

Table 16. HIV/AIDS Status

HIV/AIDS Status	#	%
HIV	75	59%
AIDS	53	41%
TOTAL	**128**	**100%**

Year of HIV and AIDS Diagnoses

As evidenced by the table on the following page, there is a wide range of years reported as the year of first HIV diagnosis by this sample of African American 'In Care' survey respondents, ranging from 1982 to 2007. "Peak" years, wherein 6 or more of the survey participants report being diagnosed with HIV include 1986, 1990, 1992, 1993, 1994, 1995, 1997, 2000, 2001,and 2004. Almost half of the survey respondents (46%) report first learning their sero-status in the years following the advent of triple combination therapy in 1996. The years for reported AIDS diagnoses range from 1986 to 2007, with 58.5% occurring since 1996, when improved HIV medications became more available.

A large percent of those reporting an AIDS diagnosis evidence having been diagnosed with HIV & AIDS simultaneously. The year of diagnosis supports a thematic pattern of an aging population of PLWH/A with evolving needs and a relatively high percent of long-term (10+ year) survivors. (See Table 17 on the following page)

Table 17. Year of HIV and AIDS Diagnoses

	HIV		AIDS		TOTAL	
Year	#	%	#	%	#	%
1982	1	1%		0%	1	1%
1983						
1984	2	2%		0%	2	1%
1985	3	2%		0%	3	2%
1986	**6**	**5%**	**2**	**2%**	**8**	**5%**
1987		0%		0%	0	0%
1988	2	2%	1	1%	3	2%
1989	5	4%		0%	5	3%
1990	**8**	**6%**	**2**		**10**	**6%**
1991	5	4%	2	2%	7	4%
1992	**12**	**9%**	**3**	**2%**	**15**	**9%**
1993	**7**	**5%**	**3**	**2%**	**5**	**3%**
1994	**7**	**5%**	**3**	**2%**	**10**	**6%**
1995	**11**	**9%**	**6**	**5%**	**17**	**10%**
1996	5	4%	3	2%	8	5%
1997	**11**	**9%**	**3**	**2%**	**14**	**8%**
1998	5	4%	1	1%	6	3%
1999	2	2%	2	2%	4	2%

2000	**7**	**5%**	**4**	**3%**	**11**	**6%**
2001	**6**	**5%**	**3**	**2%**	**9**	**5%**
2002	2	2%	2	2%	4	2%
2003	4	3%	2	2%	6	3%
2004	**6**	**5%**	**4**	**3%**	**10**	**6%**
2005	4	3%		0%	4	2%
2006	4	3%	2	2%	6	3%
2007	3	2%	1	1%	4	2%
unknown		0%	4	3%	4	2%
Grand Total	**128**	**100%**	**53**	**41%**	**176**	**100%**

Location of HIV Diagnosis

The vast majority of the African American 'In Care' survey respondents reported learning their HIV or AIDS status in New York. Only seven respondents (or 5%) reported having received their HIV and/or AIDS diagnosis outside of New York. Over 2/3 (67%) of the African American 'In Care' respondent group reports receiving their first HIV/AIDS diagnosis in one of three cities in New York: 1) Hempstead (39%); 2) East Meadow (15%); or 3) New York City (13%).

Table 18. Location of HIV/AIDS Diagnosis

City	State	HIV#	HIV%	AIDS#	AIDS%
Roosevelt	NY	4	**3%**	0	**0%**
Hempstead	NY	23	**18%**	5	**21%**
Wheatly Heights	NY	1	**1%**	0	**0%**
Mineolo	NY	1	**1%**	0	**0%**
East Meadow	NY	14	**11%**	1	**4%**
Freeport	NY	3	**2%**	7	**29%**
Dix Hills	NY	2	**2%**	0	**0%**
Los Angeles	CA	1	**1%**	1	**4%**
Nassau	NY	6	**5%**	1	**4%**
Brentwood	NY	3	**2%**	1	**4%**
Southampton	NY	1	**1%**		**0%**
Patchogue	NY	1	**1%**		**0%**
Riverhead	NY	5	**4%**	0	**0%**
Wading River	NY	1	**1%**	0	**0%**
Huntington	NY	1	**1%**	0	**0%**
New Haven	CT	1	**1%**	1	**4%**
Westbury	NY	1	**1%**	0	**0%**
Brooklyn	NY	4	**3%**	1	**4%**
Massepequa	NY	1	**1%**	0	**0%**
Yaphank (prison)	NY	2	**2%**	0	**0%**
Amityville	NY	2	**2%**	0	**0%**
Mt. Vernon	NY	1	**1%**		
Bayshore	NY	4	**3%**	1	**4%**
Stonybrook	NY	4	**3%**	1	**4%**
New Hyde Park	NY	1	**1%**	0	**0%**
Annapolis	MD	1	**1%**	0	**0%**

Wyandanch	NY	3	**2%**	0	**0%**
Speonk	NY	1	**1%**		
Glen Cove	NY	1	**1%**		
Bronx	NY	1	**1%**	1	**4%**
Bellport	NY	1	**1%**	1	**4%**
New York City	NY	16	**13%**	0	**0%**
New York (state)	NY	3	**2%**	1	
Bedford Hills	NY	1	**1%**	0	**0%**
Uniondale	NY	1	**1%**		
Syossett	NY	1	**1%**	1	**4%**
Winston	NC	1	**1%**	0	**0%**
Orlando	FL	1	**1%**		
Greenville	SC	1	**1%**	0	**0%**
	VT	1	**1%**	0	**0%**
Liberty	NY	1	**1%**		
Bohemia	NY	1	**1%**	0	**0%**
Long Beach	NY	1	**1%**		
Watertown	NY	1	**1%**	0	**0%**
Hauppauge	NY	1	**1%**	0	**0%**
Total		**127**	**100%**	**24**	**100%**

HIV Transmission Risk

A high proportion of this African American "In Care" respondent group reports acquiring HIV as a result of heterosexual risk behavior (42%); 16% as a result of injection drug use; 18% as a result of sex with a drug user; and 8% of all respondents cite MSM as the mode of HIV infection. Five percent (5%) report their mode of HIV transmission as "unknown". Three respondents report mode of transmission as "other". In summary, the African American severe need group is characterized by a high percent of Heterosexual Contact transmission. There is also a significant proportion of IVDU transmission and a growing percent of people (mostly women) testing positive from sexual contact with an IVDU.

Table 19. Mode of Transmission

Medium of HIV infection	Total	
	#	%
Male sex with male	16	8%
IDU	33	16%
Heterosexual sex	85	42%
Prison	2	1%
Sex with Drug User	36	18%
Sexual Assault	2	1%
Transfusion	9	4%
Health Care Worker	4	2%
Mother with HIV/AIDS	2	1%
Unknown	10	5%
Other	3	1%
TOTAL	**202**	**100%**

Employment
Twenty percent (20%) of the African American "In Care" survey respondents report current employment, while 79% report current unemployment (and one respondent PNTA). Of those who report current employment, 67% work full-time and 33% work part-time.

Table 20. Employment Status

Yes		No		Prefer Not to Answer	
#	%	#	%	#	%
26	20%	101	79%	1	1
128	**100%**				

Employed	YES	%
Full-Time	10	67%
Part-Time	5	33%
Total	**15**	**100%**

A substantial number of the respondents expressed a desire to work but 1) report a lack of Part-time job ideas or opportunities; 2) perceive a lack of job-related programs, and 3) fear that working will lead to a loss of benefits (many have struggled to reach base-line stability and fear doing anything to jeopardize stable benefits).

When income is considered along with employment status, the data indicates the potential need to address this emerging transitional group- "working poor PLWH/A" who have their own distinct set of needs: 1) additional job skills training and placement, especially tailored for those with a HS education or GED (see section on education background below); and 2) a list of part-time and full-time employment suitable for PLWH/A and assistance in locating these jobs.

It is likely that these same individuals, if successful in attaching with suitable employment will need additional assistance, even temporarily with food assistance; financial assistance for emergencies; help with basic necessities (food, clothing, household basics); housing & rental assistance, and perhaps child care. Reliable transportation to medical & non-medical locations remains a challenge for many.

Education
This sample of African American 'In Care' respondents reports a fairly wide variation in educational background, overall, as evidenced in the table below. *One quarter* (*25%) report only some high school education or grade school or less, evidencing significant socioeconomic disparity within this survey sample.*

Only one third of all respondents report completing high school (33%), and over 30% of the survey respondents report some college education. Only 9% report completing a college degree; and only 1% report attaining a graduate level degree.

Table 21. Educational Background

Education	#	%
Grade school or less	3	2%
Some high school	30	23%
High school grad/GED	42	33%
Some College	40	31%
College degree	12	9%
Some graduate school	0	0%
Graduate level	1	1%
TOTAL	**128**	**100%**

Living Arrangements

Only 4% of the African American 'In Care' respondents report owning their home (one reporting inheritance); two-thirds (66%) report currently renting a home or apartment (utilizing Section 8, SSI, DSS, some Options housing and some Senior citizens Section 8 apartment housing); and almost 1/5 (19%) of all survey participants report being 'temporarily housed', currently staying with friends or relatives.

A minority of the 'In Care' survey respondents (3%) report current homelessness, staying in a shelter. The 'other' reports of current living arrangements include: a motel, Group Homes: Homeworks, Options for Community Living houses; Elderly Facility, Mercy New Hope Crisis Center, and CHI Substance Abuse housing. The location of residence reported by the 'In Care' respondents is consistent with the reported income, overall.

Table 22. Living Arrangements/Residence

Residence	#	%
Own your home	5	4%
Rent	85	66%
Live with a Friend/Relative	24	19%
Stay in a Shelter	4	3%
No answer	1	1%
Other	9	7%
Total	**128**	100%

Help with Rent

Over half (or 58%) of the total survey group reports currently receiving some form of rental assistance.

Table 23. Rental Assistance

Yes		No	
#	%	#	%
74	58%	48	38%
128	**100%**		

**** Five respondents or 4% indicated rent assistance was non-applicable at this time.***

Ever Homeless

A total of 47% of the "In Care" survey respondent group reports a current or previous period of homelessness, indicating an extremely high degree of housing instability within this community. It appears that far fewer of the African American 'In Care' respondents are currently homeless than previously, which may represent a lot of recent progress in attaching PLWH/A with housing. This finding would also indicate substantial challenge in successfully facilitating entry and retention in HIV primary care and services for a large segment of the PLWH/A population residing in the EMA. A high number of respondents indicated that although not currently homeless, they easily could be made homeless by a medical emergency or other situations. Most report living "assistance check to assistance check". One client reported severe hopelessness and struggle with maintaining housing. She also has teenage child who is HIV positive, and they are struggling to stay 'In Care' amidst numerous competing financial challenges.

Table 24. Ever Homeless

Ever Homeless Response	#	%
Never	64	50%
Currently	5	4%
In past 2 years, but not now	18	14%
Longer than past 2 years, but not now	37	29%
Prefer not to answer	3	2%
TOTAL	**127**	**100%**

Incarceration in Past Six Months

A relatively small percent (5%) of the African American 'In Care' respondents report a recent incarceration over the past 6 months, evidencing incarceration as a relatively low risk indicator within this particular group of survey respondents.

Table 25. Incarceration in Past 6 Months

Yes	%	No	%
7	5%	121	95%
128	**100%**		

Health Insurance

The vast majority of the African American 'In Care' respondents cite Medicaid or Medicare (76%) as their primary health benefit resource. Only 4% of respondents reported private health insurance benefits. Only 2% report NOT having any form of health benefit. However, thirty two 'other' respondents (17%) indicated ADAP as a source of health benefits.

Table 26. Forms of Health Insurance

Health Insurance	Total	
	#	%
Private	8	4%
Medicare	43	23%
Medicaid (ACCCHS)	100	53%
VA	1	1%
None	3	2%

Other=ADAP	32	17%
TOTAL	**187**	**100%**

Current Primary Care Physician and Clinic

Over half of the African American 'In Care' survey respondents' (51%) cite Nassau University Medical Center as their HIV primary care home; 20% report Southampton as their primary care clinic; 14% report North Shore as their source for primary care; 13% cite Martin Luther King Clinic; 10% cite Patchogue Clinic and 10% cite Brentwood Clinic. As evidenced by the table below, the African American 'In Care' respondents report multiple clinic locations and HIV treating physicians. (See Table 27 and Table 28 below)

Table 27. Clinic Location for HIV Primary Care

CLINIC	#	%
NUMC	65	51%
North Shore	18	14%
SUNY-Stonybrook	14	11%
South Brookhaven	2	7%
MLK Clinic	4	13%
Port Washington Clinic	1	3%
Patchogue Clinic	3	10%
Brentwood Clinic	3	10%
Riverhead Health Center	2	7%
Queens LI Medical Group	1	3%
David E Rogers @ Southampton	6	20%
Northport VA	2	7%
Hempstead Clinic	1	3%
Central Islip Family Health Center	2	7%
Tri-Community Health Center	1	3%
Southside Clinic Bayshore	1	3%
Freeport Health Clinic	1	3%
Total	**128**	**100%**

Table 28. HIV Primary Care Physician

Doctor	#	%
Absey	28	22%
Hirsch	2	2%
McGowan	5	4%
Golinowski	4	3%
Schepp	1	1%
Sullivan	2	2%
Rita Kelly- Stonybrooky	1	1%
Steinbeigle	2	2%
Wanda Everlyn	2	2%
Bailey	1	1%
Landau	20	16%
Epstein	1	1%
Magnifico	2	2%
Sabine Haque	2	2%

Admed NUMC	1	1%
Rosenbaum	1	1%
David	2	2%
Chirch	6	5%
Northport VA	1	1%
Restrepo	1	1%
Dellato	6	5%
Herkewich - North Shore	1	1%
Sedles (North Shore)	2	2%
Griffin	2	2%
Merrick- Southside	1	1%
Verley	1	1%
Dr. Shameka--_NorthShore	1	1%
Stanley Wilson- NUMC	1	1%
Lobo	2	2%
Furhur- Stonybrook	7	5%
Nockman- Stonybrook	1	1%
Bluman	1	1%
Fingerqut (sp?) Riverhead	1	1%
Bonnano	1	1%
Stonybrook	2	2%
Mikaela Anderson	5	4%
Descharge	4	3%
prefer not to answer	4	3%
Total	**128**	**100%**

Primary Care Visit and Lab Monitoring Indicators of "In Care" Status

The vast majority of the African American 'In Care' respondents report an active "In Care" status, with most persons (of the 128 respondents who answered the question) reporting seeing their physician and receiving laboratory services in the past four to six months or less. Only 7 or fewer respondents could be characterized with an 'erratically in care' status in the past 12 months. Similar visit patterns are reported for laboratory monitoring of CD4 cell counts and viral load levels. See Table 29 & 30 below for an analysis of physician and lab visit patterns.

Table 29. Most Recent Doctor Visit & Lab Monitoring Visits

Doctor		CD4		Viral Load	
7/1/07		7/1/07	**1**	7/1/07	**1**
8/1/07	**1**	8/1/07	**1**	8/1/07	**1**
9/1/07	**4**	9/1/07	**5**	9/1/07	**5**
10/1/07	**17**	10/1/07	**21**	10/1/07	**21**
11/1/07	**16**	11/1/07	16	11/1/07	16
12/1//07	**46**	12/1//07	**43**	12/1//07	**43**
1/1/08	**44**	1/1/08	**39**	1/1/08	**39**
Don't Know		DK	**1**	DK	**1**
Totals	**128**		**127**		**127**

Table 30: Last Doctor Visit and Last Lab Monitoring Visit Patterns

	Doctor		CD4		Viral Load	
Length of Delay	**#**	**%**	**#**	**%**	**#**	**%**
Current	69	54%	56	44%	56	44%
One month	32	25%	31	24%	31	24%
Two months	19	15%	25	20%	25	20%
Three months	6	5%	12	9%	12	9%
Four months	1	1%	1	1%	1	1%
Five months	1	1%	1	1%	1	1%
Six months		0%	1	1%	1	1%
Don't Know		0%	1	1%	1	1%
Average	**3.28**		**3.282**		**3.2821**	3%
Total	**128**	**100%**	**128**	**100%**	**128**	**100%**

As evidenced by the tables on the previous page, most HIV primary medical care is centralized at Designated AIDS Centers (DACS- Nassau University Medical Center, North Shore, Stonybrook) or Clinics (i.e. MLK Clinic, Brentwood, Riverhead Health Center, and David E Rogers Center at Southampton Hospital).

Clients report liking 'all-in-one' care systems (i.e. Catholic Charities wherein mental health and dental health care, along with social and group support services could be provided; Riverhead Health Center (where PLWH/A may access mental health services, dental care, and primary medical and case management services; and/or NUMC (where the PLWH/A may access numerous services in one location, including HIV primary care, mental health services, social workers, dental care, vision care, and drug treatment).

The African American 'In Care' survey respondents also expressed the desire for a more community-based approach, describing such attributes as "Clinics treating range of patients, not just HIV+"; "More generic med bottles"; Non-segregated services (i.e. no floors marked as IDU or separated from other hospital patients); "More coordinated services across agencies and health systems"; and the "Need to be treated for all their related diseases and medical needs".

Current Antiretroviral Therapy

The majority of the African American 'In Care' survey respondents (82%) report the current receipt of antiretroviral therapy, as evidenced in the table below.

Table 31. Current ART

Yes		No		Don't Know	
#	**%**	**#**	**%**	**#**	**%**
105	82%	22	17%	1	1%
128	**100%**				

History of Mental Illness-Diagnosis and/or Treatment

Almost half of the African American 'In Care' survey respondents (44%) report a history of mental illness, including Bipolar disease; Major depression; Schizophrenia; and PTSD. Through interviews, it was also apparent that there was a significant level of undiagnosed and/or under-treated mental health issues.

Table 32. History of Diagnosis and/or Treatment of Mental Illness

Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
56	44%	70	55%	1	1%	1	1%
128	**100%**						

History of Substance Abuse-Diagnosis and/or Treatment

A greater degree of disparity is revealed for the total number of African American 'In Care' survey respondents who report having been diagnosed and/or treated for a substance abuse disorder (N=70 or 55%).

Table 33. History of Diagnosis and/or Treatment for Substance Abuse Disorder

Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
70	55%	58	45%	0	0%	0	#DIV/0!
128	**100%**						

Diagnosis and/or Treatment of STDs and/or Treatment of Diseases other than HIV Disease

Over 1/3 of this 'In Care' survey sample (39%) reports a history of other STDs and 55% of all 'In Care' respondents report diagnosis and/or treatment for diseases other than HIV, indicating high levels of co-morbidity, overall.

Table 34. History of STDs

STD Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
50	39%	73	57%	3	2%	2	2%
128	**100%**						

A large proportion of this 'In Care' survey sample reports diagnosis with other chronic illnesses (N= 71 or 55%) as evidenced in Table 35 on the following page.

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Table 35. History of Other Chronic Diseases

Other Disease-Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
71	55%	57	45%	0	0%	0	0%
128	**100%**						

NEEDS, USES, GAPS, and BARRIERS RANKING

A Needs, Uses, Gaps and Barriers ranking was developed for all African American 'In Care' respondents. The 2008 HIV/AIDS Needs Assessment provides a "snapshot" of the community service needs, barriers, and gaps as expressed by consumers of HIV related services. The rankings of the Needs Assessment were displayed for all African American 'In Care' respondents, with separation into Need, Use, Gap and Barrier. This can be further defined as:

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**
Gap	**Sum of 'In Care' client survey respondents who answered 'Yes' to Need and 'No' to availability of that service**
Barrier	**Number of 'In Care' client survey respondents who indicated that a service is 'Hard to Get'**

NEED

The highest priority HIV service needs reported by the Nassau-Suffolk African American 'In Care'" survey participants, in rank order, include: 1) Housing services; 2) Medical Transportation tied with Food Bank; 4) EFA/Help with co-pays and rent; 5) Medications; 6) Primary Medical Care tied with Health Education/I & R tied with Group Support; 9) Social Support; 10) Employment Skills training tied with Research Advocacy tied with Healthy Environment; 13) Mental Health services; 14) Health Insurance/Social Security; and 15) Community tolerance tied with Medical Case Management. The top ranking service Needs evidence a strong mix of supportive and core medical services

The Top Ranking Service <u>NEEDS</u> for African American "In Care" respondents:

Table 36: Top NEEDS Rankings-African American 'In Care' Respondents

NEEDS	NEED RANKINGS
Housing Services	1
Medical Transportation	2
Food Bank	2
Emergency Financial assistance/Help with co-pays & rent	4
Medications	5
Primary Medical Care	6
Health Education/Information & Referral	6
Group Support	6
Social Support	9
Employment Skills training	10
Research Advocacy	10
Healthy Environment	10
Mental Health services	13
Health Insurance/Social Security	14
Community tolerance	15
Medical Case Management	15

Service USES

The top 15 services reported as most often 'used' by the African American 'In Care' respondents included: 1) Primary Medical Care; 2) Medical Transportation; 3) Medications; 4) Medical Case Management; 5) Oral Health care; 6) Health Insurance/Social Security; 7) Housing services; 8) Clinics; 9) Food Bank; 10) Mental health services; 11)Group Support; 12) Social Support; 13) Vision Care; and 14) Vitamins tied with Thursday's Child.

The Top Ranking Service <u>USES</u> for African American "In Care" respondents:

The top ranking service Uses reflect a greater number of core medical services than support services, overall. However, the lack of readily available transportation is a major issue that is genuinely affecting the PLWH/A's perceptions of health on Long Island. According to the African America 'In Care' respondents, the lack of transportation limits PLWH/A's ability to take care of health basically (shelter, food, medicine, medically) and holistically (work, related illnesses, alternative and physical therapies, group support, living beyond base-line survival).

Table 37: Priority USE Rankings-African American 'In Care' Respondents

USES	USE RANKINGS
Primary Medical Care	1
Medical Transportation	2
Medications	3
Medical Case Management	4
Oral Health services	5
Health Insurance/Social Security	6
Housing services	7
Clinics	8

Food Bank	9
Mental Health services	10
Group Support	11
Social Support	12
Vision Care	13
Vitamins	14
Thursday's Child	14

Service BARRIERS

The top ranking service Barriers reported by the African American 'In Care' survey respondents include the following, in rank order: 1)Medical Transportation; 2) Housing services; 3) Food Bank; 4) EFA/Help with co-pays/rent assistance; 5) Employment Skills training; 6) Health Insurance/Social Security tied with Group Support; 8) Primary Medical Care tied with Social Support, Medical Case Management, Mental Health services and Substance abuse counseling, and Treatment Adherence counseling; 13) Research Advocacy tied with Community Tolerance tied with Health Information and Referral and Family Support. The triad of challenges relating to a lack of or difficulty in obtaining the most basic supportive services such as medical transportation, housing and food, coupled with ongoing needs for financial assistance definitely point to the unmet need for more employment skills training and job placement services. The fact that Primary Medical Care, Mental Health and Substance Abuse services and Medical Case Management services rank as much less difficult to obtain than some of the non-core services reflects the EMA's efforts to maintain the availability of core medical services for the greatest number of PLWH/A.

Table 38. Top Ranking Service Barriers for African American 'In Care' Respondents

BARRIERS	BARRIER RANKINGS
Medical Transportation	1
Housing services	2
Food Bank	3
EFA/Help with co-pays/rent	4
Employment Skills training	5
Health Insurance/Social Security	6
Group Support	6
Primary Medical Care	8
Social Support	8
Medical Case Management	8
Substance Abuse services & Treatment Adherence counseling	8
Mental Health services	8
Research Advocacy	13
Community tolerance	13
Health Education/Information & Referral	13
Family Support	13

Service Barrier Reasons for African American 'In Care' Survey Respondents

Table 39: Barrier Reasons by Service Category

Service Category Description	Need Rank	Barrier Rank	Barrier Reasons
Housing	1	2	"I moved to Suffolk County because could get Section 8 there in 2 years instead of 10"; long waiting lists for DSS or Section 8 assistance; need rent assistance or rent control for HIV+ residents; rent sometimes exceeds assistance (SSI, disability, Section 8, DSS, Veterans) & leaves little left-over; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean independent living options; need assistance for working PLWH/A; often difficult process to document "homelessness"; available housing tends to be in dangerous areas; perceived no independent living options for single women or gay men.
Quality Food - Meals and Food Boxes; Food Stamps	2 tie	3	Food boxes should include toiletries; Need nutritionally sound foods- especially protein, meat, veggies and organic options- need food program designed to boost the immune system; no transportation to grocery store or food pantry; no incentive to get job because will lose food stamp coverage; "it would be a good idea to give out nutritional meals at medical appointments"
Transportation	2 tie	1	Unreliable services, ordeal to schedule; "suspended Driver's License limits my travel"; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; "I moved to Suffolk County to get Section 8, but now I can't get a ride to my doctor just across the county line"; need help getting a car; no transportation available other than bus in some Eastern parts of Suffolk Co.; belief that Treatment Modernization Act aimed to eliminate already limited transportation; "I'm hesitant to use medical transportation because my neighbors will find out & start talking. It would be better if anyone needing a ride could have one, then people don't know why you're being picked-up"
Financial Assistance / Stability (including rental assistance)	4	4	Rent takes up most assistance, leaving little funds for groceries, toiletries, cleaning supplies, utilities, house repairs, Medicaid spend-down and medical co-payments; "I'd love to live beyond just surviving"; would like to work but would lose eligibility for financial assistance; parking, travel and food vouchers needed desperately; laundry vouchers would be good idea- especially for families; expressed need for credit resolutions / forbearance; food stamps don't stretch for healthy foods; extreme expressed need for rent assistance
Medicine	5	13 tie	Need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, high blood pressure, heart problems); paperwork onerous; Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "trying to use online pharmacy (momspharmacy.com) to have my meds delivered"; "aidsmeds.com is great resource for information about HIV meds"
Primary Medical Care	6 tie	8 tie	Hard to get appointment in emergencies; convenient when several services in one location (ex = NUMC, Catholic Charities, Riverhead Health Center); lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation
Education/ Information & Referral	6 tie	7	Education for PLWH/A (how to live with the disease, adjusting to physical & lifestyle changes, information on new meds and labs); education in elementary schools and society; need outreach campaigns against ignorance and promoting tolerance, prevention & testing
Group support & Day Programs	6 tie	6 tie	Need more socially-oriented co-ed support groups; use Hispanic Counseling Center, FEGS & Catholic Charities; need groups focusing on living with the disease and navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Social Support	9	8 tie	Need more socially-oriented co-ed support groups, focusing on living with the disease and enjoying mature range of activities (arts, socials, sports)
Employment / Skills Training	10 tie	5	Need list or ideas for part-time, suitable employment options for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin

			working again".
Research-Advocacy-prioritization	10 tie	13 tie	Lack of advocates means funding is not priority and needs are not met; priority shift needed back to provision and away from profit
Life / health / Healthy environment	10 tie	NR	No comment
Mental Health	13	8 tie	"Waiting lists unless you are referred through an agency"; "many people need mental health support but are not aware of availability or its benefits"; needed for long-term survivors who did not plan to see later phases of life
Social Security / Insurance (including ADAP & Disability)	14	6 tie	Assistance not available for working poor; "get run-around and very little explanation…not worth it and makes me want to go do drugs again"; need more logical & understandable system; Medicaid spend-down is confusing; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Community Tolerance / Understanding	15 tie	13 tie	Still face bigotry and fear in community
Case Managers / Social Workers	15 tie	8 tie	"My Case Manager at 5 Towns helped me become independent- she taught me how to fish instead of giving me the fish. I was thankfully able to cut back on case management because I've become more functional on my own"; some have multiple case managers (HIV + insurance CM); high turnover and inexperience are too common; heavy reliance on case managers for information and regiment management (appointments, coordination of care); cases being closed because clients using multiple agencies or not taking advantage of enough agency services; clients report run-around for services (ex = food vouchers) for "selective user" clients

Barrier reasons cited by the African American 'In Care' survey respondents reveal a significant circularity and inter-relationship. For example: the lack of transportation is cited as a barrier to obtaining access to many services; the lack of a job fuels financial lack, but fears of losing the assistance they do have is a barrier to finding and keeping employment; the lack of knowing how and where to access mental health services results in lack of needed treatment; and failure to meet eligibility criteria blocks access to numerous services.

Service GAPS

The top ranking service Gaps include many of the top ranking service Needs as well as a number of services that had not previously been ranked as either Needs or Barriers, including:

1) Housing services; 2) Medical Transportation tied with EFA/Help with co-pays & rent; 4) Food Bank tied with Primary Medical Care; 6) Health Insurance/Social security; 7) Employment Skills Training tied with Medications; 9) Health Education/Information & Referral; 10) Mental Health services; 11) Finding Help and Information tied with More extensive services tied with Alternative therapies tied with Legal services and Oral Health services; and 16) Medical Case Management; 17) Family Support and 18) Clinics.

Top Ranked Service GAPS and GAP Reasons for African American "In Care" respondents:

Table 40: Service GAPS and Gap Reasons

Service Category	Need Rank	Gap Rank	Gap Reasons
Housing	1	1	Problems covering 1st month's rent when relocating from out of area or prison; no assistance for non-homeless or working PLWH/A is frustrating: "I'd receive more assistance if I wasn't working. I shouldn't lose assistance for trying to be independent"; More people are testing positive but funding and services are being cut; "Options and Section 8 saved my life!"; available housing tends to be in dangerous areas; perceived no independent living options for single women or gay men; "I've heard stories about people being harassed at AIDS housing facilities"
Quality Food - Meals and Food Boxes; Food Stamps	2 tie	4 tie	Food stamps & vouchers limited or unavailable; "qualify for food assistance by no way to get there"; some agencies refuse services like food vouchers to "selective users (need food but not case management" or people enrolled with multiple agencies; Ensure protein drink coverage removed and deemed non-medically necessary; "it would be a good idea to give out nutritional meals at medical appointments"
Transportation	2 tie	2 tie	Medical transportation service is unreliable; need help to find a car; limited # and range of rides- monthly medical appointments often exceed max # of rides (especially with additional diseases), no rides to grocery store, food pantry or pharmacy; no rides across county lines limits choice of providers; discounts should be available on bus and train for PLWH/A; "I live in Port Washington but prefer services in Hempstead- like EAC Food Pantry, pharmacies, support groups and clinics. I have to rely on family or a bus, but times are limited and I live far from the bus stop."
Financial Assistance / Stability (including rental assistance)	4	2 tie	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about $s and #s, not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give me food vouchers if I came to other programs and used their case management"); public assistance barely covering basic needs
Medicine	5	7 tie	Limited transportation to doctor, no transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication; need new, more tolerable & affordable meds; many medications not covered (such as migraine medication); "sometimes I have to sacrifice my meds and health to make sure needs are met for my girls"
Primary Medical Care	6 tie	4 tie	"Many people are living with HIV but not going to the doctor. We need outreach to people who are scared or on the down-low."; high turnover in staff is discouraging; some staff not compassionate (especially in early days of epidemic); transportation is an issue (limited # per month, limited range (ex = won't cross Nassau/Suffolk county lines); hard to obtain emergency appointments; need more after-hour availability for those who work
Health Education/Information & Referral	6 tie	9	Programs to help obtain GED would be helpful; was receiving POZ magazine but subscription stopped- was great way to stay updated & in-touch with community; need workshops; need better info for newly diagnosed; clients still face discrimination & ignorance in the workplace, in the community, and even in health care facilities; "We're about to have an explosion of HIV cases and we're not prepared. Migrant workers and young African Americans and Latinos are increasingly moving to the area and testing positive. We need to be informed & prepared"
Group support & Day Programs	6 tie	NR	Support groups lacking attendance because of funding cuts and shifting interests/needs
Social Support	9	NR	Support groups lacking attendance because of funding cuts and

			shifting interests/needs; "FEGS groups give me a great way to meet other people in my situation"
Employment / Skills Training	10 tie	7 tie	"Would like skills training and job, but afraid I will lose assistance if I begin working again"; housing crisis affects working poor with HIV, who work in construction & household repair industries; "I want to work but my family and Case Manager discourage it because my budget has finally "stabilized""
Research- cure/vaccine, Advocacy- political prioritization	10 tie	NR	"National priorities focused on war and helping international HIV, but not PLWH/A here"; lack of advocates = funding cuts; need targeted outreach campaigns & PSA's geared towards specific demographics (ex = young gays where "bug chasing" is emerging)"
Mental Health	13	10	Use FEGS, Hispanic Counseling Center; no outreach efforts educating public on benefits of mental health care; still stigma attached with care
Health Insurance/Social Security / (including ADAP & Disability)	14	6	"Social Services treats HIV Patients like 5th rate citizens that deserve to be in their situation"; no life insurance available for PLWH/A; reports of extreme run-around and cold, demoralizing treatment (esp DSS); "I worked for 20+ years and now that I need help I can't get it!"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go"
Case Managers / Social Workers	15 tie	16	"There seems to be a conflict of interest between the intention of case management and the "quotas" of services and patients"; "need agencies to coordinate efforts rather than act as competitors; they are unwilling to help unless you are at the bottom of the barrel"; clients report high levels of run-around (especially with DSS), denials for case management and services (ex = seeking EOC housing assistance made LIACC stop helping with other needs), heavy reliance upon case management; "I don't need handholding...I just want assistance without the run-around"; "high staff turnover rates lead to frustration & distrust in system and movement towards "Out of Care"
Legal Services	NR	11	"I was fired from my job and it has led to a downward spiral. I'm trying to sue them, work and raise my son who is also HIV+. We're about to be evicted and I've been denied for all assistance. We don't believe anyone is out there to help us"
More extensive services	NR	11	"No job/skills training programs available, especially in my area (Glen Cove)"; services being cut due to funding cuts; services need to evolve with changing population (focus on skills training, social group outing/activities, education)
Alternative Therapies	NR	11	More holistic approach needed to treating PLWH/A- coverage and services only seem available for traditional "medical-only" needs
Finding Help & Information	NR	11	Need list of special programs available for those in need (ex = Burlington Coat Factory offer, Christmas gifts for children in affected families); need better info for newly diagnosed; often receive run-around while obtaining services; Thursday's Child was one of only sources for "real" information but they are also threatened by funding cuts; "Now that I've finally found a place for help it's closing down [Catholic Charities]. It's hard to know where to go in this area"
Dentist; dental care	NR	11	Transportation limited in # and geographic range; difficult to get dental coverage once lose it (ex = lost Delta Dental, stuck in run-around trying to get coverage)
Family support	NR	17	No voice representing the needs of "affected" families; system of care designed to support single people with HIV/AIDS
Clinics	NR	18	Lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; hard to obtain emergency appointments; need more after-hour availability for those who work

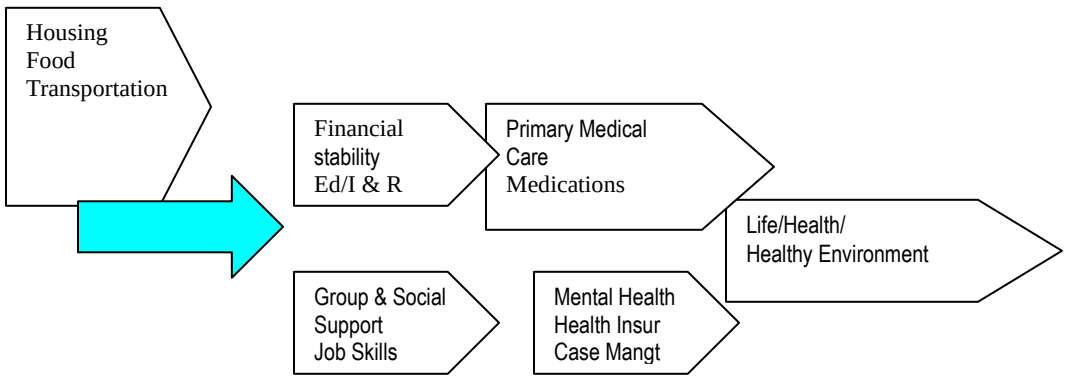
Information, useful for planners and providers alike, is contained in the voluminous comments sections for the Barrier and Gap reasons offered by the African American 'In Care' survey

respondent group.

Recommended Priority Strategies to Enhance Linkage, Engagement & Retention in Care for African American PLWH/A:

- Engaging clients in care when first diagnosed as HIV+
- Fully assessing clients needs when entering 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
- Ensuring cultural and linguistic competence of CM, MH and PMC providers to meet the needs of sub-populations
- Aligning planning processes to respond to service delivery issues
- Service Delivery: Expand Housing and Housing-Related Services
- Service Delivery: Expand transportation assistance services
- Service Delivery: Explore feasibility of expanding employment skills training for part-time jobs whereby PLWH/A could maintain level of benefits
- Service Delivery: Expand/seek additional funding to support the unmet food, housing, transportation and financial assistance needs reported by the 'In Care' African Americans
- Service Delivery: Ensure optimal collaboration among core medical and supportive services providers, co-locating to the extent possible all priority services
- Assuring services availability information- Information about service availability is limited
- Assuring high-quality services - Information about service quality is limited
- Retaining clients in care - employing systematic approaches to missed appointments/lost to follow-up and maximizing Ryan White and other funding resources
- Assisting re-entry into care – expanding peer counselors and other social engagement/outreach strategies identified as highly effective in facilitating their return to care/keeping them in care

African American 'In Care' Trajectory to Attachment, Engagement and Retention in Care:



Chapter 3: Recommendations for Comprehensive Strategic Plan

Special Strategies Directed to Optimizing Access and Retention in Care

1) ***Address African American 'In Care' Service BARRIERS inclusive of Housing; Food; Transportation; EFA; Medications; PMC; Health Information/Referral; Group Support/Social Support; Employment skills training; Mental health; Social security assistance; and Case management:***

TABLE 41: African American PLWH/A Service Barriers and Barrier Reasons

Service Category Description	Need Rank	Barrier Rank	Barrier Reasons
Housing	1	2	"I moved to Suffolk County because could get Section 8 there in 2 years instead of 10"; long waiting lists for DSS or Section 8 assistance; need rent assistance or rent control for HIV+ residents; rent sometimes exceeds assistance (SSI, disability, Section 8, DSS, Veterans) & leaves little left-over; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean independent living options; need assistance for working PLWH/A; often difficult process to document "homelessness"; available housing tends to be in dangerous areas; perceived no independent living options for single women or gay men.
Quality Food - Meals and Food Boxes; Food Stamps	2 tie	3	Food boxes should include toiletries; Need nutritionally sound foods- especially protein, meat, veggies and organic options- need food program designed to boost the immune system; no transportation to grocery store or food pantry; no incentive to get job because will lose food stamp coverage; "it would be a good idea to give out nutritional meals at medical appointments"
Transportation	2 tie	1	Unreliable services, ordeal to schedule; "suspended Driver's License limits my travel"; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; "I moved to Suffolk County to get Section 8, but now I can't get a ride to my doctor just across the county line"; need help getting a car; no transportation available other than bus in some Eastern parts of Suffolk Co.; belief that Treatment Modernization Act aimed to eliminate already limited transportation; "I'm hesitant to use medical transportation because my neighbors will find out & start talking. It would be better if anyone needing a ride could have one, then people don't know why you're being picked-up"
Financial Assistance / Stability (including rental assistance)	4	4	Rent takes up most assistance, leaving little funds for groceries, toiletries, cleaning supplies, utilities, house repairs, Medicaid spend-down and medical co-payments; "I'd love to live beyond just surviving"; would like to work but would lose eligibility for financial assistance; parking, travel and food vouchers needed desperately; laundry vouchers would be good idea- especially for families; expressed need for credit resolutions / forbearance; food stamps don't stretch for healthy foods; extreme expressed need for rent assistance
Medicine	5	13 tie	Need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, high blood pressure, heart problems); paperwork onerous; Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "trying to use online pharmacy (momspharmacy.com) to have my meds delivered"; "aidsmeds.com is great resource for information about HIV meds"
Primary Medical Care	6 tie	8 tie	Hard to get appointment in emergencies; convenient when several services in one location (ex = NUMC, Catholic Charities, Riverhead Health Center); lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation
Education/Information & Referral	6 tie	7	Education for PLWH/A (how to live with the disease, adjusting to physical & lifestyle changes, information on new meds and labs); education in elementary schools and society; need outreach campaigns against ignorance and promoting tolerance, prevention & testing

Group support & Day Programs	6 tie	6 tie	Need more socially-oriented co-ed support groups; use Hispanic Counseling Center, FEGS & Catholic Charities; need groups focusing on living with the disease and navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Social Support	9	8 tie	Need more socially-oriented co-ed support groups, focusing on living with the disease and enjoying mature range of activities (arts, socials, sports)
Employment / Skills Training	10 tie	5	Need list or ideas for part-time, suitable employment options for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin working again".
Research-Advocacy-prioritization	10 tie	13 tie	Lack of advocates means funding is not priority and needs are not met; priority shift needed back to provision and away from profit
Life / health / Healthy environment	10 tie	NR	No comment
Mental Health	13	8 tie	"Waiting lists unless you are referred through an agency"; "many people need mental health support but are not aware of availability or its benefits"; needed for long-term survivors who did not plan to see later phases of life
Social Security / Insurance (including ADAP & Disability)	14	6 tie	Assistance not available for working poor; "get run-around and very little explanation…not worth it and makes me want to go do drugs again"; need more logical & understandable system; Medicaid spend-down is confusing; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Community Tolerance / Understanding	15 tie	13 tie	Still face bigotry and fear in community
Case Managers / Social Workers	15 tie	8 tie	"My Case Manager at 5 Towns helped me become independent- she taught me how to fish instead of giving me the fish. I was thankfully able to cut back on case management because I've become more functional on my own"; some have multiple case managers (HIV + insurance CM); high turnover and inexperience are too common; heavy reliance on case managers for information and regiment management (appointments, coordination of care); cases being closed because clients using multiple agencies or not taking advantage of enough agency services; clients report run-around for services (ex = food vouchers) for "selective user" clients

2. Address African American 'In Care' Service GAPS inclusive of Housing; Food; Transportation; EFA; Medications; Primary Medical Care; Health Education/Information& Referral; Employment assistance; Mental Health; Health Insurance/SS Assistance; Case Management; Legal and other services:

TABLE 42: African American PLWH/A Service Gaps and Gap Reasons

Service Category	Need Rank	Gap Rank	Gap Reasons
Housing	1	1	Problems covering 1st month's rent when relocating from out of area or prison; no assistance for non-homeless or working PLWH/A is frustrating: "I'd receive more assistance if I wasn't working. I shouldn't lose assistance for trying to be independent"; More people are testing positive but funding and services are being cut; "Options and Section 8 saved my life!"; available housing tends to be in dangerous areas; perceived no independent living options for single women or gay men; "I've heard stories about people being harassed at AIDS housing facilities"

Quality Food - Meals and Food Boxes; Food Stamps	2 tie	4 tie	Food stamps & vouchers limited or unavailable; "qualify for food assistance by no way to get there"; some agencies refuse services like food vouchers to "selective users (need food but not case management" or people enrolled with multiple agencies; Ensure protein drink coverage removed and deemed non-medically necessary; "it would be a good idea to give out nutritional meals at medical appointments"
Transportation	2 tie	2 tie	Medical transportation service is unreliable; need help to find a car; limited # and range of rides- monthly medical appointments often exceed max # of rides (especially with additional diseases), no rides to grocery store, food pantry or pharmacy; no rides across county lines limits choice of providers; discounts should be available on bus and train for PLWH/A; "I live in Port Washington but prefer services in Hempstead- like EAC Food Pantry, pharmacies, support groups and clinics. I have to rely on family or a bus, but times are limited/ I live far from the bus stop."
Financial Assistance / Stability (including rental assistance)	4	2 tie	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about $s and #s, not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give me food vouchers if I came to other programs and used their case management");assistance barely covering basic needs
Medicine	5	7 tie	Limited transportation to doctor, no transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication; need new, more tolerable & affordable meds; many medications not covered (such as migraine medication); "sometimes I have to sacrifice my meds & health to ensure needs are met for my girls"
Primary Medical Care	6 tie	4 tie	"Many people are living with HIV but not going to the doctor. We need outreach to people who are scared or on the down-low."; high turnover in staff is discouraging; some staff not compassionate; transportation is an issue (limited # per month, limited range (ex = won't cross Nassau/Suffolk county lines); hard to obtain emergency appointments; need more after-hour availability for those who work
Health Education/Information & Referral	6 tie	9	Programs to help obtain GED would be helpful; was receiving POZ magazine but subscription stopped- was great way to stay updated & in-touch with community; need workshops; need better info for newly diagnosed; clients still face discrimination & ignorance in the workplace, in the community, and even in health care facilities; "We're about to have an explosion of HIV cases and we're not prepared. Migrant workers and young African Americans and Latinos are increasingly moving to the area and testing positive. We need to be informed & prepared"
Group support & Day Programs	6 tie	NR	Support groups lacking attendance because of funding cuts and shifting interests/needs
Social Support	9	NR	Support groups lacking attendance because of funding cuts and shifting interests/needs; "FEGS groups give me a great way to meet other people in my situation"
Employment / Skills Training	10 tie	7 tie	"Would like skills training and job, but afraid I will lose assistance if I begin working again"; housing crisis affects working poor with HIV, who work in construction & household repair industries; "I want to work but my family and Case Manager discourage it because my budget has finally "stabilized""
Research- cure/vaccine, Advocacy- political prioritization	10 tie	NR	"National priorities focused on war/helping international HIV, but not PLWH/A here"; lack of advocates = funding cuts; need targeted outreach campaigns & PSA's geared towards specific demographics (ex = young gays)"
Mental Health	13	10	Use FEGS, Hispanic Counseling Center; no outreach efforts educating public on benefits of mental health care; still stigma attached with care
Health Insurance/Social Security / (including ADAP & Disability)	14	6	"Social Services treats HIV Patients like 5th rate citizens that deserve to be in their situation"; no life insurance available for PLWH/A; reports of extreme run-around and cold, demoralizing treatment (esp. DSS); "I worked for 20+ years and now that I need help I can't get it!"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied/don't know where to go"

Case Managers / Social Workers	15 tie	16	"There seems to be a conflict of interest between the intention of case management and the "quotas" of services and patients"; "need agencies to coordinate efforts rather than act as competitors; they are unwilling to help unless you are at the bottom of the barrel"; clients report high levels of run-around (especially with DSS), denials for case management and services (ex = seeking EOC housing assistance made LIACC stop helping with other needs), heavy reliance upon case management; "I don't need handholding...I just want assistance without the run-around"; "high staff turnover rates lead to frustration & distrust in system and movement towards "Out of Care"
Legal Services	NR	11	"I was fired from my job and it has led to a downward spiral. I'm trying to sue them, work and raise my son who is also HIV+. We're about to be evicted and I've been denied for all assistance. We don't believe anyone is out there to help us"
More extensive services	NR	11	"No job/skills training programs available, especially in my area (Glen Cove)"; services being cut due to funding cuts; services need to evolve with changing population (focus on skills training, social group outing/activities, education)
Alternative Therapies	NR	11	More holistic approach needed to treating PLWH/A- coverage and services only available for traditional "medical-only" needs
Finding Help & Information	NR	11	Need list of special programs available for those in need (ex = Burlington Coat Factory offer, Christmas gifts for children in affected families); need better info for newly diagnosed; often receive run-around while obtaining services; Thursday's Child was one of only sources for "real" information but they are also threatened by funding cuts; "Now that I've finally found a place for help it's closing down [Catholic Charities]. It's hard to know where to go in this area"
Dentist; dental care	NR	11	Transportation limited in # and geographic range; difficult to get dental coverage once lose it (ex = lost Delta Dental, stuck in run-around trying to get coverage)
Family support	NR	17	No voice representing the needs of "affected" families; system of care designed to support single people with HIV/AIDS
Clinics	NR	18	Lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; hard to obtain emergency appointments; need more after-hour availability for those who work

3) Ensure Case Management provider awareness and use of all Ryan White and other local funding sources available in the EMA for securing the comprehensive service needs expressed by PLWH/A.

Recommended Priority Strategies to Optimize Retention in Care

- Engaging clients in care when first diagnosed as HIV+
- Fully assessing clients needs when entering 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
- Ensuring cultural and linguistic competence of CM, MH and PMC providers to meet the needs of sub-populations
- Aligning planning processes to respond to service delivery issues
- Service Delivery: Expand Housing and Housing-Related Services
- Service Delivery. Expand Medical Transportation assistance
- Service Delivery. Expand Employment/Job skills training and assistance programs
- Service Delivery: Expand/seek additional funding to support the unmet food, housing, and transportation needs reported by the 'In Care' populations

- Service Delivery: Ensure optimal collaboration among core medical and supportive services providers, co-locating to the extent possible all priority services
- Assuring services availability information- Information about service availability is limited
- Assuring high-quality services - Information about service quality is limited
- Retaining clients in care - employing systematic approaches to missed appointments/lost to follow-up and maximizing Ryan White and other funding resources
- Assisting re-entry into care – expanding peer counselors and other outreach strategies identified as highly effective in facilitating their return to care/keeping them in care

Retention of newly diagnosed persons in HIV primary medical care is essential for providing access to ART that can delay disease progression, and is especially critical for those PLWH/A whose immune systems are already seriously compromised. Retention in care also has the added benefit of preventing the further transmission of HIV by promoting safer sex practices.

Suggested Strategies for Newly Diagnosed PLWH/A:

Improved links and system navigation between prevention and care, such as:

1. *Locating HIV Testing programs in HIV primary clinics, with aggressive offers of testing to the Patients' sexual and drug-using partners, spouses, and*
2. *Expanded use of rapid testing in clinical and outreach testing settings*
3. *Expanded use of peer outreach testing specialists to locate and test other high risk individuals within their own unique social networks*
4. *Implementing same day referrals into primary medical care upon testing positive*
5. *Use of peer mentors/system navigators to ease transition into care and assist with navigation of care systems, accompany patients to appointments as needed, and help with reducing barriers to care*
6. *Implementing service need level assessments which target those persons newly entering care who are most likely to drop out or be most challenging to retain in care, and creating intensive care coordination plans to enhance engagement/retention.*
7. *Assess funded providers for training needs relative to relationship building and skills development relative to engaging, validating and partnering as key patient engagement and retention strategies*

Suggested Strategies for PLWH/A Receiving Some Services but NOT Primary Medical Care

Improved Linkages between Supportive and Primary Care Services

1. *Case Managers and other Support staff who provide services should implement more routine follow-up strategies to inquire about and encourage entry/re-entry into primary medical care for those 'erratically' in care.*
2. *Case Managers and Therapists should ensure that the necessary supportive services are provided to stabilize the person's life situation (i.e., stable housing, food, safety) and then help ensure that these services are extended to facilitate entry into and retention in care, as indicated*
3. *Expansion of Spanish speaking Therapists and Primary Care Providers and/or interpreters in settings where substantial numbers of non-English speaking PLWH/A receive services*
4. *Perform a cultural awareness/sensitivity assessment with all RW funded providers and offer trainings to ensure cultural competency among funded providers*

5. *Strengthen substance abuse treatment and primary medical care linkages; consider co-location of these services wherever possible and ensure ongoing on-site support for recovering PLWH/A*
6. *Co-locate, to the extent possible, HIV PMC and other primary medical and specialty care services*
7. *Strengthen peer outreach to ensure engagement/retention linkages with the most underserved and most likely to disengage*

Suggested Strategies for PLWH/A Who Have Dropped Out of Care

Improved Provider-Patient Partnerships and Collaborations with Peers

1. *Primary Care providers should make appointment reminder calls; facilitate transportation assistance; regularly reassess changing needs; and implement/maintain "no-show" tracking and follow-up protocols*
2. *At least biannually, Primary Medical providers should examine patient lists to determine who has not returned for care and initiate telephone and/or letter contact to make appointments and encourage re-entry into care*
3. *Expand use of peer advocates/peer outreach to locate, help reduce barriers and facilitate re-entry into care*
4. *Focus on reducing known barriers to care and resolving gaps in continuum of care*

Suggested Strategies for PLWH/A NEVER in Care

Peer-facilitated Linkages between Points of Entry/Testing/Counseling & Primary Care

1. Active follow-up by Testing/Counseling agency to maintain contact and confirm entry into care

2. Peer Outreach to specific populations and locations, including homeless shelters, drug treatment centers, etc

3. Regular marketing of primary care services' availability and directions on making referrals with all points of entry staff and agencies

4. Social marketing efforts regarding benefits of care and treatment

5. Co-location of primary medical care services with substance abuse treatment/rehab services

6. Co-location of HIV PMC and other PMC wherever possible.