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

'Out of Care' Unmet Needs Assessment of Persons Living with HIV/AIDS in the Nassau Suffolk EMA

2008 REPORT OF FINDINGS

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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 "Out of Care" 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.

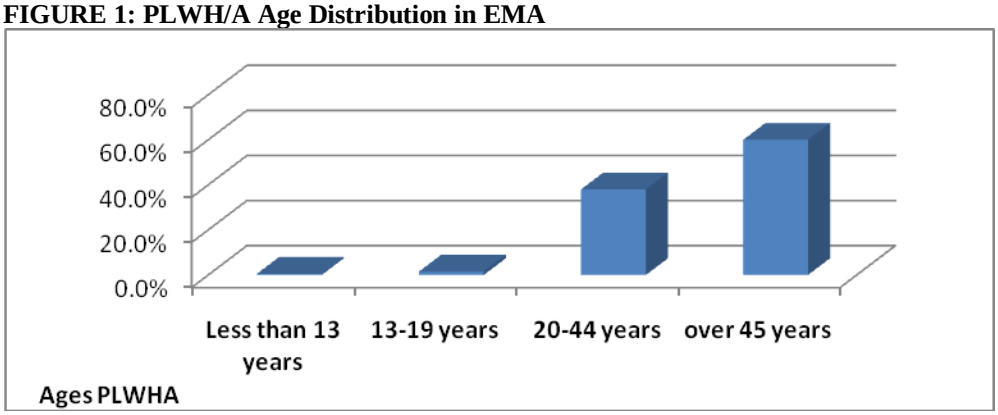
TABLE 3: AGE GROUP DISTRIBUTION (New AIDS and HIV, PLWH/A), 2007

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

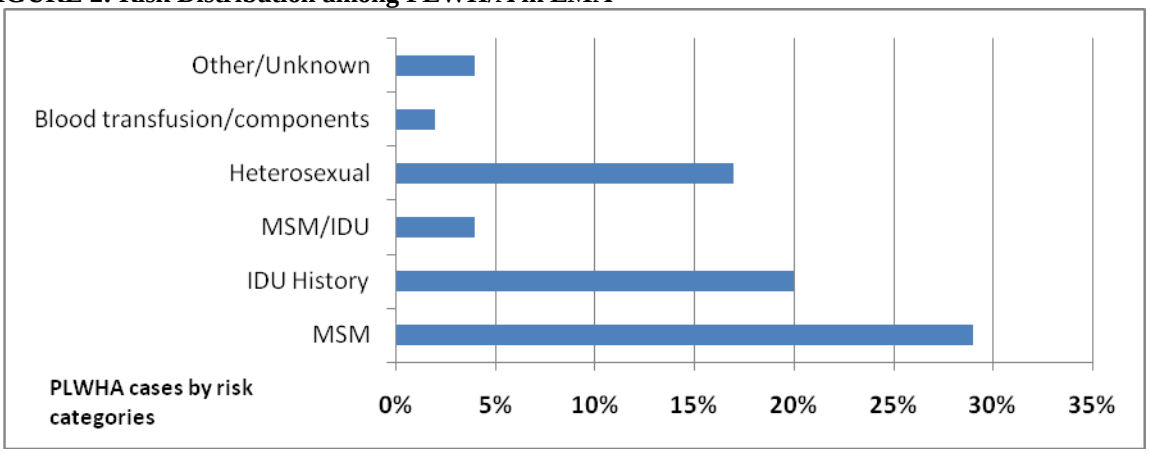
Source: New York State Department of Health, 2007

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. (*Please see Attachment 4*). 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 a 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.

Hispanics: Hispanics comprise 10% of the general Nassau population and 11% of the general Suffolk population, yet account for almost 30% of the new HIV cases and 27.9% of emergent AIDS cases. Hispanics comprise 38.65% of all PLWH/A and 32.4% of the concurrent HIV/AIDS cases, evidencing the greatest proportion of the 'late to testing and care' pattern among the Severe Need Groups in the EMA**.** Hispanics comprised 15% of the Part A client base in 2007. Based on these statistics, in 2008 the Nassau-Suffolk EMA Planning Council commissioned a special Needs Assessment Study for the Hispanic "In Care" population, to determine the service needs, gaps and barriers to care for this special population, the results of which 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

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)*

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%**

As evidenced in the table above, there are consistent disparities noted for each of the severe needs populations, when their relative proportion in the local epidemic is compared to their relative proportion in Part A funded core medical care services. 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.

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.

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***

***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 and Hispanic "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. A total of 53% of the 2008 Hispanic PLWH/A survey respondents reported current employment, yet 91% reported incomes at or below 200% FPL. The vast majority of the African American "In Care" respondents cite Medicaid or Medicare (76%), while only a minority of the Hispanic "In Care" respondents cite Medicaid or Medicare (24%) 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.

Overview of 'Out of Care' Needs Assessment of PLWH/A in the EMA

Relevance of 'Out of Care' Needs Assessment

Based on the EMA's 2008 Unmet Need Estimate there are 1,863 PLWH/A (approximately 31%) who are aware and out of care. To further explore the barriers to care for the Out of Care population, the Nassau-Suffolk HIV Health Service Planning Council commissioned this Out of Care Needs Assessment to gather data on the Out of Care populations within the EMA for use in the 2009 Priority Setting process.

For Grant Year 2008, the DNP committee set a goal of bringing 10% (n=160) of PLWH/A aware and out of care into care. Based on trending data of the In Care population, the DNP committee determined that all individuals brought into care would require Primary Medical Care, Mental Health, Medical Case Management and Treatment Adherence Services.

Additionally, outcomes from the 2008 Out of Care Needs Assessment will be incorporated into the EMA's Standard of Care development process. Finally, the Planning Council will use the NYSDOH Community Need Index (CNI) to target services for communities disproportionately impacted by HIV/AIDS in Nassau and Suffolk.

Overview of Characteristics of the Out of Care Sample

A total of 104 Out of Care respondents participated in the 2008 needs assessment survey process:

- ***Gender of OOC Survey Participants:*** 48% males and 52% females
- ***Transmission Risk of OOC Survey Participants***
- The majority of the OOC respondents identify heterosexual sex as their mode of transmission (59%), followed by IDU (31%); IDU (23%); and MSM (17%).
- ***Age Ranges of OOC Survey Participants:*** The greatest proportion of the 'Out of Care' respondents (66%) reported their ages in the 35-54 range, reflective of the total OOC population in the EMA.
- ***Race/Ethnicity of OOC Survey Participants: Over*** half of all the OOC survey respondents were African American (52%), followed by 15% Hispanic; 26% White; reflecting similar proportions of the reported race/ethnicities within the total affected population in the EMA.

- ***Only 23% of the OOC respondents are employed--the lack of employment/job skills training is a theme throughout the 'In Care' and 'Out of Care' survey findings.***
- ***OOC respondents demonstrate 100% STD co-morbidity and high other chronic illness.***

TABLE 8: 2008 'Out of Care' PLWH/A NEED, GAP and BARRIER MATRIX

Service Category Description	Need Rank	Use Rank	Gap Rank	Barrier Rank	Gap Reasons	Barrier Reasons
Housing services	1	7	3	1 tie	I don't qualify for asst because of my immigration status"; 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"; available housing tends to be in dangerous areas; no assistance for moving- "my partner + I would be homeless w/out kindness of friends. It was major ordeal just to move across the courtyard"; not many options for Sr Citizens- "I'll be forced into senior citizens residences at a certain age, but I take care of my family and grandkids- that's not a good environment for me or them"	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; need affordable, clean, safe independent living options; need assistance for working PLWH/A; often difficult process to document "homelessness"; "I used a "working shelter" which provided job + living assistance- don't know where to find those on Long Island"; "I was recently homeless and Homeworks helped out!"
Medical Transportation	2	6	1	1 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 prefer NUMC for my primary care, but can't get a ride there since I've moved. I don't like the care I receive at Stonybrook but have no other option"	Unreliable services, ordeal to schedule; "Case Managers can no longer help out with transpo to appointments or store"; 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.; transportation ends too early
Food Bank	3	4	6	3 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	"EAC Food Pantry is very helpful"; need food ideas for special diets (ex = diabetic); "I see other people getting food vouchers at the doctor's office, but not me!?..."; Need

					multiple agencies; Ensure protein drink coverage removed and deemed non-medically necessary; "I'm not eligible for food stamps and no one can tell me why"	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
Primary Medical Care	4	1	8 tie	9 tie	e require a program like Americorps or ave to work with disprivileged"; "patients coverage for relate medical needs (ex = e living with HIV but not going to the h to people who are scared or on the staff It is discouraging; some staff not early days of epidemic); transportation is nth, limited range (ex = won't cross hard to obtain emergency appointments; ity for those who hours care for people	l medical system- maybe need r coordination of care- both on Island but for people moving or away; "I'd prefer more dential or universal care rs, where everyone is treated aren't labeled by what floor o to or what trailer you enter"; 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; accessibility is major issue
Medications	5 tie	9	8 tie	9 tie	No transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication ("Medicaid spend-down means I sometimes go without my meds"; many medications not covered (such as migraine medication); "I've been inconsistent with meds- sometimes I hoard them out of fear the government will cut funding"	Bottles (privacy); "I need to know there will be assistance with paying for meds once off public assistance"; need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, migraines, high blood pressure, heart problems); Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "I was using online delivery pharmacy but got a letter in the mail saying something about ADAP/Medicaid...confusing + discouraging "
Medical Case Management	5 tie	2	4	6 tie	It seems like some agencies are more concerned with making money and creating paperwork than helping clients"; need better coordinated "mobile case management" (ex = for people who move or travel for work- care is always somehow linked to them + available); 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"	Expressed need for caring, quality case management; cases closing as clients gain independence (some clients proud "I can be independent", others scared "how do I fill out the paperwork with 4th grade math skills?"); "my case manager saved me by helping to fight for assistance during my bout with cancer"; high turnover and inexperience / lack of compassion are common; heavy reliance on case managers for information and regiment management (appointments, coordination of care); cases reportedly 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; clients dropped + marked "non-compliant" even if missed meeting due to transp lapse or health issues (memory, emergencies)
Financial Assistance	7	13	7	5	Gaps in assistance for basic or emergency needs; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give food vouchers to "good clients" who are dependent upon them"); public assistance barely covering basic needs; Thursday's Child was organization helping with emergency financial needs but struggling with funding; "there seems to be plenty of wealth + development on Long Island but little assistance for the dis-privileged"	Especially need emergency assistance; 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; expressed need for credit resolutions / forbearance; food stamps don't stretch for healthy foods; extreme expressed need for rent assistance
Social Support	8 tie	12	NR	NR		
Group Support	8 tie	10	12	8	Need "stop smoking" programs; need programs addressing isolation of disease (isolation = sickness); 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"; "my transpo ends at 7pm and most groups meet later than that"	Lack of groups for women or women with children; 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)14
Mental Health services	10 tie	5	5	12	Clients express isolation, hopelessness, severe depression and fear of losing the few things they have (medications, housing, food); still stigma attached with care	Hard to get appointments (waiting list); drug problems = personal barrier; "many people need mental health support but are not aware of availability or its benefits"
Employment/Job skills training	10 tie	NR	10 tie	6 tie	Need ideas for disabled (VESID is potential program for the disabled to learn skills + job training)"would like skills training and job, but afraid I will lose assistance if I begin working again"; "I applied for a home health aid job @ Board of Health. I'm qualified by was denied for no reason…can't help think it has something to do with HIV status"	Need health coverage for part-time employees; need list or ideas for part-time, suitable employment options for PLWH/A to remain active + work without losing benefits; "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"
Clothing/ Furniture	12	NR	NR	NR		
Finding Information & Help	13	NR	NR	9 tie		Need better info for newly diagnosed; often receive run-around while obtaining

						services; need list of doctors taking ADAP or offering alternative medical services; need better information regarding system of care and services available; need less complicated medical-funding system
Health Insurance	14	8	2	3 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 know someone who waited 4 years for SSI + Medicaid"; "I had to relocate to work the system"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; gap in transitional care ("I moved from Seattle where everything was fine + now on Long Island I don't qualify for any kind of assistance. Doesn't make sense...")	"Red tape, too many questions, denied when they find out you're HIV+"; little to no assistance 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
Oral Health care	NR	3	NR	NR		
Substance Abuse treatment	NR	11	NR	NR		
Legal services	NR	14	10 tie	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"; many in need of legal assistance by unaware of availability (ex = client using television attorneys (Bender + Bender (?)) to fight for health assistance	
Information/ Education	NR	NR	NR	13		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 promoting tolerance, prevention & testing
Vision care	NR	15	NR	NR		
Immigration protection/assistance	NR	NR	13	NR	Many not eligible for services due to immigration / documentation status	

Reasons Why PLWH/A Don't Get Medical Care for Their HIV

The top ranking reasons offered by this sample of OOC respondents to explain why PLWH/A do not enter or remain in HIV primary medical care include: 'Privacy/Confidentiality concerns'; 'Fears about telling others'; 'Actively using substances';' Can't get transportation'; 'Feel healthy'; 'Don't want to take meds'; 'Can't afford it'; and 'Communication difficulties/cultural differences'. PLWH/A comments included: "No organized effort to reach out to affected and

isolated communities. Health care should be made accessible and non-discriminatory."; "Different than NYC- there you assume everyone is HIV+, reverse on Long Island".

Motivators to Return to Primary Care if Out of Care for a Period of Greater than 6 months Most Recently

The top three ranking motivators which might encourage those PLWH/A who have been absent from care for a period of six months or greater include: *'Transportation'; 'Free medical care'; and 'Health insurance'*. The next most frequently offered motivators/facilitators include: *'Employment opportunities'; 'More information about services and referrals or advice', and 'Better quality of services'*. Finally, 'Substance abuse treatment services' and 'More outreach services', along with 'more government services' are viewed as helpful to those re-engaging with care.

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 current focus of the Annual Needs Assessment process is to survey PLWH/A who are "Aware and Not in Care"[1] and determine their unmet needs. PLWH/A failing to access primary medical care for a period of time exceeding one year are deemed 'Out of Care'. Primary Medical Care is technically defined as the receipt of one or more of three forms of service—use of (1) antiretroviral drugs (2) CD4 lab tests and (3) Viral Load lab test.[2] The Nassau-Suffolk EMA considers an individual with HIV or AIDS to have an unmet need for care (or to be 'Out of Care') when there is no evidence that the person received any of the above forms of service during a defined 12 month time frame.

A comprehensive assessment of the service needs, gaps and barriers of 'Out of Care' PLWH/A within the Nassau-Suffolk EMA was conducted in the spring of 2008. This assessment of need included an "Out of Care" Survey questionnaire plus additional written surveys completed by PLWH/A in the Upstate Prison facility, utilizing the Out of Care Needs Assessment Client Survey (NACS) tool.

Relevance of the Part A Comprehensive "Out of Care" Needs Assessments

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. The 'Out of Care' needs assessment survey process and resulting report highlights the differing needs, gaps and barriers to HIV primary medical care experienced by the 'Out of Care' PLWH/A within the Nassau-Suffolk EMA.

The unmet need estimate in 2007 indicated that 37% of all PLWH/A are 'Out of Care' in the Nassau-Suffolk EMA. This was reduced to approximately 32% in 2008, representing a substantial reduction in the level of unmet need in the EMA. Four (4) subgroups exist among the 'Out of Care', two of whom do not technically adhere to the HRSA definition of at least one year not accessing primary medical care, but do shed insight into the 'Out of Care' issue.

OOC & Aware: CDC estimate of 850-900,000 currently HIV positive, 2/3 or 670,000 know they are infected. Of this, 1/3 or 233,000 do not receive HIV-related primary health care (CDC, February 2002)

1) CD4 – CD4 (T4) or CD4 + CELLS. HIV's preferred target cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4+ lymphocyte levels appear to be the best indicator for developing opportunistic infections.

2) VIRAL LOAD TEST - Test that measures the quantity of HIV RNA in the blood. Results are expressed as the number of copies per milliliter of blood plasma.

3) ANTIRETROVIRAL DRUGS - Substances used to kill or inhibit the multiplication of retroviruses such as HIV.

The four (4) groups are: 1) Newly diagnosed (risk of 'ever' attaching to care); 2) Those at 'risk of going Out of Care' (over 6 months not accessing primary medical care, display warning signs of non-compliance with treatment regimens); 3) the 'Technically Out of Care' (over 12 months not accessing primary care); and, 4) the Never in Care.

According to the most recently available data, the following table depicts the number and proportion of PLWH/A who are 'In Care' and 'Out of Care' in the Nassau-Suffolk EMA.

2008 Unmet Need Framework

Input	Value	Data Source		
Population Sizes				
Total Number of PLWH/A, through 12/2007	**5,928**	Jurisdiction specific surveillance data, includes prisoners		
AIDS	3,821	64%		
HIV+	2,107	36%		
Care Patterns (Met Need)				**Total population Identified**
Number of PLWH/A "In Care"				
A) Medicaid / ADAP (FFY07)	**2,366.00**	Total Medicaid / ADAP met need		**3,467.00**
AIDS	1,536.00			2,034.00
HIV+	830.00			1,433.00
B) Veteran's Administration (FY03 HRSA Data Run)	**84.61**	(1) Total VA met need		**95.58**
AIDS	54.54			61.61
HIV+	30.07			33.97
C) Corrections (Epi Data)	**119.43**	(2) Total Corrections Met Need		**175.00**
AIDS	76.98	64%	Assume Epi HIV/AIDS Split	107.00
HIV+	42.45	36%	Assume Epi HIV/AIDS Split	68.00
D) Other Payor	**1,494.82**	(3) Total Other Payor met need		**2,190.42**
AIDS	963.51	64%	Assume Epi HIV/AIDS Split	1,411.88
HIV+	531.31	36%	Assume Epi HIV/AIDS Split	778.55
E) Total	**4,064.86**	68.57%	Total Met Need	**5,928.00**
AIDS	2,631.03	68.86%	AIDS Met Need	3,614.48
HIV+	1,433.83	68.05%	HIV Met Need	2,313.52

Calculated Result (Unmet Need)				
Number of PLWH/A not "In Care"	**1,863.14**	31.43%	Total Unmet Need	-
	1,189.97	31.14%	AIDS Unmet Need	
	673.17	31.95%	HIV+ Unmet Need	

Source: New York State Department of Health, 2007

According to the Nassau-Suffolk EMA's Unmet Need Assessment, there are 1,863 PLWH/A who are aware and out of care, representing approximately 32% of the total living population of persons with HIV/AIDS.

To further explore the barriers to care for the Out of Care population, the Nassau-Suffolk HIV Health Services Planning Council commissioned this Out of Care Needs Assessment. The study data was used for the 2009 Priority Setting and Resource Allocation process. Additionally, outcomes from the 2008 Out of Care Needs Assessment will be incorporated into the EMA's Standard of Care development process.

Finally, the Planning Council will use the NYSDOH Community Need Index (CNI) to target services for communities disproportionately impacted by HIV/AIDS in Nassau and Suffolk. The NYSDOH's CNI lists 13 zip codes in Nassau County and 20 zip codes in Suffolk County as having a moderate to high level of demonstrated need.

The initial and significant burden is attaching persons to care immediately upon a positive HIV diagnosis. Individuals tend to not enter care until they 'feel sick'. In cultures that tend to not disclose or accept illness, particularly ones that are sexually transmitted or incurred due to injection drug use, this pattern exerts a dual deterrent to entering care. The 'late to care' pattern as evidenced by seroconversion to an AIDS diagnosis within a year of being diagnosed HIV-positive is most pronounced among African-Americans, Hispanics, Injection Drug Users, Other Substance Users and the Incarcerated/Recently Released.

Upon entry to primary medical care, the reasons for detachment include inability or unwillingness to maintain a rigorous treatment regimen (one in which adherence should be 94% or more to attain optimal benefit), side effects of HIV medications, the high cost of drugs or the co-payment related to HIV medications, and the pressure of other subsistence needs such as employment, housing and transportation to either access primary medical care or in lieu of paying for primary medical care.

Key points along the Continuum of Care can be assessed in a study specific to the 'Out of Care' to confirm that these are the risk flags for PLWH/A considering abandoning their care regimen. Flags include erratic appointment compliance (missing three or more appointments); tendency to not disclose issues, repeated concerns about medication regimens and drug resistance that may be flags for non-compliance with medication regimens. Questioning PLWH/A that are 'Out of Care' about their decision to abandon primary medical care will better highlight these risk points.

The Never in Care are one of the most troubling and least known subgroups. This group evidences confidentiality/privacy concerns, interest in alternative medicine and other resistance issues related to initial attachment to care upon positive HIV diagnosis. Subgroups exist within the 'Never in Care' including PLWH/A who self-manage (majority are long-term survivors and wary of HIV medications from the first generation of HIV drugs such as AZT), the 'unconnected' which includes undocumented citizens, the Incarcerated/Recently Released, Injection Drug Users and some Substance Abusers. The Never in Care frequently do not wish to expose themselves to any legal ramifications nor change their current patterns of behavior. Entering medical care is perceived as an exposure risk.

Project Design for the 'Out of Care' PLWH/A Needs Assessment Studies

Based upon the total number of 'Out of Care' the 95% CI required that at least 50-100 'Out of Care' Survey Respondents be targeted. The unmet need survey process was implemented under the direction of Collaborative Research. The survey site for the survey process included the local testing/counseling sites, food banks, homeless shelters, and Ryan White funded service providers, in order to access those PLWH/A who are not receiving any Ryan White funded services; to access those PLWH/A accessing only supportive services; and to access those PLWH/A just returning to RW funded primary medical services in order to ensure the widest possible level of participation among this difficult to reach population of potential survey participants. The actual number of 'Out of Care' respondents was 104 and each received a $20 gift card for participating in the survey process.

The objectives of the 'Out of Care' PLWH/A Needs Assessment Study:

The Ryan White Treatment Modernization Act Part A and Part B Grantees and planning bodies to determine how many people in their service area know they are HIV positive but are not receiving regular HIV-related primary medical care. The ultimate goal of the unmet need process is to get the 'Out of Care' into care and facilitate retention in care. The two major initial process steps for addressing unmet need include:

1. Estimating the number of people in each service area who know they are HIV-positive but not receiving HIV-related medical care: the number NOT "in care".
2. Assessing the service needs and barriers to care for such people, including finding out whom they are and where they live.
   (HRSA/Mosaica Unmet Need TA Center, 2006)

Based upon the Unmet Need Framework, the Nassau-Suffolk EMA undertook a rapid needs assessment process in order to begin to address the following two items:

1. Describe the demographics and location of persons who know their status and are NOT in care; and

2. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities.

Chapter 2: Out of Care Survey Findings

Introduction

According to the Nassau-Suffolk EMA's Unmet Need Assessment, there are 1,863 PLWH/A who are aware and out of care (or approximately 31% of all PLWH/A).To further explore the barriers to care for the Out of Care population, the Nassau-Suffolk HIV Health Services Planning Council commissioned this Out of Care Needs Assessment. A total of 104 PLWH/A with unmet need participated in the needs assessment process. The study data was used for the 2009 Priority Setting and Resource Allocation process.

Additionally, outcomes from the 2008 Out of Care Needs Assessment will be incorporated into the EMA's Standard of Care development process. Finally, the Planning Council will use the NYSDOH Community Need Index (CNI) to target services for communities disproportionately impacted by HIV/AIDS in Nassau and Suffolk. The NYSDOH's CNI lists 13 zip codes in Nassau County and 20 zip codes in Suffolk County as having a moderate to high level of demonstrated need.

The Unmet Need Study findings will address Items 1 and 2 below in the following narrative:

1. Describe the demographics and location of persons who know their status and are NOT in care;
2. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities.

A. Describe the demographics and location of persons who are 'Aware but NOT in care'

1. What subpopulations are most likely to be 'Out of Care'?

The 2008 Study of Unmet Need, based on 2007 data, revealed that 31.4% of all PLWH/A were 'Out of care' (32% PLWH and 31% PLWA). The un-met need estimate in this region for PLWH/A who are aware of their HIV status but are not in care is approximately 31 % (n=1,863). Priority number one, objective 1.4 Maintenance in Care provides a structured system of interactions designed to identify PLWH/A who have "dropped" out-of care, are erratically engaged in care, or who are at risk for poor primary care adherence.

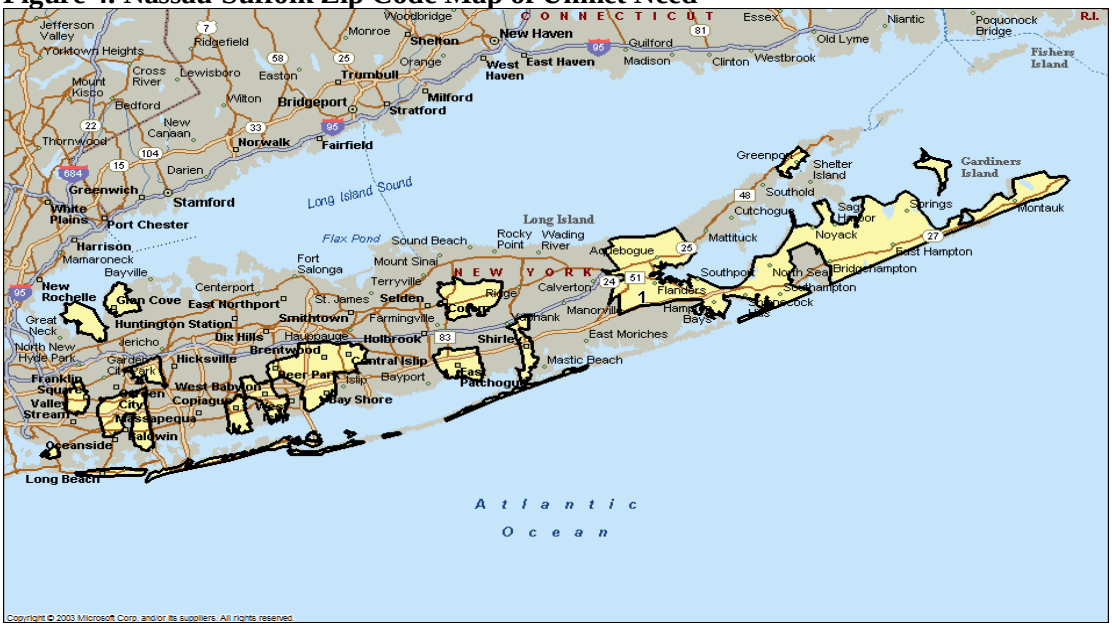
Through assessments of PLWH/A needs, barriers to accessing and maintaining medical care and treatment can be addressed, thereby increasing the likelihood of returning to care and treatment services. Based upon an analysis of the 2008 'Out of Care' needs assessment findings, the populations most likely to be out of care are Male and Female Heterosexuals and White MSM, MSM of Color and IDU.

2. Location of PLWH/A with Unmet Need in the EMA

There was no current location information (i.e. zip code or county of residence) available for the entire OOC population. The NYSDOH's CNI lists 13 zip codes in Nassau County and 20 zip

codes in Suffolk County as having a moderate to high level of demonstrated need. The following map highlights CNI zip codes areas as defined by NYSDOH.

Figure 4. Nassau-Suffolk Zip Code Map of Unmet Need



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Zip Code of Residence for OOC Respondents

According to this needs assessment survey, the majority of OOC respondents (63%) report their residence in one of twelve major zip codes, including 11550, 11520, 11717, 11901, 11798, 11704, 11722, 11573, 11553, 11969, 11003, and 11763. The remainder of the survey group reports numerous zip codes for their residence.

Table 9. Zip code of Residence for OOC Respondents

ZIP	#	%
11550	15	14%
11520	6	6%
11717	5	5%
11901	5	5%
11798	5	5%
11704	4	4%
11772	4	4%
11573	4	4%
11553	4	4%
11969	4	4%
11003	4	4%
11763	4	4%
11731	3	3%
11968	3	3%
11746	3	3%
11722	3	3%
11755	2	2%

11779	2	2%
11729	2	2%
11590	2	2%
11554	2	2%
11561	2	2%
11726	2	2%
11751	2	2%
11701	2	2%
11763	2	2%
11720	2	2%
11951	1	1%
11953	1	1%
11788	1	1%
11730	1	1%
11575	1	1%
11762	1	1%
TOTAL	**104**	**100%**

3. Characteristics of the PLWH/A with Unmet Need in the EMA Inferred from the 2008 'Out of Care' Needs Assessment Study

Gender of OOC Survey Participants

Forty one percent (41%) of the OOC survey sample was comprised of males and 59% were females, with none of the respondents self-identifying as transgender.

Table 10. Gender of OOC

Gender	#	%
Male	50	48%
Female	54	52%
Transgender		0%
Total	**104**	**100%**

Sexual Orientation of OOC Respondents

Eighty percent (80%) of the OOC survey respondents identify as heterosexual; 13%as homosexual and 6% as bisexual. One respondent identifies as Lesbian**.**

Table 11. Sexual Orientation

Sexual Orientation	#	%
Heterosexual-Straight	82	80%
Homosexual-Gay Man	14	13%
Homosexual-Lesbian	1	1%
Bisexual	7	6%
TOTAL	**104**	**100%**

Transmission Risk of OOC Survey Participants

The majority of the OOC respondents identify Heterosexual contact as their mode of transmission (60 respondents or 59%). The transmission risks reported by the remainder of the OOC respondents include 18 MSM (17%); 24 IDU (23%); 32 Sex with IDU (31%); followed by 4% transfusion; 2% prison; 2% assault; 1% health care worker; and 9% unknown. One respondent reports prostitution as likely mode of HIV acquisition. Several survey respondents listed more than one mode of transmission, though heterosexual risk and IDU and Sex with IDU, and to a lesser degree—MSM--are the predominant behavioral transmission risks reported by this Out of Care survey sample.

Table 12. Mode of HIV Transmission

Medium of HIV infection	Total	
	#	%
Male sex with male	18	17%
IDU	24	23%
Female sex with female	0	0%
Heterosexual sex	60	59%
Prison	3	2%
Sex with Drug User	32	31%
Sexual Assault	2	2%
Transfusion	5	4%
Health Care Worker	1	1%
Unknown	10	9%
Other: Prostitution	1	1%
TOTAL	**>104**	**100%**

Age Ranges of OOC Survey Participants

The greatest proportion of the 'Out of Care' respondents (N=68 or 67%) reported ages in the 35-54 range, reflective of the aging population of PLWH/A in the EMA.

Table 13. Age of OOC Respondents

Age Range	#	%
0-13		0%
13-24	3	3%
25-34	14	13%
35-44	32	31%
45-54	36	35%
55-64	18	17%
65-74	1	1%
TOTAL	**104**	**100%**

Race/Ethnicity of OOC Survey Participants

Over half of all the OOC survey respondents reported their ethnicity as African American (54%), followed by 25%White; 15% Hispanic; 2% Native Hawaiian, and 2% Multiracial.

Table 14. Race/Ethnicity of OOC Respondents

Race/Ethnic Group	#	%
American Indian/AN		0%
Asian		0%
Black or African American	54	52%
Hispanic of Latino/Latina	16	15%
Native Hawaiian/PI	2	2%
White	28	26%
Multiracial	2	2%
Other=Jewish Latino	2	2%
Total	**104**	**100%**

Primary Language of OOC Respondents

Nine percent (9%) of the OOC respondents speak Spanish as their primary language, and the remaining majority of OOC respondents identify English as their first language.

Table 15. Primary Language

Primary Language	#	%
English	96	91%
Spanish	8	9%
TOTAL	**104**	**100%**

Relationship Status of OOC Respondents

The majority of the OOC respondents report currently being single—never married (54%); followed by 13% who report being separated and 15% reporting divorce. Five percent (5%) report being legally married and another 7% report being partnered.

Table 16. Relationship Status of OOC Respondents

Relationship Status	#	%
Single-Never Married	55	54%
Legally Married	6	5%
Common Law	2	2%
Partnered	8	7%
Separated	14	13%
Divorced	16	15%
Widowed or partner passed away	2	2%
Other=engaged	1	1%
Total	**104**	**100%**

Current and/or Previous Homelessness

An extremely high proportion of the 2008 Out of Care survey respondent group (54%) reports current or previous homelessness, obviously acting as a major variable contributing to the high level of unmet need.

Half of the OOC respondents reports homelessness in the past two years or longer. Only 4% report current homelessness, either living on the street or in a homeless shelter.

Table 17. Extent of Homelessness

Homeless Status	#	%
Never	48	46%
Currently homeless (on the street, in car)	1	1%
Currently homeless (homeless shelter)	3	3%
Been homeless in past 2 yrs, not now	6	5%
Been homeless longer than past 2 yrs, not now	46	45%
Total	**104**	**100%**

Current Residence of OOC Respondents

Almost half (or 48%) of those OOC PLWH/A who denied current homelessness report residing in their own apartment or house. However, over 26% report currently "temporarily housed", living with friends or relatives. Twelve respondents report current residence in jail/prison, but the majority report previous homelessness/precarious housing prior to their incarceration.

Table 18. Current Living Situation

Residence	Live Now	
	#	%
In apartment/house I own/rent	50	48%
At my parent's/relative's house	14	13%
Someone else's apartment/house	14	13%
In a rooming or boarding house	1	1%
In a supportive living facility	1	1%
In a group home or residence	2	2%
In a halfway house, transitional housing or treatment facility	4	4%
Skilled nursing home	1	1%
Living in men's shelter	3	3%
Jail or correctional facility	12	11%
Other housing provided by city or state	2	2%
TOTAL	**104**	**100%**

Education Level

Overall, this sample of OOC respondents evidences a fairly wide range in educational backgrounds, with almost 1/3 reporting 'some high school' or grade school or less (31%). An additional 20% report graduating from high school; 32% report some college coursework; and 12% report a college degree. Four percent (4%) reports graduate level coursework, and 2% reports a graduate school degree.

Table 19. Educational Background

Education	#	%
Grade school	1	1%
Some high school	30	30%
High school degree / GED	21	20%
Some college	33	32%
College degree	12	12%
Some graduate school	4	4%
Graduate school degree	2	2%
Total	**104**	**100%**

Employment Status

The vast majority of the OOC respondents report current work eligibility, with only two respondents reporting a lack of U.S. citizenship and one PNTA. However, only one quarter (25%) of the OOC respondents report current employment. (See Tables 82 & 83 below)

Table 20. Work Eligible/Citizenship

Yes	%	No	%	PNTA	%
101	98%	2	1%	1	<1%
104	**100%**				

Table 21. Current Employment

Yes	%	No	%	Don't Know	%
24	23%	80	77%	1	<1%
104	**100%**				

Time Span since HIV/AIDS Diagnosis-Year of Diagnosis

The OOC respondents reported their year of HIV diagnosis ranging from 1986 to 2007, with 67% reporting diagnosis since the advent of combination therapy, evidencing a relatively recently diagnosed group of survey participants, overall.

Table 22. Length of Time since HIV and/or AIDS Diagnosis

	HIV		AIDS		TOTAL	
Year	#	%	#	%	#	%
1986	2	2%		0%	2	2%
1987	5	5%	2	2%	7	6%
1988	7	6%	3	3%	10	9%
1990	3	3%	2	2%	5	5%
1991	2	2%		0%	2	2%
1992	5	5%	2	2%	7	6%
1993	4	4%	1	1%	5	5%
1995	7	6%	3	3%	10	9%
1996	5	5%	2	2%	7	6%
1997	3	3%		0%	3	3%
1998	10	9%	5	5%	15	14%
1999	6	6%	1	1%	7	6%
2000	6	6%	2	2%	8	7%
2001	4	4%	1	1%	5	5%
2002	6	6%		0%	6	5%
2003	4	4%		0%	4	4%
2004	2	2%	1	1%	3	3%
2005	9	8%	3	3%	12	11%
2006	3	3%		0%	3	3%
2007	12	11%	3	3%	15	14%
unknown	1	1%	1	1%	2	2%
Grand Total	**104**	**100%**	**32**	**100%**	**>104**	**100%**

State of First HIV/AIDS Diagnosis

Unlike the 'In Care' survey respondents who report a wide variation in first diagnosis locations, the vast majority of the OOC respondents report receiving their first HIV diagnosis in the Nassau-Suffolk EMA, or in the state of New York. Only twelve respondents report receipt of their first diagnosis outside of New York.

Table 23. State of First HIV Diagnosis

Where Learned HIV Positive:		Status at Diagnosis			
		HIV		AIDS	
City	State	#	%	#	%
Upstate Prison	NY	2	2%	2	6
Beaver Hill	NY	8	8%	2	6
Brentwood	NY	4	4%		0%
Mastic	NY	3	3%	2	6%
Hackensack	NJ	6	6%	2	6%
Bellport	NY	4	4%		0%
Patchogue	NY	3	3%	2	6%
Ithaca	NY	1	1%		0%
East Meadow	NY	12	12%	5	15%
Brooklyn	NY	6	6%	3	9%
New York City	NY	6	6%		0%
Albany	NY	3	3%		0%
Wyandanch	NY	2	2%		0%
Fire Island	NY	2	2%	2	6%
Sag Harbor	NY	4	4%		0%
Hempstead	NY	8	8%	3	6%
Coram	NY	3	3%		0%
Long Beach	NY	4	4%	2	6%
North Babylon	NY	1	1%		0%
Central Islip	NY	2	2%	2	6%
West Islip	NY	2	2%		0%
Bronx	NY	7	7%	2	6%
Stonybrook	NY	5	5%	2	2%
Stamford	CN	2	2%		
Palm Beach	FL	1	1%		
Dallas	TX	1	1%	1	1%
Houston	TX	1	1%		0%
Seattle	WA	1	1%		0%
Total		**104**	**100%**	**32**	**100%**

Reason for Testing

Less than 1/3 (or 27%) of the OOC respondents report receiving an HIV test upon a voluntary request of their health care provider; and additional 13% were tested as a result of an 'outreach' testing encounter. However, 33% first learned their HIV status as a result of an ER/hospital visit for some other reason, and 17% report being tested as part of a routine health examination. Ten women report learning their HIV status as part of routine prenatal care. Ten others first learned their HIV status upon entry into a drug rehab program or prison setting.

Table 24. Mode of Discovery

Discovery Method	#	%
Received testing when asked a health provider to test you for HIV	28	27%
Tested as part of an outreach clinic or street outreach program that offered HIV testing	14	13%
Tested when went to hospital/ER for something else	34	33%
Tested as part of a routine physical exam	18	17%
Tested as part of routine care while pregnant (for women)	10	9%
Other (specify): (2) prison, by mail after routine exam (1); entering rehab program at VA (1); at drug rehab program(1)	10	9%
Total	**>104**	**100%**

Extent of Referral into Care upon Diagnosis

Twenty two percent (22%) of the OOC respondents report NOT receiving any kind of referral upon HIV diagnosis (albeit a substantial minority were diagnosed in mid-to-late '80's and early 90's). *The majority of OOC respondents report the receipt of a direct referral into HIV medical care upon diagnosis (66%). Several respondents report the receipt of more than one referral upon diagnosis: an additional 22% report receiving a referral for non-HIV related medical treatment; 20% report substance abuse treatment referrals; and 24% report mental health counseling referrals.* Almost half of the OOC respondents report a concurrent referral into case management services.

Table 25. Extent of Referral

Referred Services	Total	
	#	%
I was not referred for any services	24	22%
Medical care related to the HIV diagnosis	68	66%
Medical care for a condition other than HIV	24	22%
Substance abuse counseling/treatment	22	20%
Mental health services (other than substance abuse counseling)	26	24%
Case Management services	50	48%
Don't know or Don't remember	4	4%
Other: Went to jail	4	4%
TOTAL	**>104**	**100%**

Length of Time between Initial Diagnosis and Entry into HIV Medical Care

Over half (54%) of the 2008 OOC survey respondents report initially entering HIV primary medical care within the three month recommended time frame. An additional 8% entered HIV care within 6 months of diagnosis. ***However, 36% delayed care entry for longer than one year, and 4% never entered care.***

Table 26. Initial Delay into HIV Medical Care

Time to receive medical care	Total	
	#	%
Within 3 months	54	54%
Within 6 months	8	8%

Within a year	2	2%
Longer than 1 year	36	36%
I have not gotten medical care for HIV	4	4%
TOTAL	104	100%

Reason for Initial Delay into HIV Medical Care of Greater than One Year

The top ranking reasons offered by the Out of Care respondents who delayed entry into primary medical care, in rank order include: 1*) "Couldn't afford it"; 2) "Couldn't get transportation; 3) "Didn't need medical care"; tied with 3) "Didn't know where to go to get medical care".* ***"****Other" reasons cited by this OOC sample for their initial delay between diagnosis and entry into HIV medical care of more than one year's time included:* "Shock, denial" (9)**;** "Scared, fear" (2); Was homeless & wanted to die"; "No insurance- was on mom's insurance & dropped at certain age--Hard to get insurance after that"; "I was in prison for 7 years and had moved to new area"; "Very private about status- will see attention when I need it"; "Recently diagnosed- new to care"; "Was in rehab at VA (no one on staff who treated HIV+) in Brooklyn, entered care once moved to Northport VA"; "Disbelief- felt healthy"; and "Was prostituting and using drugs".

Table 27. Reasons for Delay of Care Greater than One Year

Reasons for delay > 1 year of medical care	Total	
	#	%
Couldn't afford it	8	20%
Didn't need medical care	6	17%
Couldn't get transportation	7	18%
Don't know where to go to get medical care	6	17%
Other	15	28%
TOTAL	**42**	**100%**

Most Recent Primary Medical Care Visit, Laboratory Monitoring & Antiretroviral Therapy

The majority of the OOC respondents have just recently re-connected with care, after having been 'out of care' for varying lengths of time, with 63% reporting some form of primary medical care in the previous three months. Nine percent (9%) report their most recent care within the past 4-6 months; 20% report last care 7-12 months ago; and 3% report last medical care over one year ago. Four respondents have yet to enter care. A large number and percent of respondents have not received medical care or lab tests for more than 6-12 months. Among those "Out of Care" or on reporting "Brink of Care", medications are the last service to drop (i.e. they report taking meds even if not accessing doctor/lab visits in months). *(See Tables 28, 29, 30 & 31 below)*

Table 28. Most Recent Physician Visit

Most Recent Medical Care		
Months ago	**#**	**%**
Never received care	4	4%
Within last 3 months	65	63%
4-6 months ago	10	9%
7-12 months ago	22	21%
Over 12 months ago	3	3%
Total	**104**	**100%**

Table 29. Most Recent ART

Most Recent Medications		
Months ago	**#**	**%**
Never taken HIV meds	20	20%
Within last 3 months	32	31%
4-6 months ago	6	5%
7-12 months ago	18	17%
Over 12 months ago	28	27%
Total	**104**	**100%**

Table 30. Most Recent Lab Monitoring

Most Recent Lab Work		
Months ago	#	%
Never had lab work	4	4%
Within last 3 months	34	24%
4-6 months ago	15	15%
7-12 months ago	18	18%
Over 12 months ago	28	28%
Other	2	2%
Don't know / remember	3	3%
Total	**104**	**100%**

Table 31. Reasons for Lack of Care in Past Six Months

Reasons for delay > 6 months of medical care	**#**	**%**
Not applicable, I received medical care within the past 6 months	42	36%
I do not think that I need medical care now because I am not sick	15	13%
I do not think that medical care would do me any good	4	3%
I have not found a doctor or nurse who I wanted to treat me	6	5%
I lack transportation to get to medical care appointments	12	8%
I lack child care for when I go to medical care	2	0%
I do not know where to go for medical care	8	0%
I do not want to receive medical care	4	5%
I use alternative treatments	1	0%
I cannot afford medical care now	7	5%
I get anxious about going to a doctor or nurse about HIV	3	3%
Other:	9	23%
TOTAL	**>104**	**100%**

'Other' reasons the OOC respondents offer for their lack of primary medical care over the past six months include: "have not had time to fit appointments into busy schedule"; feel healthy, don't see need to go through all of the hassle"; "can't qualify for or reactivate assistance I was receiving"; "travel frequently, very private about status"; "newly diagnosed, scared, trying to figure out system"; "new to area, still getting aid & assistance set-up"; "substance abuse- was sober + relapsed"; "used to go to NUMC, but moved to Suffolk County--Can't get ride to county line to NUMC, bad experience with Stonybrook so far is discouraging"; "case worker at LIACC didn't renew my Medicare/Medicaid and it has caused huge problems"; and "Trying to figure out how to access ADAP".

Reasons Why PLWH/A Don't Get Medical Care for Their HIV

The top reasons offered by this sample of OOC respondents to explain why PLWH/A do not enter or remain in HIV primary medical care include: 'Privacy/Confidentiality concerns'; 'Fears about telling others'; 'Actively using substances';' Can't get transportation'; 'Feel healthy'; 'Don't want to take meds'; 'Can't afford it'; and 'Communication difficulties/cultural differences'.

Additional PLWH/A comments included: "No organized effort to reach out to affected and isolated communities". "Health care should be made accessible and non-discriminatory."; "Different than NYC- there you assume everyone is HIV+, reverse on Long Island".

Table 32. Reasons Why PLWH/A Don't Get Care

Reasons	#	%
Worried that other people will find out/Privacy	37	36%
Fear of telling someone else	34	33%
Feel healthy	23	22%
Can't afford it	17	16%
Don't have transportation	24	23%
Couldn't get an appointment	10	9%
Actively Using Substances	30	29%
Don't want to take HIV medications	18	17%
Material/ instructions are confusing	11	10%
Communication difficulties	17	16%
Cultural issues	15	14%
Total	**>104**	**100%**

Motivators to Return to Primary Care if Out of Care for a Period of Greater than 6 months Most Recently

The top three ranking motivators which might encourage those PLWH/A who have been absent from care for a period of six months or greater include: 'Transportation'; 'Free medical care'; and 'Health insurance'. The next most frequently offered motivators/facilitators include: 'Employment opportunities'; 'More information about services and referrals or advice', and 'Better quality of services'. Finally, 'Substance abuse treatment services' and 'More outreach services', along with 'more government services' are viewed as helpful to those re-engaging with primary medical care.

Table 33. Motivators to Return to Care

Motivators	#	%
Transportation	15	15%
Acute illness	6	6%
Free medical care	12	12%
Insurance	12	12%
Better quality of services	7	7%
Referrals or advice	8	8%
More information about services	8	8%
Better trained doctors and nurses	4	4%

Employment opportunities	9	9%
Substance abuse treatment	5	5%
More outreach services	4	4%
More government services	3	3%
Nothing	11	11%
Total	**104**	**100%**

History of STIs/Communicable Diseases

There is an extremely high level of communicable disease co-morbidity reported by the OOC respondents. Thirty one percent (31%) report a history of Gonorrhea and (29%) report a history of Chlamydia; 47% report previous yeast infections. Another 38 respondents (or 37%) report a history of hepatitis (primarily Hepatitis C, correlated to IDU), and 17% report Genital herpes; while 15% report genital warts. Thirteen percent report a history of syphilis and 11% report treatment for TB or exposure to TB.

Table 34. Co-Morbidity with STDs

History of STDs	Total	
	#	%
Chlamydia	30	29%
Genital warts	16	15%
Gonorrhea	32	31%
Hepatitis (ABC)	38	37%
Genital herpes	18	17%
Syphilis	14	13%
Yeast infections (+ thrush)	48	47%
Tuberculosis	12	11%
Other:Trich	1	1%
TOTAL	**>104**	**100%**

Diagnosis with Other Diseases

A substantial proportion of the OOC respondents reports diagnosis and/or treatment for diseases other than HIV disease. The most frequently cited chronic diseases reported by this OOC sample include lung problems (59%); emotional problems (57%), neuropathy (41%); problems with thought or memory (39%); high blood pressure (37%); high cholesterol (25%); heart problems (19%): Diabetes (15%); TB (11%); and cancer (11%).

Table 35. Other Chronic Disease

Chronic Disease	#	%
Cancer	12	11%
Diabetes	16	15%
Heart Problems	20	19%
High Blood Pressure	38	37%
Tuberculosis	12	11%
High Cholesterol	26	25%
Kidney Problems	8	8%
Liver Problems	36	35%
Lung/Breathing Problems	60	59%

Neuropathy	42	41%
PCP Pneumonia	36	35%
Problems with Thought or Memory	40	39%
Emotional Problems	58	57%
	>104	**100%**

Currently Prescribed non-ART Medications

The majority of the OOC respondents (68%) reports taking other medications, which include thyroid medication, seizure medication, medication for neuropathy, anxiety meds, sleeping meds, medications for diabetes, cholesterol and pain management; bone strengthener, anti-depressants, ointment for chronic eczema, Tylenol, meds for shingles, asthma pump; arthritis meds, post-brain surgery medications, allergy meds, high blood pressure meds and 'water' pills, oxycontin; hormone replacement therapy, meds for back spasms, vitamins, meds for severe depression and bipolar rage; Vicodin, Paxil, Advil, Hepatitis C meds, and sinus medication.

Table 36. Non-ART Medication

Yes	%	No	%	Don't Know	%
70	68%	34	32%		0%
104	**100%**				

Substance Use

Substance use and abuse acts as a serious deterrent to both entry into and retention in HIV primary medical care among the Nassau-Suffolk EMA 'Out of Care' survey respondents. 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.

Table 37. Substance Abuse

Yes	%	No	%
62	60%	42	40%
104	**100%**		
Substance Use Frequency			
Substance	**Daily**	**Weekly**	**Monthly**
Alcohol	8	18	12
Cocaine		2	4
Crack	4	6	2
Crystal Meth		2	2
Heroin			
Marijuana or hash	6	18	2
Speedball		2	2
Ecstasy			
Tobacco	48	6	4
Other			
Total	**64**	**54**	**28**

The substances/drugs most frequently reported by the OOC respondents as regularly used include: alcohol, marijuana, crack and crystal methamphetamine.

Historical and Current IV Drug Use

As evidenced below, twenty eight respondents (26%) admit to previous injection drug use and two of the OOC respondents reported current injection use.

Table 38. History of IDU

Yes	%	No	%
28	26%	76	74%
104	**100%**		

Table 39. Current IDU

Yes	%	No	%
2	1%	102	99%
104	**100%**		

Frequency of Sharing Needles or Works

As evidenced by Table 40 below, one of the OOC survey respondents who reports active injection drug use reports he/she "always shares" needles/works and one OOC respondent who reports current IDU reports "sometimes shares needles/works".

Table 40. Frequency of Sharing

Frequency	#	%
Not applicable, I am not currently injecting	102	98%
All the time	1	1%
Usually, but not always	0	0%
Sometimes	1	1%
Never	0	0%
	104	**100%**

Degree of Cleaning Works when Sharing

One OOC IDU always cleans his works and one OOC IDU sometimes cleans his works before sharing.

Table 41. Frequency of Cleaning before Sharing

Frequency	#	%
Not applicable, I am not currently injecting	102	98%
All the time	1	1%
Usually, but not always		0%
Sometimes	1	1%
Never		0%
	104	**100%**

4. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities

A service Need ranking, Use ranking, Gap ranking (services needed but perceived as unavailable) and Barrier ranking (services needed but 'hard to get') was developed for ALL Out of Care respondents. (1 is highest ranking)

Service Needs, Uses, Gaps, and Barriers

NEED	Sum of 'Out of Care' client survey respondents who stated "I currently need this service."
USE	Sum of 'Out of Care' client survey respondents who indicated service use in the past year
GAP	Sum of 'Out of Care' client survey respondents who answered 'Yes' to Need and 'No' to availability of that service
BARRIER	Sum of 'In Care' client survey respondents who indicated that a service is 'Hard to Get'

Top Ranking NEEDS of ALL OOC Respondents

Table 42. Top Ranking OOC NEEDS

Service Category Description	Need Rank
Housing services	**1**
Medical Transportation	**2**
Food Bank	**3**
Primary Medical Care	**4**
Medications	**5**
Medical Case Management	**5**
Financial Assistance	**7**
Social Support	**8**
Group Support	**8**
Mental Health services	**10**
Employment/Job skills training	**10**
Clothing/Furniture	**12**
Finding Information & Help	**13**
Health Insurance	**14**

Top Ranking Services USED to Stay in Care

Table 43. Top Ranking OOC USES

Service Category Description	USE Rank
Primary Medical Care	**1**
Medical Case Management	**2**
Oral Health services	**3**
Food Bank	**4**

Mental Health services	**5**
Transportation	**6**
Housing services	**7**
Health Insurance	**8**
Medications	**9**
Group Support	**10**
Substance Abuse treatment	**11**
Social Support	**12**
Financial Assistance	**13**
Legal services	**14**
Vision care	**15**

Top Services that are "Hard to Get" (BARRIERS)

Table 44. Top Ranking OOC Service BARRIERS and Reasons for BARRIERS

Service Category Description	BARRIER Rank	BARRIER REASONS
Medical Transportation	**1 tie**	Unreliable services, ordeal to schedule; "Case Managers can no longer help out with transport to appointments or store"; 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.; transportation ends too early
Housing services	**1 tie**	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; need affordable, clean, safe independent living options; need assistance for working PLWH/A; often difficult process to document "homelessness"; "I used a "working shelter" which provided job + living assistance- don't know where to find those on Long Island"; rely upon CDC Centereach (Community Development Corp.); "I was recently homeless and Homeworks helped out!"
Food Bank	**3 tie**	"EAC Food Pantry is very helpful"; need food ideas for special diets (ex = diabetic); "I see other people getting food vouchers at the doctor's office, but not me!?..."; 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
Health Insurance	**3 tie**	"Red tape, too many questions, denied when they find out you're HIV+"; little to no assistance 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
Financial Assistance	**5**	Especially need emergency assistance; 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; need for credit resolutions / forbearance; food stamps don't stretch; extreme expressed need for rent assistance

Employment/Job skills training	**6 tie**	Need health coverage for part-time employees; need list or ideas for part-time, suitable employment options for PLWH/A to work without losing benefits; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job; afraid I will lose assistance if I begin working again"
Medical Case Management	**6 tie**	Expressed need for caring, quality case management; cases closing as clients gain independence (some clients proud "I can be independent", others scared "how do I fill out the paperwork with 4th grade math skills?"); "my case manager saved me by helping to fight for assistance during my bout with cancer"; high turnover and inexperience / lack of compassion are common; heavy reliance on case managers for information and regiment management (appointments, coordination of care); cases reportedly 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; clients dropped + marked "non-compliant" even if missed meeting due to transport lapse or health issues (memory, emergencies)
Group Support	**8**	Lack of groups for women or women with children; 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)
Finding Help and Information	**9 tie**	Need better info for newly diagnosed; often receive run-around while obtaining services; need list of doctors taking ADAP or offering alternative medical services; need better information regarding system of care and services available; need less complicated funding system
Medications	**9 tie**	Bottles (privacy); "I need to know there will be assistance with paying for meds once off public assistance"; need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, migraines, high blood pressure, heart problems); Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "I was using online delivery pharmacy (momspharmacy.com) but got a letter in the mail saying something about ADAP/Medicaid...confusing + discouraging "
Primary Medical Care	**9 tie**	Need better coordination of care- both on Long Island but for people moving here or away; "I'd prefer more confidential or universal care centers, where everyone is treated + you aren't labeled by what floor you go to or what trailer you enter"; 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; accessibility is major issue
Mental Health services	**12**	Hard to get appointments (waiting list); drug problems = personal barrier; "many people need mental health support but are not aware of availability or its benefits"
Education/Information	**13**	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, prevention & testing

Top Ranking OOC Service Gaps and Reasons for Gaps

Table 45. Top Ranking OOC Service GAPS and Reasons for GAPS

Service Category Description	GAP Rank	GAP REASONS
Medical Transportation	1	Medical transportation service is unreliable; limited # and range of rides- monthly 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 prefer NUMC for my primary care, but can't get a ride there since I've moved. I don't like the care I receive at Stonybrook but have no other option"

Health Insurance	2	"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 know someone who waited 4 years for SSI + Medicaid"; "I had to relocate to work the system"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; gap in transitional care ("I moved from Seattle where everything was fine + now on Long Island I don't qualify for any kind of assistance. Doesn't make sense...")
Housing services	3	"I don't qualify for asst because of my immigration status"; 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"; available housing tends to be in dangerous areas; no assistance for moving- "my partner + I would be homeless w/out kindness of friends. It was major ordeal just to move across the courtyard"; not many options for Sr Citizens- "I'll be forced into senior citizens residences at a certain age, but I take care of my family and grandkids- that's not a good environment for me or them"
Medical Case Management	4	It seems like some agencies are more concerned with making money and creating paperwork than helping clients"; need better coordinated "mobile case management" (ex = for people who move or travel for work- care is always somehow linked to them + available); 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"
Mental Health services	5	Clients express isolation, hopelessness, severe depression and fear of losing the few things they have (medications, housing, food); still stigma attached with care
Food Bank	6	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; "I'm not eligible for food stamps/no one can tell me why"
Financial Assistance	7	Gaps in assistance for basic or emergency needs; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give food vouchers to "good clients" who are dependent upon them"); public assistance barely covering basic needs; Thursday's Child was organization helping with emergency financial needs but struggling with funding; "there seems to be plenty of wealth + development on Long Island but little assistance for the dis-privileged"
Medications	8 tie	No transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication ("Medicaid spend-down means I sometimes go without my meds"; many medications not covered (such as migraine medication); "I've been inconsistent with meds- sometimes I hoard them out of fear the government will cut funding"
Primary Medical Care	8 tie	ned medical system- maybe require a program like Americorps or ve to work with disprivileged"; "patients are treated like lab rats"; need eds (ex = orthopedic); "Many people are living with HIV but not going to ach to people who are scared or on the down-low"; high turnover in taff not compassionate (especially in early days of epidemic); ed # per month, limited range (ex = won't cross Nassau/Suffolk county y appointments; need more after-hour availability for those who hours
Employment/Job skills training	10 tie	Need ideas for disabled (VESID is potential program for the disabled to learn skills + job training)"would like skills training and job, but afraid I will lose assistance if I begin working again"; "I applied for a home health aid job @ Board of Health. I'm qualified by was denied for no reason…can't help think it has something to do with HIV status"
Legal services	10 tie	"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"; many in need of legal assistance by unaware of availability (ex = client using television attorneys (Bender + Bender) to fight for health assistance

Group Support	12	Need "stop smoking" programs; need programs addressing isolation of disease (isolation = sickness); 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"; "my transport ends at 7pm and most groups meet later than that"
Immigration Protection and Assistance	13	Many not eligible for services due to immigration / documentation status

The Service Gaps listed by the 'Out of Care' population (services needed but perceived as unavailable) include a heavy mix of 'supportive' services and core medical services. A lack of transportation to access certain services (i.e. Primary care, Pharmacy, Food Banks, etc), lack of knowledge about how to access some services (i.e. confusing Medicaid spend-down to get meds) and the lack of funding (i.e. food stamps and vouchers perceived as unavailable), and wait lists or inconvenient hours are cited by OOC respondents as reasons impeding access to care and services.

The Barriers cited by this OOC survey sample are almost identical with their identified service Gaps, except that the rankings are slightly different, and some additional reasons were offered to explain the perceived difficulty is accessing these services, including lengthy eligibility screening process. Addressing the 'Unmet Need' is the most important aspect of the Unmet Need Framework and process.

Different strategies will be necessary for different sub-groups of PLWH/A. For example, different strategies will be necessary for the Newly diagnosed, for PLWH/A receiving medical and supportive services other than primary HIV medical care, for those PLWH/A who have either 'erratically' been in care or who have dropped out of care, and for those PLWH/A who have NEVER been in care. The chosen intervention strategies must effectively close the identified Gaps and overcome the perceived Barriers in needed services and may require some changes to the existing continuum of care in the Nassau-Suffolk EMA.

Chapter 3: Recommendations for Comprehensive Strategic Plan

Special Strategies Directed to Reducing Unmet Need in the EMA

For newly diagnosed PLWH/A, the testing/linkages to care appear strong in the EMA, based on these R.A.R.E. study findings. Most PLWH/A respondents report active referrals into HIV primary medical care within three months of diagnosis. However, it is also evident that many PLWH/A enter care only to drop out later and a substantial minority never attach or do so at a point much later in their disease process, when acute illness or symptoms become too difficult to ignore.

1) Address 'Out of Care' PLWH/A Service BARRIERS and GAPS inclusive of:

TABLE 46: Out of Care Service Barriers and Barrier Reasons

Service Category Description	BARRIER Rank	BARRIER REASONS
Medical Transportation	1 tie	Unreliable services, ordeal to schedule; "Case Managers can no longer help out with transpo to appointments or store"; 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 across county line"; no transportation available other than bus in some Eastern parts of Suffolk Co.; transportation ends too early
Housing services	1 tie	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; need affordable, clean, safe independent living options; need assistance for working PLWH/A; often difficult to document "homelessness"; "I used a "working shelter" (job + living assistance)- don't know where to find those on Long Island"; "I was recently homeless and Homeworks helped out!"
Food Bank	3 tie	"EAC Food Pantry is very helpful"; need food ideas for special diets (ex = diabetic); "I see other people getting food vouchers at the doctor's office, but not me!?..."; 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
Health Insurance	3 tie	"Red tape, too many questions, denied when they find out you're HIV+"; little to no assistance 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
Financial Assistance	5	Especially need emergency assistance; rent takes up most assistance, leaving little funds for groceries, 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; expressed need for credit resolutions / forbearance; food stamps don't stretch; extreme need for rent assistance
Employment/Job skills training	6 tie	Need health coverage for part-time employees; need list or ideas for part-time, suitable employment options for PLWH/A to remain active + work without losing benefits; "need more services geared towards making clients independent"; "would like skills training and job, but afraid I will lose assistance if I begin working again"
Medical Case Management	6 tie	Expressed need for caring, quality case management; cases closing as clients gain independence; high turnover and inexperience / lack of compassion are common; heavy reliance on CM for information and

		regiment management (appointments, coordination of care); cases reportedly 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; clients dropped + marked "non-compliant" even if missed due to transport lapse or health issues (memory, emergencies)
Group Support	8	Lack of groups for women or women with children; 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)
Finding Help and Information	9	Need better info for newly diagnosed; often receive run-around while obtaining services; need list of doctors taking ADAP or offering alternative medical services; need better information regarding system of care and services available; need less complicated medical-funding system
Medications	10 tie	Bottles (privacy); "I need to know there will be assistance with paying for meds once off public assistance"; need new, more tolerable & affordable meds; can't afford co-pays (esp. for non-HIV/AIDS meds treating depression, migraines, high blood pressure, heart problems); Medicaid spend-down confusing; no coverage for alternative medications; no transportation to pharmacy; "I was using online delivery pharmacy (momspharmacy.com) but got a letter in the mail saying something about ADAP/Medicaid...confusing + discouraging "
Primary Medical Care	10 tie	Need better coordination of care- both on Long Island but for people moving here or away; "I'd prefer more confidential or universal care centers, where everyone is treated + you aren't labeled by what floor you go to or what trailer you enter"; 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; accessibility is major issue
Mental Health services	12	Hard to get appointments (waiting list); drug problems = personal barrier; "many people need mental health support but are not aware of availability or its benefits"
Education/Information	13	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

TABLE 47: Out of Care Service Gaps and Gap Reasons

Service Category Description	GAP Rank	GAP REASONS
Medical Transportation	1	Medical transportation service is unreliable; 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; "I prefer NUMC for my primary care, but can't get a ride there since I've moved. I don't like the care I receive at Stonybrook but have no other option"
Health Insurance	2	"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 know someone who waited 4 years for SSI + Medicaid"; "I had to relocate to work the system"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; gap in transitional care ("I moved from Seattle where everything was fine + now on Long Island I don't qualify for any kind of assistance. Doesn't make sense...")
Housing	3	"I don't qualify for asst because of my immigration status"; 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

services		for trying to be independent"; available housing tends to be in dangerous areas; no assistance for moving- "my partner + I would be homeless w/out kindness of friends. It was major ordeal just to move across the courtyard"; not many options for Sr Citizens- "I'll be forced into senior citizens residences at a certain age, but I take care of my family and grandkids- that's not a good environment for me or them"
Medical Case Management	4	It seems like some agencies are more concerned with making money and creating paperwork than helping clients"; need better coordinated "mobile case management" (ex = for people who move or travel for work- care is always somehow linked to them + available); 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"
Mental Health services	5	Clients express isolation, hopelessness, severe depression and fear of losing the few things they have (medications, housing, food); still stigma attached with care
Food Bank	6	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; "I'm not eligible for food stamps and no one can tell me why"
Financial Assistance	7	Gaps in assistance for basic or emergency needs; little to no assistance available for "working poor"; Long Island agencies restricting services for "selective users" ("they would only give food vouchers to "good clients" who are dependent upon them"); public assistance barely covering basic needs; Thursday's Child was organization helping with emergency financial needs but struggling with funding; "there seems to be plenty of wealth + development on Long Island but little assistance for the dis-privileged"
Medications	8 tie	No transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication ("Medicaid spend-down means I sometimes go without my meds"; many medications not covered (such as migraine medication); "I've been inconsistent with meds- sometimes I hoard them out of fear the government will cut funding"
Primary Medical Care	8 tie	Need coverage for relate medical needs (ex = orthopedic); "Many ot going to the doctor HIV. We need outreach to people who are gh turnover in staff It is discouraging; some staff not compassionate demic); transportation is an issue (limited # per month, limited range lk county lines); hard to obtain emergency appointments; need more who hours care for people who work.
Employment/Job skills training	10 tie	Need ideas for disabled (VESID is potential program for the disabled to learn skills + job training)"would like skills training and job, but afraid I will lose assistance if I begin working again"; "I applied for a home health aid job @ Board of Health. I'm qualified by was denied for no reason…can't help think it has something to do with HIV status"
Legal services	10 tie	"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"; many in need of legal assistance by unaware of availability (ex = client using television attorneys (Bender + Bender (?)) to fight for health assistance
Group Support	12	Need "stop smoking" programs; need programs addressing isolation of disease (isolation = sickness); 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"; "my transport ends at 7pm and most groups meet later than that"
Immigration Protection and Assistance	13	Many not eligible for services due to immigration / documentation status

The 2008 Unmet Need Assessment study findings emphasize the importance of the Case Managers' and Providers' roles in ensuring that PLWH/A have the information about available services and are linked to the necessary housing, food, and transportation, along with mental health and substance abuse counseling services to stabilize their life situation and ensure needed services are extended as necessary to facilitate retention in care.

In order to prevent patients from becoming lost to care, primary care providers should implement the Planning Council's recommendations and make appointment reminder calls; facilitate transportation assistance; and implement/maintain "no-show" tracking and follow-up protocols. At least biannually, 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. Planning bodies and providers must focus on reducing known barriers to care and resolving gaps in continuum of care.

In order to reduce unmet need and bring the 'never in care' into care it is evident that a number of strategies will be necessary, including regular marketing of primary care services' availability and directions on making referrals with all points of entry staff and agencies, combined with social marketing efforts regarding new treatments available and the benefits of care and treatment. *(Adapted from Mosaica TA Information, 2006)*

Summary of OOC Service Needs, Barriers and Gaps

It is concerning that the OOC sample essentially cite as 'hard to get' many of their top ranking service Needs (Housing, Transportation, Food, Employment assistance), The Barriers cited by this OOC survey sample are almost identical with their identified service Gaps, except that the rankings are slightly different, and some additional reasons were offered to explain the perceived difficulty is accessing these services, including lengthy eligibility screening process.

The Service Gaps listed by the Nassau-Suffolk 'Out of Care' population (services needed but perceived as unavailable) include a heavy mix of 'supportive' services and core medical services. A lack of awareness of exact service location, lack of knowledge about how to access some services, and the lack of funding and wait lists are cited by OOC respondents as the primary reasons impeding access to care and services.

Addressing the 'Unmet Need' is the most important aspect of the Unmet Need Framework and process. Different strategies will be necessary for different sub-groups of PLWH/A. The chosen intervention strategies must effectively close the identified Gaps and overcome the perceived Barriers in needed services and may require some changes to the existing continuum of care in the Nassau-Suffolk EMA.

Describe Plans to Find People NOT in Care and Get Them into Care

Ideally, PLWH/A transition from being "unaware of HIV status" to being "fully engaged in care"; however, patients also transition from full or partial engagement to "dropping out of care".

Thus, the continuum is bidirectional, indicating that both initial engagement and ongoing retention require thoughtful consideration and strategic planning. (*AIDS Patient Care and STDs, Vol. 21, Supp. 1, 2007)* Addressing the disengaged, non-retained, and never-in-care PLWH/A (the 'Unmet Need') is the most important aspect of the Unmet Need Framework and process.

The strategies developed and implemented to address Unmet Need should:

- Ensure equitable access to care regardless of OOC population characteristics or location within the service area;
- Effectively help the OOC into care;
- Effectively retain them in care;
- Ensure that supportive services contribute to primary care entry and retention in care. (Mosaica Unmet Need TA Center of the TAC, June 2006 Meeting with Ryan White Part A & B Programs)

Different strategies will be necessary for different sub-groups of PLWH/A. For example, different strategies will be necessary for the Newly diagnosed, for PLWH/A receiving medical and supportive services other than primary HIV medical care, for those PLWH/A who have either 'erratically' been in care or who have dropped out of care, and for those PLWH/A who have NEVER been 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.

Summary

In summary, the persons living with HIV/AIDS in the Nassau-Suffolk EMA who are most likely to be out of care include Heterosexual Males and Females, White MSM and MSM of color, and IDU. Blacks and Hispanics are disproportionately impacted among the OOC populations, when their representation in the local epidemic and proportion in the general population is considered.

The Nassau-Suffolk OOC population includes those who have been erratically in care, those who have dropped out of care and are 'technically' out of care, and those who have never entered primary HIV medical care. *The HRSA SPNS Outreach Initiative (published in AIDS Patient Care and STDs, Vol. 21, Supp.1, 2007) investigated the process of engagement in HIV medical care and their findings reveal that PLWH/A who cycled in and out of care did so for reasons related to their:*
1) Level of acceptance of being diagnosed with HIV;
2) Ability to cope with substance use, mental illness, and stigma;
3) Health care provider relationships;
4) The presence of external support systems; and
5) Ability to overcome practical barriers to care.

A useful framework for examining barriers to care which hinder effective engagement and retention in HIV primary medical care is provided by the Institute of Medicine, which characterizes barriers to health care into three primary categories: structural, financial, and personal/cultural *(Tobias, et al., AIDS Patient Care and STDs, 2007, p. S-4)*

The HRSA SPNS "Outreach Initiative" defined four main barriers to care:

1) Practical/Structural barriers which include six items: a) finding a place for HIV medical care; b) paying for care; c) not having a telephone to make appointments; d) getting someone to answer calls for appointments; e) finding convenient times for appointments; and f) having providers who speak your language.

2) Stigma barriers include: a) fears that people would find out about HIV status; b) worries about people finding out about sexual orientation; c) worries that family members or partners would be upset; d) fears that children would be taken away; e) worries that providers would ask about drug use; f) worries that providers would ask about sexual practices; and g) worries that providers would ask if you were taking HIV medications.

3) Belief barriers include: a) feeling too healthy to seek care; spiritual beliefs; b) believing there is no cure for HIV; c) believing the medications are worse than the disease; d) preferring alternative treatments; e) mistrust of the medical system; believing HIV does not exist; f) making basic needs a higher priority than addressing HIV.

4) Unmet need for support services barriers include: a) unmet needs for mental health counseling and treatment; b) substance abuse counseling/treatment; and c) unmet needs for housing; financial; transportation; food; and benefits/entitlements.

The Nassau-Suffolk EMA OOC respondents cited many of these barriers as reasons why PLWH/A are not in care/delayed entry and/or return into primary medical care. Funding and service cutbacks are perceived to be at least part of the reason(s) for the perceived unavailability of needed services. It will be important to continue to delineate specific continuum of care plans for each of the major Severe Need Groups in the EMA. The chosen intervention strategies must effectively reduce the identified barriers to needed services and may require some additional changes to the existing continuum of care.