

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

Hispanic ‘In Care’ PLWHA Needs Assessment in the Nassau Suffolk EMA

2008 REPORT OF FINDINGS

Prepared by



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IN CARE CLIENT SURVEY INSTRUMENT

2008 “In Care” Hispanic PLWH/A Needs Assessment

Nassau-Suffolk EMA HIV Health Services Planning Council

May 2008

Executive Summary

Overview of Nassau-Suffolk EMA: In the Long Island region, the Eligible Metropolitan Area (EMA) is made up of Nassau and Suffolk Counties. The Nassau-Suffolk region is an island, 100 miles long, an average of 12 miles wide, (287 square miles for Nassau and 911 square miles for Suffolk) with a population of over 2.8 million people. Long Island is the most populous island in the 48 contiguous U.S. states and the most populated of any U.S. state or territory with a population density of 5,470 people per square mile. The eastern end of the EMA splits into two peninsulas, known as the North Fork and the South Fork. The region’s link to the mainland is on its western border, through New York City. The geography of the EMA poses unique problems for delivery of, and access to, services. There is little mass transportation available in either county except the Long Island Railroad, which is primarily designed to serve commuters traveling from the suburbs into New York City. There is one interstate highway, I-495, that goes from New York City to the East End (Eastern Long Island) but does not reach to the end of the EMA. Additionally, there is no north/south mass transportation making it virtually impossible to get from the north side of the island to the south side. Thus, even for persons who do have an automobile, travel within the region is often quite difficult. The general population for both counties is primarily White (Nassau County 79%; Suffolk County 85%); followed by the Hispanic populations (Nassau County 10%; Suffolk County 11%) and African American populations (Nassau County 10%; Suffolk County 7%). Despite areas of affluence throughout this two-county EMA, there remain pockets of poverty and problems traditionally viewed as urban. *The EMA has an estimated 50,000 homeless persons, many substance users, a large immigrant population and, cumulatively, more persons living with AIDS than any other suburban region in the country.*

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

Relevance of the 2008 “In Care” Hispanic 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.

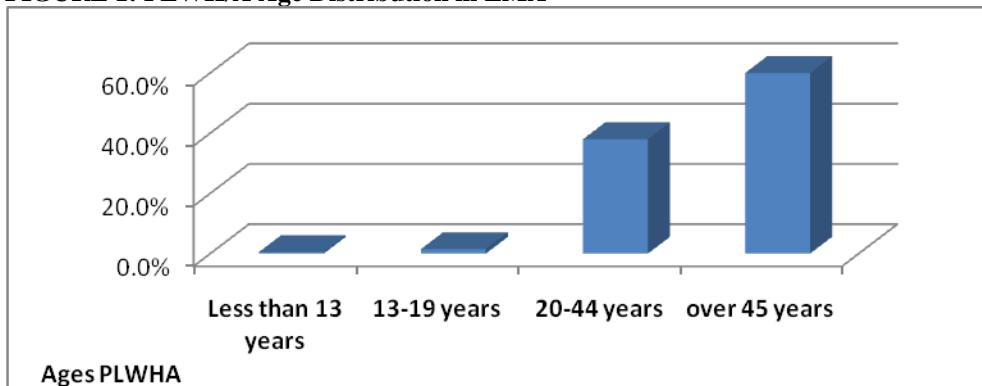
TABLE 3: AGE GROUP DISTRIBUTION (New AIDS and HIV, PLWH/A), 2007

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

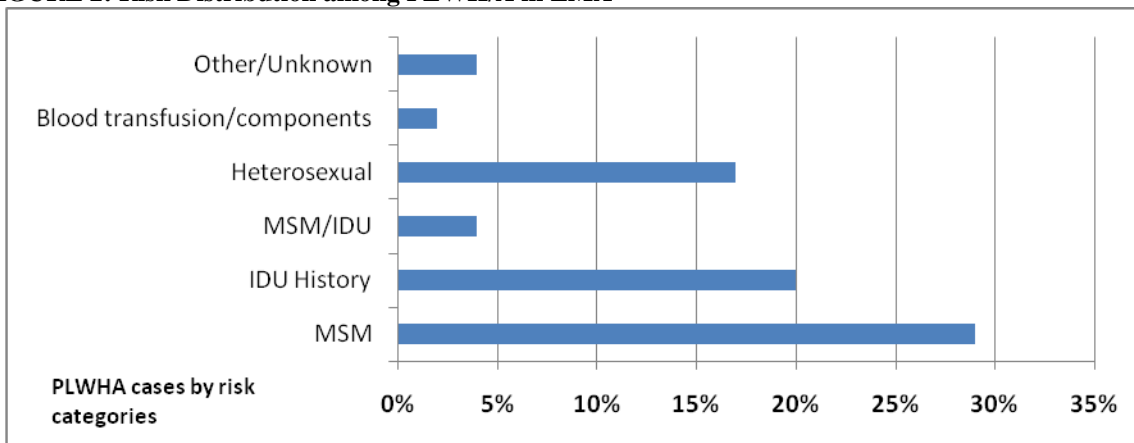
Source: New York State Department of Health, 2007

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 this 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. Based upon their highly disproportionate impact within the EMA, as evidenced in Table 8 below, the ‘In Care’ needs assessment survey process and resulting report highlights the differing needs, uses, and barriers to HIV primary medical care experienced by the severe need groups of ‘In Care’ Hispanic PLWH/A residing within the Nassau- Suffolk EMA.

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

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

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

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

Overview of ‘In Care’ Needs Assessments of Hispanic PLWH/A and their sub-populations in the EMA

The special characteristics of the Severe Needs Group of Hispanic PLWHA and their sub-populations especially targeted for participation in the 2008 ‘In Care’ needs assessment process in the EMA are described below.

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

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

Characteristics of Hispanic PLWH/A in the EMA

The Hispanic population comprises **19% of the total PLWH/A** prevalent cases within the EMA. The Hispanic population is also representative of higher rates of uninsured or under-insured individuals. Hispanics are more likely than any other racial or ethnic group in the U.S. to be uninsured or under-insured and are less likely to use health services when they are available. Barriers to accessing care by the Hispanic population include linguistic issues, gender related issues, and stigma related to the diagnosis. Language barriers can pose significant problems between the consumer and the healthcare provider. Cultural influences related to *fatalismo* (a sense of fatalism), *curanderismo* (use of folk healers to cure illness), and *castigo divino* (divine punishment) may cause the Hispanic client to avoid seeking services from health care providers that practice traditional Western Medicine. *Familismo* (importance of the opinion of family members) plays an important role with the Hispanic client. Individuals may delay or refuse treatment because of the advice given by, or opinion of, a family member. Hispanics who cannot obtain health insurance may stay out of care until it is absolutely necessary, **delaying entry into care**. Hispanics will often use the emergency department settings when seeking care. It is estimated that roughly 30% of Hispanics lack a steady source of health care.

Hispanics present with high rates of cardiovascular disease (males 31.6%; females 34.3%), hypertension, and diabetes. These populations also tend to exhibit risk factors that lead to cardiovascular disorders, including high smoking rates among the males, diets high in fats and sodium, and increased occurrence of obesity. According to the National Minority AIDS Education and Training Center (NMAETC), the Hispanic population is less likely to take medications, even if prescribed. In addition to these complicated cultural/ethnic issues, Hispanics, like African Americans, tend to present late in the course of HIV disease.

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

Characteristics of the Sub-population of IDU PLWH/A in the EMA: Injection drug use accounts for **19% of the PLWH/A prevalent cases** within the EMA. In addition, the risk factor

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

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

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

To further explore the care patterns and care complications for the Hispanic populations, the Nassau-Suffolk HIV Health Services Planning Council conducted the Hispanic 'In Care' Needs Assessments of these special need populations. The study data was used for the 2009 Priority Setting and Resource Allocation process.

Overview of Hispanic 'In Care' Study Findings

- A total of 76 Hispanic 'In Care' survey respondents participated in the 2008 Needs Assessment process.
- The Hispanic respondents represented a younger group of PLWH/A, overall, with the greatest number reporting their age in the 35-44 age range (36 respondents or 48%), as compared to the older African American 'In Care' respondent group.
- By gender, 47% are Male; 51% Female; and one respondent reports Transgender.
- The majority of Hispanic respondents report their sexual orientation as heterosexual; with 18% reporting 'gay' and none reporting bisexual.
- Modes of transmission include a predominance of heterosexual risk (66%); followed by MSM risk behavior (18%).
- 53% report an AIDS diagnosis and 46% report HIV disease only, with many reporting concurrent diagnosis with HIV/AIDS.
- Few of the Hispanic 'In Care' respondents report health insurance benefits (with a substantial number undocumented). Only 18% report Medicaid and 6% report Medicare. 68% report ADAP as their primary source of health benefits.

- The majority of the Hispanic ‘In Care’ respondent group reports employment, despite low education attainment (only 18% finished high school and 66% report some high school or grade school or less), and very low income, overall.
- Only 24% of the Hispanic respondent group reports current or previous homelessness (24%) compared to the 47% reported by the African American respondent group. A much lower proportion of Hispanics (16%) currently receive rental assistance.
- Many Hispanic PLWH/A report diagnosis or treatment for mental disorder (57%), but few report a history of substance abuse (11%)
- Less than 1/3 report STD co-morbidity (30%) and fewer (28%) report living with another chronic illness other than HIV disease.
- The Hispanic ‘In Care’ respondent group evidences a strong ‘In Care’ status overall, with their most recent physician or laboratory monitoring visits occurring, on average, approximately two months ago.

Overview of Hispanic ‘In Care’ Respondents’ Service Needs, Uses, Gaps and Barriers

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

Service Category	Need Rank	Use Rank	Gap Rank	Barrier Rank	Gap Reasons	Barrier Reasons
Medications- e medicina femenino; (medication)	1	4	NR	NR		
Transportation - transporte masculino; means of transportation medio masculino de transporte; public transportation transporte masculino público	2 tie	2	3 tie	1	Because of documentation / immigration status; "I don't know how to request services"; language barriers; lack of funding; "really need a car but seems impossible"; 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; need metro cards + travel vouchers	Need travel vouchers; because of documentation / immigration status; language barrier + lack of funding; unreliable services, ordeal to schedule; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; need help getting a car; no transportation available other than bus in some Eastern parts of Suffolk Co.
Mental Health	2 tie	3	NR	11 tie		"I'm glad I got AIDS- it forced me to get help and get my life back"; many utilize FECS + Hispanic Counseling Center; "many people need mental health support but don't know it"

Primary Medical Care- ustantivo medicina médico masculino, médica femenino; masculino, doctora femenino	4	1	9 tie	NR	"I'm new to the area and am figuring out where to go"; lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; transportation is an issue (limited range + # per month, limited range (ex = won't cross Nassau/Suffolk county lines)	
Food Stamps; Quality Food - Meals and Food Boxes- bueno para alguien conida (food)	5	9 tie	2	2 tie	Most ineligible for food assistance because of immigration / documentation status; "I get no assistance with food"; those who do qualify can't get transportation: "qualify for food assistance by no way to get there"	Food boxes should include toiletries; Need nationally 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; vast majority don't qualify for food assistance
Health insurance/ Social Security Insurance- seguro	6	5	7	10	Most are ineligible due to immigrations status or lack of documentation; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go"	Assistance not available for working poor; need more logical & understandable system; Medicaid not available for most; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Immigration Ppaers/Docu mentation	NR	NR	8	11 tie	Difficult to find someone to help; many not eligible for services due to immigration / documentation status	Undocumented or incomplete immigration status; little help available to figure everything out
Life / health / healthy environment- salud / sano ambiente	7	NR	NR	NR		
Housing- vivienda femenino; tecnología cubierta femenino	8	NR	5	4	"Because I don't make very much money at my job"; 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"; many ineligible because of immigration / documentation status	Most ineligible for food assistance because of immigration / documentation status; extreme expressed need for rent assistance or rent control for HIV+ residents (see seperate "Rental Assistance" below; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean healthy living options; need assistance for working PLWH/A; often difficult process to document "homelessness"
Rental Assistance	9	13 tie	1	5	Most claim ineligible for rental assistance or Section 8 because of immigration / documentation status; extreme expressed need for rent assistance; "Housing assistance does not exist for me"	Most claim ineligible for rental assistance because of immigration / documentation status; extreme expressed need for rent assistance

Financial Assistance- ayuda / asistencia; money = dinero	10	11 tie	3 tie	2 tie	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about \$s and #s, not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; no emergency funds; many don't qualify for aid because of immigration + documentation status	Major need for rental assistance (lack of availability or knowledge about availability); need availability of emergency funds; "no assistance available if I wanted to or had to move off of Long Island to find better schools or better healthcare"; need help with household bills- heat, electric, water; rent takes up most assistance, leaving little funds for basic necessities like groceries, toiletries, cleaning supplies, utilities, house repairs, and medical co-payments; "I'd love to live beyond just surviving"; no help for those working; many agency employees are not friendly- "I feel threatened when trying to reach out"; would like to work but would lose eligibility for financial assistance; parking, travel and food vouchers needed
Employment Skills Training- trabajo , skill = destreza femenino, habilidad femenino	11	NR	6	6	Not enough good jobs- many working and still not making ends meet; need list or ideas for part-time, suitable employment for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin working again"	Not enough good jobs; not eligible for help because undocumented; "jobs are scarce"; "I work long hours which leaves little time for relaxing or spending time with family"
Language	NR	NR	NR	7		Not enough bilingual people— Some service agency employees seem to dislike working with native Spanish-speakers
Social Support	12 tie	9 tie	NR	NR		
Medical Case Management / Social Workers- caso encardo	12 tie	6	11 tie	9	Many claim they don't qualify because of immigration status or because undocumented; "I never see my case manager. Calls are never returned + they have not helped me";	Unpleasant experiences; language barriers; extreme run-around when do try to reach out for social services = discouraging
Oral health/ Dentist; dental care	14 tie	7	NR	NR		
Group support- grupo / agrupar soporte (sostener, mantener)	14 tie	8	11 tie	11 tie	No funding; "nothing interesting available in my area + don't want to attend groups in my immediate neighborhood, but no transportation to other areas + groups"	"I wish I could attend groups outside of my area, but I have no way of getting there. The Railroad doesn't stop near me and the buses stop too early"; need more socially-oriented co-ed support groups, focusing on living with the disease while navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Legal services	NR	13 tie	NR	NR		

More extensive services-mas servicios	NR	13 tie	NR	NR		
Treatment adherence counseling-apoyo	NR	13 tie	NR	NR		
Pharmacy	NR	11 tie	NR	NR		
Alternative therapies-masaje	NR	NR	11 tie	11 tie	More holistic approach needed to treating PLWH/A- coverage and services only seem available for traditional "medical-only" needs; Alternative and non-medical services not covered	Not covered by insurance or ADAP; need list of doctors or clinics offering alternative therapies and accepting insurances
Car	NR	NR	11 tie		"I really need a car but that seems impossible"	
VISA-permits for work and travel	NR	NR	11 tie	8	Need Green Card; difficult to find someone to help; many not eligible for services due to immigration / documentation status	Difficult to find someone to help; many not eligible for services due to immigration / documentation status; "travel visa so can travel to Honduras"
Child care-hijo, hija	NR	NR	NR	11 tie		Child care would make it more realistic for me to get a job"
Family Support	NR	NR	NR	11 tie		Need family living options; barely or not enough assistance to cover households basics
Vision care-ojo	NR	13 tie	NR	11 tie		

Chapter 1: Introduction

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

A comprehensive assessment of the service needs, gaps and barriers of “In Care”¹ Hispanic PLWH/A receiving Ryan White funded services in the Nassau-Suffolk EMA was conducted in the Spring of 2008 using the In Care Needs Assessment Client Survey (NACS) tool.

Relevance of the Part A Comprehensive “In Care” Hispanic Needs Assessments

The targeted minority groups, their sub-populations and the EMA’s severe needs groups remain a major focus of study for the planning area. The Planning Council is continuously challenged in identifying the changing needs of the PLWH/A community in order to best facilitate access, engagement and retention in care for all those living with HIV/AIDS in the service area.

Based upon their highly disproportionate impact within the EMA, as evidenced in the table below, the ‘In Care’ needs assessment survey process and resulting report highlights the differing needs, uses, gaps and barriers to HIV primary medical care experienced by the ‘In Care’ severe need group of **Hispanics** within the Nassau-Suffolk EMA.

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

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

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

¹ 1) **CD4 – CD4 (T4) or CD4 + CELL COUNT and PERCENT.**

2) **VIRAL LOAD TEST** - Test that measures the quantity of HIV RNA in the blood.

3) **ANTIRETROVIRAL DRUGS** - Substances used to interfere with replication or inhibit the multiplication of retroviruses such as HIV.

Characteristics of Hispanic PLWH/A in the EMA

The Hispanic population comprises **19% of the total PLWH/A** prevalent cases within the EMA. The Hispanic population is also representative of higher rates of uninsured or under-insured individuals. Hispanics are more likely than any other racial or ethnic group in the U.S. to be uninsured or under-insured and are less likely to use health services when they are available. Barriers to accessing care by the Hispanic population include linguistic issues, gender related issues, and stigma related to the diagnosis. Language barriers can pose significant problems between the consumer and the healthcare provider.

Cultural influences related to *fatalismo* (a sense of fatalism), *curanderismo* (use of folk healers to cure illness), and *castigo divino* (divine punishment) may cause the Hispanic client to avoid seeking services from health care providers that practice traditional Western Medicine. *Familismo* (importance of the opinion of family members) plays an important role with the Hispanic client. Individuals may delay or refuse treatment because of the advice given by, or opinion of, a family member. Hispanics who cannot obtain health insurance may stay out of care until it is absolutely necessary, **delaying entry into care**. Hispanics will often use the emergency department settings when seeking care. It is estimated that roughly 30% of Hispanics lack a steady source of health care.

Similar to the African American population, Hispanics present with high rates of cardiovascular disease (males 31.6%; females 34.3%), hypertension, and diabetes. These populations also tend to exhibit risk factors that lead to cardiovascular disorders, including high smoking rates among the males, diets high in fats and sodium, and increased occurrence of obesity. According to the National Minority AIDS Education and Training Center (NMAETC), the Hispanic population is less likely to take medications, even if prescribed. In addition to these complicated cultural/ethnic issues, Hispanics, like African Americans, tend to present late in the course of HIV disease.

Project Design for the ‘In Care’ Hispanic PLWH/A Needs Assessment Studies

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

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

The sample for surveying the ‘In Care’ population was first determined by establishing a 95% confidence interval (CI) for a representative sampling of the estimated number of PLWH/A with unmet need in the Nassau-Suffolk EMA. The survey process was designed to target as high level participation as possible among the Hispanic severe needs group (N=50-100). The actual participation rate for ‘In Care’ Hispanic survey respondents was 76 participants in the 2008 Needs Assessment process.

Chapter 2: “In Care” Hispanic Survey Findings²

The Hispanic ‘In Care’ survey sources included NUMC, Catholic Charities, Circulo de la Hispanidad, FECS and the Hispanic Counseling Center, in addition to flyers and mailings circulated throughout the Ryan White funded provider sites.

The ‘In Care’ client surveys were scheduled over a two-month period in the winter of 2008. The tables below indicate the age, gender, and sexual orientation of the Hispanic ‘In Care’ survey population. All respondents report Hispanic ethnicity and one respondent reports as multiracial ethnicity, as a Native American Hispanic.

Age

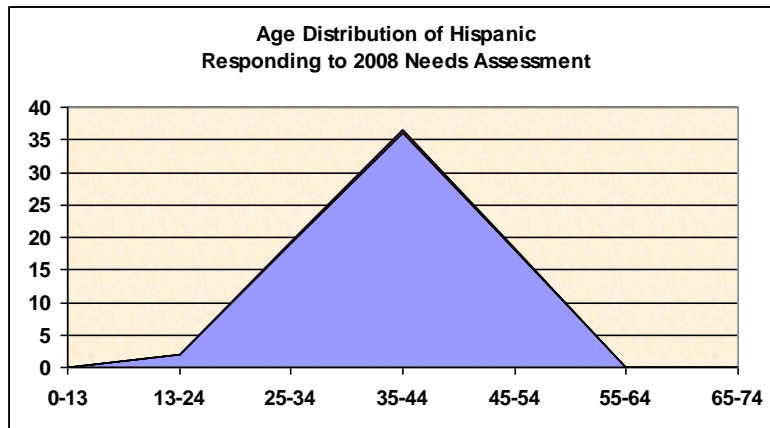
The Hispanic ‘In Care’ survey respondent group is a younger group of PLWH/A, as compared to the African American ‘In Care’ survey group. The greatest proportion of the ‘In Care’ survey participants (48%) report ages in the 35-44 age range. A substantial minority--(24%)--report their ages in the 45-54 age range, with none reporting their age in the 55-64 age range. Almost 1/5 of the Hispanic survey respondents (19%) report their age between 25 and 34 years of age.

Table 11. Age of Hispanic Respondents

Age Range	#	%
13-24	2	3%
25-34	19	25%
35-44	36	48%
45-54	18	24%
TOTAL	75	100%

The figure below provides a visual depiction of the bell curved age distribution of the 2008 Hispanic ‘In Care’ survey respondents.

Figure 3. Age Distribution of Hispanic ‘In Care’ Survey Participants



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

Gender

The Hispanic ‘In Care’ survey participants are almost evenly split by gender, with 47% Male respondents and 51% Female respondents, and one respondent identifying as Transgender.

Table 12. Gender of Hispanic Respondents

Gender	#	%
Male	36	47%
Female	39	51%
Transgender	1	1%
	76	100%

Sexual Orientation

As evidenced by the table below, the greatest proportion of survey respondents identify as heterosexual or ‘straight’ (78%), reflective of their larger community impacted by HIV in the EMA. None of the Hispanic respondents identifies as bisexual and 18% identify as ‘gay’. One respondent reports ‘other’ for sexual orientation (identifying as Transgender), and two respondents PNTA.

Table 13. Sexual Orientation of Hispanic Respondents

Sexual Orientation	#	%
Gay	14	18%
Bisexual	0	0%
Straight	59	
Other	1	1%
Prefer not to Answer	2	3%
	76	100%

Zip Code of Residence

Almost 2/3 (60%) of the Hispanic ‘In Care’ survey respondents reported their current residence in the following five zip codes, in rank order from greatest to least: 11550 (25%); 11717 (11%); 11722 (8%); 11575 (8%); and 11520 (8%). The remainder of the sample reported a wide variation in zip code of residence. The range of zip codes points towards people living on all parts of Long Island, including many remote and rural areas not serviced effectively by current public transportation options.

The clustering of zip codes suggests “pockets of poverty”.

Zip Codes with 3+ respondents: 1) 11550 (Hempstead), 11575 (Roosevelt), 11520 (Freeport): All in Eastern Nassau County near Nassau University Medical Center, Clinics, and Hempstead / Freeport based Service Providers; 2) 11717 (Brentwood), 11722 (Central Islip): Both Central / Southern Suffolk cities; 3) 11050 (Port Washington), 11746 (Huntington Station), 11542 (Glen Cove): Central + Northeast Central cities- smaller, more isolated towns; greater distance from Primary Health Centers and Service Providers.

Table 14. Zip Codes of Residence for Hispanic ‘In Care’ Respondents

ZIP	#	%
11550	19	25%
11717	8	11%
11722	6	8%
11575	6	8%
11520	6	8%
11746	3	4%
11542	3	4%
11050	3	4%
11940	2	3%
11754	2	3%
11561	2	3%
11552	2	3%
11952	1	1%
11932	1	1%
11795	1	1%
11779	1	1%
11772	1	1%
11757	1	1%
11751	1	1%
11726	1	1%
11710	1	1%
11704	1	1%
11558	1	1%
11553	1	1%
11415	1	1%
11003	1	1%
Grand Total	76	100%

Zip Code of Residence and Approximate Yearly Income

The ‘In Care’ survey respondents represent a highly impoverished group overall, with almost half of those respondents who answered this question reported their income in the \$0-9999 range. An additional 22% of the Hispanic ‘In Care’ respondents report incomes in the \$10-19,999 range. ***Therefore, 91% of all survey respondents reported annual incomes equal to or less than 200% of the federal poverty level.***

As evidenced by the table on the following page, there exists a high level of correlation between the survey participants’ reported zip code of residence and level of poverty. Over one quarter of all Hispanic respondents (26%) did not answer this question, perhaps perceiving it to be an invasion of privacy.

Table 15. Annual Income by Zip Code: Hispanic ‘In Care’ Respondents

ZIP Code	0-9,999	10,000-19,999	20,000-29,999	30,000-39,999	40,000-49,999	Over 50,000	Blank	Grand Total	%
11722	2	2					2	6	8%
11550	15	1		1			2	19	25%
11940		2						2	3%
11520	5				1			6	8%
11415							1	1	1%
11575	2						4	6	8%
11542		3						3	4%
11552		2						2	3%
11561	1						1	2	3%
11952	1							1	1%
11932	1							1	1%
11704	1							1	1%
11553				1				1	1%
11050							3	3	4%
11558							1	1	1%
11757	1							1	1%
11754	1	1						2	3%
11003		1						1	1%
11746	2						1	3	4%
11717	1	3	1				3	8	11%
11772							1	1	1%
11751	1							1	1%
11710							1	1	1%
11779		1						1	1%
11726					1			1	1%
11795		1						1	1%
Totals	34	17	1	2	2	0	20	76	100%
	45%	22%	1%	3%	3%	0%	26%	100%	

HIV/AIDS Status

The majority of “In Care” survey respondents (53%) report an AIDS diagnosis and only 46% report an HIV diagnosis currently, representing a more experienced group of PLWH/A, overall.

Year of Diagnosis with HIV versus AIDS

As stated above, 53% of all the Hispanic ‘In Care’ respondents report an AIDS diagnosis, and as evidenced in the table below, a large percentage of those were diagnosed with HIV and AIDS simultaneously. *Also evident is the large number of the “recently diagnosed”--- (70% were diagnosed with HIV since the year 2000) ---many of whom were already living with AIDS at the time of their first diagnosis.* These findings suggest that Hispanics are finding out they are HIV+ when already sick or as part of routine physicals or community outreach efforts. These findings also indicate the need for expanded outreach, education and early testing programs for

the Hispanic community. It is highly likely that many more HIV+ Hispanics are unaware or are aware but Out of Care.

Table 16. Year of HIV and AIDS Diagnoses

Year	HIV#	%	AIDS#	%	TOTAL#	%
1983		0%		0%	0	0%
1984		0%		0%	0	0%
1985		0%		0%	0	0%
1986		0%		0%	0	0%
1987		0%		0%	0	0%
1988		0%		0%	0	0%
1989		0%		0%	0	0%
1990	3	4%	4	5%	7	6%
1991	1	1%	1	1%	2	2%
1992		0%		0%	0	0%
1993	1	1%		0%	1	1%
1994	1	1%		0%	1	1%
1995	6	8%		0%	6	5%
1996		0%		0%		0%
1997	3	4%	2	3%	5	4%
1998	3	4%	3	4%	6	5%
1999	5	7%	2	3%	7	6%
2000	5	7%	4	5%	9	8%
2001	1	1%		0%	1	1%
2002	8	11%	2	3%	10	9%
2003	10	13%	2	3%	12	10%
2004	3	4%	4	5%	7	6%
2005	3	4%	2	3%	5	4%
2006	12	16%	8	11%	20	17%
2007	11	14%	6	8%	17	15%
Grand Total	76	100%	40	53%	116	100%

Location of HIV Diagnosis

The vast majority of all of the Hispanic ‘In Care’ survey respondents reported learning their HIV or AIDS status in New York. Approximately 10% of all the Hispanic ‘In Care’ respondents report receiving their first HIV/AIDS diagnosis in a state other than New York. The states most frequently identified included: Louisiana (13); Texas (5); New Jersey (5); and Puerto Rico.

Table 17. Location of First HIV/AIDS Diagnosis

City	State	HIV		AIDS	
		#	%	#	%
Central Islip	NY	1	1%	1	3%
Roosevelt	NY	1	1%		0%
Brentwood	NY	7	9%	1	3%
New York City	NY	6	8%	1	3%

Hempstead	NY	13	17%	5	16%
Glen Cove	NY	2	3%	1	3%
Freeport	NY	5	7%	4	13%
Long Beach	NY	1	1%		0%
Westbury	NY	1	1%	1	3%
East Meadow	NY	2	3%	1	3%
Rockville Center	NY	1	1%	1	3%
Long Island	NY	5	7%	2	6%
Nassau	NY	7	9%	4	13%
Huntington	NY	2	3%	2	6%
Queens	NY	1	1%	1	3%
Stonybrook	NY	1	1%		0%
Edgewood	NY	1	1%		0%
Bay Shore	NY	1	1%		0%
Riverhead	NY	2	3%	2	6%
Newark	NJ	1	1%	1	3%
Shirley	NY	2	3%		0%
Patchogue	NY	1	1%		0%
Puerto Rico	US	4	5%	2	6%
New Orleans	LA	1	1%	1	3%
Houston	TX	1	1%		0%
New York State	NY	4	5%	1	3%
Prefer not to answer		2	3%		0%
Total		76	100%	32	100%

HIV Transmission Risk

Two thirds of all the Hispanic ‘In Care’ survey respondents (66%) identify their HIV transmission mode as Heterosexual contact. Eighteen percent (18%) of the Hispanic respondents report acquiring HIV as a result of MSM risk behavior; 7% as a result of a transfusion; and 7% report mode of transmission as ‘unknown’. One ‘other’ mode is reported by a migrant farm worker who was raking leaves and reports being impaled by dirty syringes.

Table 18. Mode of HIV Transmission

Medium of HIV infection	Total	
	#	%
Male sex with male	14	18%
IDU		0%
Heterosexual sex	50	66%
Prison		0%
Sex with Drug User	1	1%
Sexual Assault		0%
Transfusion	5	7%
Mother with HIV/AIDS		0%
Unknown	5	7%
Other	1	1%
TOTAL	76	100%

Employment

Greater than half (53%) of the Hispanic “In Care” survey respondents report current employment, (characteristic of this minority population), while only 45% report current unemployment.

Table 19. Employment Status

Yes		No		Prefer Not to Answer	
#	%	#	%	#	%
40	53%	34	45%	2	3%
76	100%				

Employed	YES	%
Full-time	1	50%
Part-time	1	50%
Total	2	100%

Education

This sample of Hispanic ‘In Care’ respondents reports a disparately low level of educational background, overall. *Two thirds of all Hispanic survey respondents (66%) report only some high school education or grade school or less, evidencing significant socioeconomic disparity within this survey sample.* Only 18% of all respondents report completing high school and only 8% of the survey respondents report some college education, with 1% reporting a college degree and 1% reporting some graduate level course work.

Table 20. Education Background

Education Background	#	%
Grade school or less	22	29%
Some high school	28	37%
High school grad/GED	14	18%
Some College	6	8%
College degree	1	1%
Some graduate school	1	1%
Graduate level		0%
No answer	3	4%
Other:	1	1%
TOTAL	76	100%

Living Arrangements

Only 7% of the Hispanic ‘In Care’ respondents report owning their home. The majority (70%) report currently renting a home or apartment; and over 1/5 (22%) of all Hispanic survey participants report being ‘temporarily housed’, currently staying with friends or relatives. The location of residence reported by the ‘In Care’ respondents is consistent with the reported

income, overall. *Only a small minority---16% of the total survey group--reports currently receiving any form of rental assistance.*

Table 21. Living Arrangements

Residence	#	%
Own your home	5	7%
Rent	53	70%
Live with a Friend/Relative	17	22%
Stay in a Shelter	0	0%
Other	1	1%
Total	76	100%

Help with Rent

Table 22. Rental Assistance

Yes		No		Not Applicable / No Answer	
#	%	#	%	#	%
12	16%	61	80%	3	4%
76	100%				

Ever Homeless

A total of 24% of the Hispanic “In Care” survey respondent group reports a current or previous period of homelessness, indicating a moderate degree of housing instability within this community. This finding would indicate some degree of challenge in successfully facilitating entry and retention in HIV primary care and services but less risk for impending homelessness than among other populations, for example, the African American respondents in the Nassau-Suffolk EMA.

Table 23. Extent of Homelessness

Ever Homeless	#	%
Never	56	74%
Currently	4	5%
In past 2 years, but not now	4	5%
Longer than past 2 years, but not now	11	14%
Prefer not to answer	1	1%
Total	76	100%

Incarceration in Past Six Months

Only one respondent (or <1%) of the Hispanic ‘In Care’ respondents reports having been incarcerated over the past 6 months.

Table 24. Recent Incarceration

Yes	%	No	%
1	1%	75	99%
76	100%		

Health Insurance

A minority of the Hispanic ‘In Care’ respondents cite Medicaid or Medicare (24%) as their primary health benefit resource. Only 4% of respondents reported private health insurance benefits, and 4% report having any form of health benefit, however 53 of the 76 respondents identifies ADAP as their major form of insurance benefit.

Table 25. Health Insurance Benefits

Health Insurance	Total	
	#	%
Private	3	4%
Medicare	5	6%
Medicaid (ACCCHS)	14	18%
VA		0%
None	3	4%
Other= ADAP	53	68%
TOTAL	78	100%

Current Primary Care Physician and Clinic

The majority of the ‘In Care’ survey respondents’ (53%) report the Nassau University Medical Center as their primary medical home, followed by the Brentwood Clinic (40%); followed by SUNY at Stonybrook (11%). The remaining respondents reported multiple other clinic sites.

See Table 26 below for reported Clinic location and Table 27 on the following page for the list of individual physicians the Hispanic ‘In Care’ respondents report as their HIV primary care specialist.

Drs. Absy, Landau, Hague, Magnifico, and the NUMC physicians are most frequently listed as serving the HIV primary care needs of the Hispanic ‘In Care’ population.

Table 26. Location of HIV Primary Care Clinic

HIV CLINIC	#	%
NUMC	40	53%
SUNY-Stonybrook	8	11%
North Shore	1	1%
David E. Rogers Center @ Southampton Hospital	2	8%
South Brookhaven Clinic	1	4%
Tri-Community Health Center	1	4%
Good Samaritan Hospital	1	4%
Patchogue Clinic	1	4%
Suffolk Health System	1	4%
Brentwood Clinic	10	40%
Riverhead Health Center	2	8%
Freeport Clinic	3	12%
NYC Hospitals	1	4%
Other	1	4%
Mercy Hospital	1	4%

Table 27. HIV Treating Physicians

Doctor	#	%
Absy	5	7%
Furhur- Stonybrook	3	4%
McGowan	1	1%
Griffin	1	1%
Janikouska Natalish	1	1%
Anderson	4	5%
Natalia O NUMC	1	1%
Steinbegle	2	3%
Landau	10	13%
Chirch	2	3%
Verley	1	1%
Lobo	1	1%
Gebre	1	1%
Delatto	2	3%
Descharge	1	1%
Haque	9	12%
Bonnano (sp?)	3	4%
Gebre	1	1%
Magnifico	7	9%
Febles	1	1%
Feleke	1	1%
Sethi	1	1%
Stonybrook Hospital	2	3%
MLK Clinic	1	1%
Rita Cally- Stonybrook	1	1%
NYC Hospitals	1	1%
Riverhead	1	1%
NUMC Physicians	6	8%
Prefer no answer	5	7%
Total	76	100%

Primary Care Visit and Lab Monitoring Indicators of “In Care” Status

The majority of the Hispanic ‘In Care’ respondents report active “In Care” status, with most persons (of the 76 respondents who answered the question) reporting seeing their physician and receiving laboratory services in the past six months or less. Only 8 or fewer respondents reported an ‘erratically in care’ status in the past 12 months. Similar visit patterns are reported for laboratory monitoring of CD4 cell counts and viral load levels.

See Tables 28 and 29 on the following page for a pattern analysis of ‘In Care’ status among the Hispanic survey respondents, which evidences that the majority have been ‘In Care’ within the past two months or less, as compared with the three to four month average for the African American ‘In Care’ respondent group.

Table 28: Last Doctor Visit and Last Lab Monitoring Visit Patterns

Doctor		CD4		Viral Load	
3/1/07			1		1
7/1/07		7/1/07		7/1/07	1
8/1/07	2	8/1/07	2	8/1/07	2
9/1/07	9	9/1/07	10	9/1/07	10
10/1/07	13	10/1/07	15	10/1/07	14
11/1/07	21	11/1/07	18	11/1/07	20
12/1/07	18	12/1/07	14	12/1/07	15
1/1/08	13	1/1/08	9	1/1/08	8
Totals	76		76		76

Table 29. Pattern of ‘In Care’ Status

Length of Delay	Doctor		CD4		Viral Load	
	#	%	#	%	#	%
Current	35	1%	24	32%	26	34%
One month	19	25%	15	20%	15	20%
Two months	17	22%	24	32%	24	32%
Three months	4	5%	7	9%	7	9%
Four months	1	1%	1	1%	1	1%
Five months		0%		0%		0%
Six months		0%		0%		0%
Seven months-1 Year		0%	1	1%	1	1%
Don't Know		0%	4	5%	2	3%
Average	1.95		1.949		1.9487	3%
Total	76	100%	76	100%	76	100%

Current Antiretroviral Therapy

The vast majority of Hispanic ‘In Care’ survey respondents (87%) report the receipt of antiretroviral therapy, as evidenced in the table below, which correlates with their reported level of advanced HIV disease and HIV primary care visit status.

Table 30. Current ART

Yes		No		Don't Know		No Answer	
#	%	#	%	#	%	#	%
66	87%	9	12%	0	0%	1	1%
76	100%						

History of Mental Illness-Diagnosis and/or Treatment

Over half, or fifty seven percent (57%) of the Hispanic ‘In Care’ respondents reported a history of mental health issues. The Hispanic ‘In Care’ respondents report a higher proportion of mental health issues than did the African American ‘In Care’ respondents, (44% of whom reported a history of mental illness).

Table 31. History of Mental Illness

Yes		No		Don't Know		No answer	
#	%	#	%	#	%	#	%
43	57%	31	41%		0%	2	3%
76	100%						

History of Substance Abuse-Diagnosis and/or Treatment

While the Hispanic respondents report a greater extent of mental health disorders than the African American respondents, a far smaller proportion report substance abuse or treatment for a substance abuse disorder.

Only 11% of all Hispanic ‘In Care’ respondents admit to a diagnostic history of and/or treatment for substance use/abuse, as compared to the majority of African American respondents who reported a history of substance abuse.

Table 32. History of Substance Abuse

Yes		No		Don't Know		No answer	
#	%	#	%	#	%	#	%
8	11%	68	89%	0	0%		0%
76	100%						

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

The Hispanic ‘In Care’ respondent group reports a moderate level of history of other STDs (30%) versus the 39% STD co-morbidity reported by the African American ‘In Care’ respondent group.

Table 33. Diagnosis and Treatment of STDs

Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
23	30%	43	57%		0%	10	13%
76	100%						

As evidenced in the table below, the Hispanic ‘In Care’ respondents also report far less other chronic disease co-morbidity (28%) than the African American ‘In Care’ respondent group (59%).

Table 34. Co-morbidity with other Chronic Disease

Yes		No		Don't Know		Prefer Not to Answer	
#	%	#	%	#	%	#	%
21	28%	49	64%	1	1%	5	7%
76	100%						

NEEDS, USES, GAPS, and BARRIERS RANKING

A Needs, Uses, Gaps and Barriers ranking was developed for all Hispanic ‘In Care’ respondents. The 2008 HIV/AIDS Needs Assessment provides a “snapshot” of the community service needs, barriers, and gaps as expressed by consumers of HIV related services.

The rankings of the Needs Assessment were displayed for all Hispanic ‘In Care’ respondents, with separation into Need, Use, Gap and Barrier. This can be further defined as:

Need	Number of ‘In Care’ client survey respondents who stated “I currently need this service.”
Use	Number of ‘In Care’ client survey respondents who indicated service use in the past year
Gap	Sum of ‘In Care’ client survey respondents who answered ‘Yes’ to Need and ‘No’ to availability of that service
Barrier	Number of ‘In Care’ client survey respondents who indicated that a service is ‘Hard to Get’

NEED

The highest priority HIV service needs reported by the Nassau-Suffolk EMA Hispanic “In Care” survey participants, in rank order, include: 1) Medications; 2) Medical Transportation; 2) Mental health services; 4) Primary Medical Care; 5) Food Bank; 6) Health Insurance/Social security; 7) Health/Life/Healthy environment; 8) Housing services’ 9) Rental assistance; 10) Financial assistance; 11) Employment skills training; 12) Social Support tied with 12) Medical Case management; 14) Oral health services tied with 14) Group Support.

The Top Ranking Service NEEDS for Hispanic “In Care” Respondents were:

Table 35: NEEDS Rankings-Hispanic ‘In Care’ Survey Respondents

NEEDS	NEED RANKINGS
Medications- e medicina femenino; (medication) medicina femenino, medicamento masculino	1
Medical Transportation- transporte masculino; means of transportation medio masculino de transporte; public transportation transporte masculino público	2 tie
Mental Health services	2 tie
Primary Medical Care- uestantivo medicina médico masculino, médica femenino; form of address doctor masculino, doctora femenino	4
Food Bank; Quality Food - Meals and Food Boxes- bueno para alguien conida (food)	5
Health Insurance/Social Security / - seguro	6
Life / health / healthy environment- salud / sano ambiente / entorno	7
Housing services- vivienda femenino; tecnología cubierta femenino	8
Rental Assistance	9
Financial Assistance- ayuda / asistencia; money = dinero	10
Employment / Job Skills Training- trabajo , skill = destreza femenino, habilidad femenino	11

Social Support	12 tie
Medical Case Management / Social Workers- caso encardo (?)	12 tie
Oral Health services /Dentist; dental care	14 tie
Group support - grupo / agrupar soporte (sostener, mantener)	14 tie

Service USES

The top 15 services reported as most often ‘used’ by Hispanic ‘In Care’ respondents included: 1) Primary Medical Care; 2) Medical Transportation; 3) Mental Health services; 4) Medications; 5) Health Insurance; 6) Medical Case Management; 7) Oral Health services; 8)Group Support; 9) Food Bank tied with Social Support; 11) Financial assistance tied with Pharmacy; 13) Rental assistance tied with Vision care tied with Legal services tied with More extensive services tied with Treatment adherence.

Table 36: USE Rankings-Hispanic ‘In Care’ Survey Respondents

USES	NEED RANKINGS	USE RANKINGS
Medications - e medicina femenino; (medication) medicina femenino, medicamento masculino	1	4
Transportation - transporte masculino; means of transportation medio masculino de transporte; transporte masculino público	2 tie	2
Mental Health services	2 tie	3
Primary Medical Care - uestantivo medicina médico masculino, médica femenino; form of address doctor masculino, doctora femenino	4	1
Food Bank; Quality Food - Meals and Food Boxes- bueno para alguien conida (food)	5	9 tie
Health Insurance /Social Security- seguro	6	5
Life / health / healthy environment - salud / sano ambiente / entorno	7	NR
Housing - vivienda femenino; tecnología cubierta femenino	8	9 tie
Rental Assistance	9	13 tie
Financial Assistance - ayuda / asistencia; money = dinero	10	11 tie
Employment / Skills Training - trabajo , skill = destreza femenino, habilidad femenino	11	NR
Social Support	12 tie	9 tie
Medical Case Management / Social Workers- caso encardo (?)	12 tie	6
Oral health /Dentist; dental care	14 tie	7
Group support - grupo / agrupar soporte (sostener, mantener)	14 tie	8
Legal services	NR	13 tie
More extensive services -mas servicios	NR	13 tie
Treatment adherence counseling -apoyo	NR	13 tie
Pharmacy	NR	11 tie
Vision services	NR	13 tie

Service BARRIERS

The Top Ranking Service Barriers and Barrier Reasons for Hispanic “In Care” respondents include:

- 1) Transportation;
- 2) Financial Assistance tied with Food Bank;
- 4) Housing services;
- 5) Rental Assistance;
- 6) Employment Skills training;
- 7) Language/lack of interpreters;
- 8) Visa-for work/travel;
- 9) Medical Case Management;
- 10) Health Insurance; and
- 11) Alternative therapies tied with Child care tied with Family Support tied with Group Support tied with Immigration/Documentation tied with Mental Health services tied with Vision care.

Service -Specific BARRIERS & BARRIER Reasons--Hispanic 'In Care' Survey Respondents

Table 37: Barrier Reasons by Service Category

Service Category Description	Need Rank	Barrier Rank	Barrier Reasons
Transportation- transporte masculino; medio masculino de transporte; transporte público	2 tie	1	Need travel vouchers; because of documentation / immigration status; language barrier + lack of funding; unreliable services, ordeal to schedule; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; need help getting a car; no transportation available other than bus in some Eastern parts of Suffolk Co.
Financial Assistance- ayuda / asistencia; money = dinero	10	2 tie	Major need for rental assistance (lack of availability or knowledge about availability); need availability of emergency funds; "no assistance available if I wanted to or had to move off of Long Island to find better schools or better healthcare"; need help with household bills- heat, electric, water; rent takes up most assistance, leaving little funds for basic necessities like groceries, toiletries, cleaning supplies, utilities, house repairs, and medical co-payments; "I'd love to live beyond just surviving"; no help for those working; many agency employees are not friendly- "I feel threatened when trying to reach out"; would like to work but would lose eligibility for financial assistance; parking, travel and food vouchers needed
Food Bank; Meals and Food Boxes- bueno para alguien conida (food)	5	2 tie	Food boxes should include toiletries; Need nationally 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; vast majority don't qualify for food assistance
Housing services- vivienda femenino; tecnología cubierta femenino	8	4	Most ineligible for food assistance because of immigration / documentation status; extreme expressed need for rent assistance or rent control for HIV+ residents (see separate "Rental Assistance" below; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean healthy living options; need assistance for working PLWH/A; often difficult process to document "homelessness"
Rental Assistance	9	5	Most claim ineligibility for rental assistance because of immigration / documentation status; extreme expressed need for rent assistance
Employment / Skills Training- trabajo , skill = destreza femenino, habili	11	6	Not enough good jobs; not eligible for help because undocumented; "jobs are scarce"; "I work long hours which leaves little time for relaxing or spending time with family"

Language	NR	7	Not enough bilingual people; some service agency employees seem to dislike working with native Spanish-speakers
Visa- permits for work + travel	NR	8	Difficult to find someone to help; many not eligible for services due to immigration / documentation status; "travel visa so can travel to Honduras"
Medical Case Management / Social Workers- caso encardo (?)	12 tie	9	Many claim they don't qualify because of immigration status or because undocumented; "I never see my case manager. Calls are never returned + they have not helped me"; unpleasant experiences; language barriers; extreme run-around when do try to reach out for social services = discouraging
Health Insurance/Social Security -seguro	6	10	Assistance not available for working poor; need more logical & understandable system; Medicaid not available for most; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Alternative / Complimentary Therapies	NR	11 tie	Not covered by insurance or ADAP; need list of doctors or clinics offering alternative therapies and accepting insurances
Child Care- hijo, hija	NR	11 tie	"Child care would make it more realistic for me to get a job"
Family support	NR	11 tie	Need family living options; barely or not enough assistance to cover households basics
Group support- grupo / agrupar soporte (sostener, mantener)	14 tie	11 tie	"I wish I could attend groups outside of my area, but I have no way of getting there. The Long Island Railroad doesn't stop near me and the buses stop too early"; need more socially-oriented co-ed support groups, focusing on dating & living with the disease while navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Immigration papers / Documentation	NR	11 tie	Undocumented or incomplete immigration status; little help available to figure everything out
Mental Health services	2 tie	11 tie	"I'm glad I got AIDS- it forced me to get help and get my life back"; many utilize FECS + Hispanic Counseling Center; "many people need mental health support but don't know it"
Vision Care- ojo = eye	NR	11 tie	No comment

The Hispanic 'In Care' survey respondents list numerous service Barriers for many of their top ranking service Needs. Many of the perceived Barriers reflect their unmet need to be 'legalized', with several obstacles noted to obtaining work and travel visas and their lack of eligibility for state funded services because of their undocumented status.

Service GAPS

Top Ranked Service GAPS and GAP Reasons for Hispanic "In Care" respondents were:

Table 38: Service GAPS and Gap Reasons

Service Category	Need Rank	Gap Rank	Gap Reasons
Rental Assistance	9	1	Most claim ineligible for rental assistance or Section 8 because of immigration / documentation status; extreme expressed need for rent assistance; "Housing assistance does not exist for me"
Food Bank Quality Food - Meals and Food Boxes- bueno para alguien conida (food)	5	2	Most ineligible for food assistance because of immigration / documentation status; "I get no assistance with food"; those who do qualify can't get transportation: "qualify for food assistance by no way to get there"
Medical Transportation- transporte masculino; means of	2 tie	3 tie	Because of documentation / immigration status; "I don't know how to request services"; language barriers; lack of funding; "really need a car but seems impossible"; limited # and range of rides- monthly medical appointments often exceed max # of rides

transportation medio masculino de transporte; public transportation transporte masculino público			(especially with additional diseases), no rides to grocery store, food pantry or pharmacy; no rides across county lines limits choice of providers; need metro cards + travel vouchers
Financial Assistance- ayuda / asistencia; money = dinero	10	3 tie	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about \$\$s and #s, not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; <u>no emergency funds; many don't qualify for aid because of immigration + documentation status</u>
Housing services - vivienda femenino; tecnología cubierta femenino	8	5	"Because I don't make very much money at my job"; 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"; many ineligible because of immigration / documentation status
Employment / Skills Training- trabajo , skill = destreza femenino, habilidad femenino	11	6	Not enough good jobs- many working and still not making ends meet; need list or ideas for part-time, suitable employment for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin working again"
Health Insurance Social Security / - seguro	6	7	Most are ineligible due to immigrations status or lack of documentation; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go"
Immigration papers / Documentation	NR	8	Difficult to find someone to help; many not eligible for services due to immigration / documentation status
Primary Medical Care- ustantivo medicina médico masculino, médica femenino; r doctora femenino	4	9 tie	"I'm new to the area and am figuring out where to go"; lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; transportation is an issue (limited range + # per month, limited range (ex = won't cross Nassau/Suffolk county lines)
Alternative / Complimentary Therapies	NR	9 tie	More holistic approach needed to treating PLWH/A- coverage and services only seem available for traditional "medical-only" needs
Car	NR	11 tie	"I really need a car but that seems impossible"
Alternative therapies Massage Therapy- masaje	NR	11 tie	Alternative and non-medical services not covered
Medical Case Management / Social Workers- caso encardo	12 tie	11 tie	Many claim they don't qualify because of immigration status or because undocumented; "I never see my case manager. Calls are never returned + they have not helped me"; unpleasant experiences; language barriers; extreme run-around when do try to reach out for social services = discouraging
Visa- permits for work + travel	NR	11 tie	Need Green Card; difficult to find someone to help; many not eligible for services due to immigration / documentation status
Group support- grupo / agrupar soporte (sostener, mantener)	14 tie	11 tie	No funding; "nothing interesting available in my area + don't want to attend groups in my immediate neighborhood, but no transportation to other areas + groups"

The majority of the reasons offered to explain the Hispanic 'In Care' respondents' inability to successfully access and obtain many supportive services appear to relate to their lack of citizenship status and the resulting gap in state funded support services for undocumented persons. It will be essential to locate Ryan White and other privately funded resources in the community in order to fill these service Gaps.

Chapter 3: Recommendations for Comprehensive Strategic Plan

Special Strategies Directed to Optimizing Access and Retention in Care

- 1. Address Hispanic 'In Care' Service BARRIERS inclusive of Transportation; EFA; Food; Housing; Rental assistance; Employment skills; Interpreters; Visa assistance; Case Management; Health Insurance/SS Assistance:**

TABLE 39: Hispanic PLWH/A Service Barriers and Barrier Reasons

Service Category Description	Need Rank	Barrier Rank	Barrier Reasons
Transportation- transporte; medio masculino de transporte Público	2 tie	1	Need travel vouchers; because of immigration status; language barrier + lack of funding; unreliable services, ordeal to schedule; limited # and range of rides- monthly medical appointments often exceed max # of rides, no rides to grocery store, food pantry or pharmacy; no transportation available other than bus in some Eastern parts Suffolk Co.
Financial Assistance- ayuda / asistencia; money = dinero	10	2 tie	Major need for rental assistance (lack of availability or knowledge about availability); need availability of emergency funds; "no assistance available if I wanted to or had to move off Island to find better schools or better healthcare"; need help with household bills-rent takes up most assistance, leaving little funds for basic necessities and medical co-payments; no help for those working; - would like to work but would lose financial assistance; parking, travel and food vouchers needed
Food Bank; bueno para alguien comida (food)	5	2 tie	Food boxes should include toiletries; Need nutritionally sound foods-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 stamps; majority don't qualify for food assistance
Housing services- vivienda femenino; tecnología cubierta femenino	8	4	Most ineligible for food assistance because of immigration / documentation status; extreme expressed need for rent assistance or rent control for HIV+ residents (see separate "Rental Assistance" below; substandard conditions in some HIV housing (rodents, cracked walls, drug users across hall); need affordable, clean healthy living options; need assistance for working PLWH/A; often difficult process to document "homelessness"
Rental Assistance	9	5	Most claim ineligible for rental assistance because of immigration / documentation status; extreme expressed need for rent assistance
Employment / Skills Training- trabajo , skill =, habilidad femenino	11	6	Not enough good jobs; not eligible for help because undocumented; "jobs are scarce"; "I work long hours which leaves little time for relaxing or spending time with family"
Language	NR	7	Not enough bilingual people; some service agency employees seem to dislike working with native Spanish-speakers
Visa- permits for work + travel	NR	8	Difficult to find someone to help; many not eligible for services due to immigration / documentation status; "travel visa so can travel to Honduras"
Medical Case Management / Social Workers- caso encardo (?)	12 tie	9	Many claim they don't qualify because of immigration status or because undocumented; "I never see my case manager. Calls are never returned + they have not helped me"; unpleasant experiences; language barriers; extreme run-around when do try to reach out for social services = discouraging
Health Insurance/Socia ISecurity -seguro	6	10	Assistance not available for working poor; need more logical & understandable system; Medicaid not available for most; need better assistance for co-pays, especially for related meds; difficulties in documenting "homelessness" to qualify for assistance
Alternative / Complimentary Therapies	NR	11 tie	Not covered by insurance or ADAP; need list of doctors or clinics offering alternative therapies and accepting insurances
Child Care- hijo, hija	NR	11 tie	"Child care would make it more realistic for me to get a job"

Family support	NR	11 tie	Need family living options; barely or not enough assistance to cover households basics
Group support- grupo / agrupar soporte (sostener, mantener)	14 tie	11 tie	"I wish I could attend groups outside of my area, but I have no way of getting there. The Long Island Railroad doesn't stop near me and the buses stop too early"; need more socially-oriented co-ed support groups, focusing on dating & living with the disease while navigating the lifestyle and physical changes; need mature range of activities (arts, socials, outdoors, sports)
Immigration papers / Documentation	NR	11 tie	Undocumented or incomplete immigration status; little help available to figure everything out
Mental Health services	2 tie	11 tie	"I'm glad I got AIDS- it forced me to get help and get my life back"; many utilize FECS + Hispanic Counseling Center; "many people need mental health support but don't know it"
Vision Care- ojo = eye	NR	11 tie	No comment

2. Address Hispanic 'In Care Service GAPS inclusive of Rental assistance; Food; Medical Transportation; EFA; Housing assistance; Employment skills; Health Insurance/SS Assistance; Immigration assistance; and Primary Medical Care.

TABLE 40: Hispanic PLWH/A Service Gaps and Gap Reasons

Service Category	Need Rank	Gap Rank	Gap Reasons
Rental Assistance	9	1	Most claim ineligible for rental assistance or Section 8 because of immigration / documentation status; extreme expressed need for rent assistance; "Housing assistance does not exist for me"
Food Bank Quality Food - Meals and Food Boxes- bueno para alguien comida (food)	5	2	Most ineligible for food assistance because of immigration / documentation status; "I get no assistance with food"; those who do qualify can't get transportation: "qualify for food assistance by no way to get there"
Medical Transportation- transporte masculino; public transportation transporte masculino público	2 tie	3 tie	Because of documentation / immigration status; "I don't know how to request services"; language barriers; lack of funding; "really need a car but seems impossible"; 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; need metro cards + travel vouchers
Financial Assistance- ayuda / asistencia; money = dinero	10	3 tie	System designed to keep you as client rather than promoting independence ("AIDS agencies on Long Island care about \$\$s and #s, not clients"); should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; <u>no emergency funds; many don't qualify for aid because of immigration + documentation status</u>
Housing services - vivienda femenino; tecnología cubierta femenino	8	5	"Because I don't make very much money at my job"; 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"; many ineligible because of immigration / documentation status
Employment / Skills Training- trabajo , skill = destreza femenino, habilidad femenino	11	6	Not enough good jobs- many working and still not making ends meet; need list or ideas for part-time, suitable employment for PLWH/A to remain active; needs ideas for disabled; "need more services geared towards making clients independent vs. sustaining the system"; "would like skills training and job, but afraid I will lose assistance if I begin working again"

Health Insurance Social Security / - seguro	6	7	Most are ineligible due to immigrations status or lack of documentation; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go"
Immigration papers / Documentation	NR	8	Difficult to find someone to help; many not eligible for services due to immigration / documentation status
Primary Medical Care - médico masculino, médica femenino; r doctora femenino	4	9 tie	"I'm new to the area and am figuring out where to go"; lack of mobile health units providing range of services (including HIV/AIDS) to all in need and lacking transportation; transportation is an issue (limited range + # per month, limited range (ex = won't cross Nassau/Suffolk county lines)
Alternative / Complimentary Therapies	NR	9 tie	More holistic approach needed to treating PLWH/A- coverage and services only seem available for traditional "medical-only" needs
Car	NR	11 tie	"I really need a car but that seems impossible"
Alternative therapies	NR	11 tie	Alternative and non-medical services not covered
Medical Case Management / Social Workers - caso encardo	12 tie	11 tie	Many claim they don't qualify because of immigration status or because undocumented; "I never see my case manager. Calls are never returned + they have not helped me"; unpleasant experiences; language barriers; extreme run-around when do try to reach out for social services = discouraging
Visa- permits for work + travel	NR	11 tie	Need Green Card; difficult to find someone to help; many not eligible for services due to immigration / documentation status
Group support - grupo / agrupar soporte	14 tie	11 tie	No funding; "nothing interesting available in my area + don't want to attend groups in my immediate neighborhood, but no transportation to other areas + groups"

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

Recommended Priority Strategies to Optimize Retention in Care

- Engaging clients in care when first diagnosed as HIV+
- Fully assessing clients needs when entering care; targeting those deemed at high risk for erratic care use and/or disengagement from care and strongly engaging them in care during the first year of primary medical care participation
- Ensuring cultural and linguistic competence of CM, MH and PMC providers to meet the needs of sub-populations
- Aligning planning processes to respond to service delivery issues
- Service Delivery: Expand Housing and Housing-Related Services
- Service Delivery. Expand Medical Transportation assistance
- Service Delivery. Expand Employment/Job skills training and assistance programs
- Service Delivery: Ensure availability of Spanish speaking providers and more assistance for the undocumented Hispanic population
- Service Delivery: Expand/seek additional funding to support the unmet food, housing, and transportation needs reported by the 'In Care' populations
- Service Delivery: Ensure optimal collaboration among core medical and supportive services providers, co-locating to the extent possible all priority services
- Assuring services availability information- Information about service availability is limited
- Assuring high-quality services - Information about service quality is limited

- Retaining clients in care - employing systematic approaches to missed appointments/lost to follow-up and maximizing Ryan White and other funding resources
- Assisting re-entry into care – expanding peer counselors and other outreach strategies identified as highly effective in facilitating their return to care/keeping them in care

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

Suggested Strategies for Newly Diagnosed PLWH/A:

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

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

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

Improved Linkages between Supportive and Primary Care Services

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

6. *Co-locate, to the extent possible, HIV PMC and other primary medical and specialty care services*
7. *Strengthen peer outreach to ensure engagement/retention linkages with the most underserved and most likely to disengage*

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

Improved Provider-Patient Partnerships and Collaborations with Peers

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

Suggested Strategies for PLWH/A NEVER in Care

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

1. *Active follow-up by Testing/Counseling agency to maintain contact and confirm entry into care*
2. *Peer Outreach to specific populations and locations, including homeless shelters, drug treatment centers, etc*
3. *Regular marketing of primary care services’ availability and directions on making referrals with all points of entry staff and agencies*
4. *Social marketing efforts regarding benefits of care and treatment*
5. *Co-location of primary medical care services with substance abuse treatment/rehab services*
6. *Co-location of HIV PMC and other PMC wherever possible.*