

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

Aged/45+ 'In Care' PLWH/A Needs Assessment in the Nassau Suffolk EMA

2009 REPORT OF FINDINGS

Prepared by



COLLABORATIVE RESEARCH, LLC

MAY 2009



UNITED WAY OF LONG ISLAND

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2009 “In Care” Aged/45+ PLWH/A Needs Assessment

Nassau-Suffolk EMA HIV Health Services Planning Council

May 2009

Executive Summary

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



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

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

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

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

Relevance of the 2009 “In Care” Aged PLWH/A 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).

Aged/45+: PLWH/A, ages 45 years or greater, comprise almost 47% of the total living AIDS population and almost 64% of the total PLWH population in the EMA, evidencing substantial disparity among the living population of HIV/AIDS. The aged make up 26% of emergent HIV cases and 37% of emergent AIDS cases. (NYSDOH, 2007)

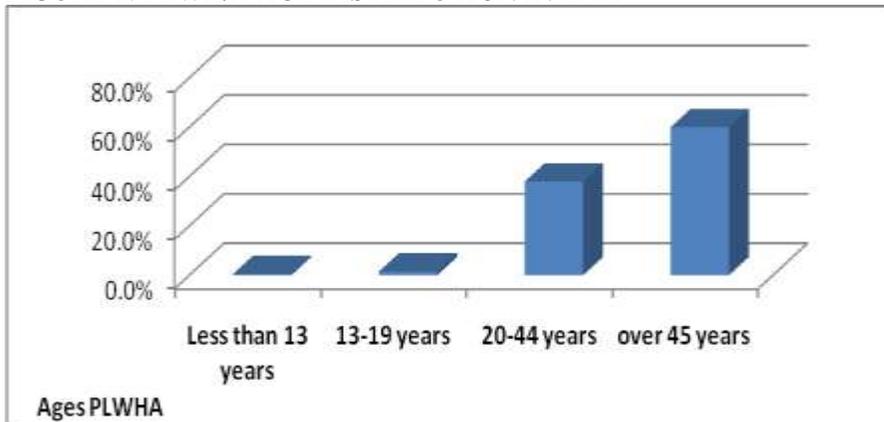
TABLE 1: AGE GROUP DISTRIBUTION (New AIDS and HIV, PLWH/A), 2007

| Age Group (years) | New AIDS Cases | | New HIV Cases | | PLWA | | PLWH | |
|-------------------|----------------|---------------|---------------|--------------|-------------|-------------|-------------|--------------|
| | Total # | % 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 graph on the following page provides a visual representation of the number of PLWH/A in the EMA who are 45 years or greater in age. (See Figure 1 below)

FIGURE 1: PLWH/A AGE DISTRIBUTION IN EMA



Source: New York State Department of Health; 2007

TABLE 2. AGED/45+ PLWH/A DISPROPORTION COMPARED TO GENERAL POPULATION

| Nassau-Suffolk GENERAL POPULATION Age Group (years) | Percent of General Population in Each Age Category | Percent PLWA N-S Age Category | Percent PLWH N-S Age Category |
|--|--|----------------------------------|----------------------------------|
| < 13 | 20.1% | 2.46% | .13% |
| 14-44 | 42.9% | 50.99% | 36.05% |
| Over 45 | 37.0% | 46.50% | 63.81% |
| Total | 100% | 100% | 100% |

(Source: Free Demographics, 2009 and NYSDOH, 2008)

As evidenced in the comparison table above, PLWH/A, ages 45+ are disproportionately impacted and carry the heaviest burden of HIV/AIDS, when compared to their representation in the general population. The disparity for the 45+ age band is 9.5% for PLWA and almost 27% for PLWH. As evidenced in the table below, 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 the 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.

TABLE 3. POPULATIONS OF PLWH/A UNDERREPRESENTED IN THE CARE ACT 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% |

The Aged PLWH/A clients comprised 46% of the Part A core medical services population, but made up 68% of the supportive services clientele in 2007. (*NYSDOH and Part A Services, 2007*). 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 and osteoporosis, diabetes, liver disease, and dementia, further complicating the treatment and care of HIV/AIDS within the EMA's aged population.

A massive number of PLWH/A 45 years and over will begin to confront aging issues in the next decade. The existing knowledge base regarding older PLWH/A is scarce. A review of the literature for those over 45-50 years of age evidences that aged PLWH/A tend to be diagnosed at a later stage of disease, presenting to care with a compromised immune system; have increased morbidity and a slower response to antiretroviral therapy (ART); progress more quickly to AIDS, with a slower CD4 cell reconstitution on ART; tend to experience worse treatment side effects, with more drug interactions, (in part for their greater number of medications prescribed for other chronic illnesses); and have an increased risk for and early onset of aging conditions. (*Ryan White Grantee Conference Reports, 2008*)

Additionally, the literature supports that aging PLWH/A have higher rates of dementia, depression, and have a more limited and fragile support system. The aged PLWH/A evidence limited financial, socioeconomic and emotional support, as compared with their younger PLWH/A counterparts. The aging PLWH/A have not been widely exposed to HIV prevention services, often do not personalize their risk, have low HIV knowledge/awareness and were not perceived as at-risk by their providers. (*Ryan White Grantee Conference Reports, 2008*)

To further explore the care patterns and care complications for the aged population, the Nassau-Suffolk HIV Health Services Planning Council commissioned this Aged/45+ PLWH/A Needs Assessment. The findings will be used for the 2010 Priority Setting and Resource Allocation process.

Overview of 2009 Aged/45+ PLWH/A 'In Care' Study Findings

A total of 222 PLWH/A, ages 45+ participated in the 2009 'In Care' survey process. Of these, 56% were male and 44% female. Forty-five percent (45%) were African American; 31% Caucasian; 15% Hispanic; 2% American Indian; 5% Multiracial; and 2% 'other', reporting Jamaican and Haitian heritage. Almost 2/3 (or 62%) reported their age in the 45-54 age group; 35% in the 55-64 age group; and 3% reported their age as 65+.

The majority of the Aged/45+ PLWH/A respondent group (78%) reports their sexual orientation as Heterosexual; 15% report a 'Gay' sexual orientation; 5% report Bisexuality; and 2% preferred not to answer or stated 'celibate'. Risk exposure modes reported by the 2009 Aged/45+ PLWH/A respondent group include: 67% Heterosexual sex; 24% IDU; 20% MSM; 8% Transfusion related; 4% Sex with Drug user; 3% Sexual assault; and 4% reported their risk exposure mode as 'unknown'.

The vast majority of the 2009 Aged/45+ respondents report high levels of poverty (over 87% are living at or below 200-250% of FPL) and most of the aging population currently possess indigent health care benefits: 71% report Medicaid benefits; 36% Medicare benefits; 9% private health insurance; and 28% ADAP-Ryan White or no insurance. Over one-third of the 45+ respondents reports previous or current homelessness and 7% report they are temporarily housed at present, staying with friends or family.

Fully 4/5 or 80% of the Aged/45+ PLWH/A respondent group reports the diagnosis and treatment of one or more chronic illnesses, in addition to HIV disease. Thirty nine percent (39%) report previous diagnosis and/or treatment for a mental health disorder; 51% report a previous diagnosis and/or treatment for a substance abuse disorder; and 36% report diagnosis with STDs, other than HIV disease.

Overall, the Aged/45+ PLWH/A respondents' evidence a strong 'In Care' presence, with 94% reporting current antiretroviral therapy.

Overview of Aged/45+ PLWH/A 'In Care' Respondents' Services Needs, Uses, Gaps and Barriers

TABLE 4: 2009 'IN CARE' Aged/45+ NEED, USE, GAP, & BARRIER MATRIX

| SERVICE CATEGORY | Need Rank | Use Rank | Gap Rank | Barrier Rank |
|--|-----------|----------|-----------|--------------|
| Food Bank/Nutrition Services | 1 | 8 tie | 2 tie | 4 tie |
| Primary Medical Care | 2 | 1 | NR | 7 tie ** |
| Housing Assistance | 3 | 10 | 1 | 2 |
| Medications | 4 | 5 | | 6 |
| Medical Transportation | 5 | 2 | 2 tie | 1 |
| Emergency Financial/Utility Assistance | 6 | 12 tie | 4 | 4 tie |
| Psychological Support/Support Groups | 7 | 6 | 5 tie ** | 7 tie ** |
| Mental Health Counseling | 8 | 4 | 5 tie | 7 tie |
| Health Insurance/Co-pay Assistance | 9 | 7* | NR | 5 tie |
| Case Management | 10 | 3 | NR | 8 tie |
| Oral Health Care | 11 tie | 9 | 5 tie | 5 tie |
| Employment Assistance | 11 tie | NR | 3 | 3 |
| Substance Abuse Treatment | 12 tie | 8 tie | NR | NR |
| Health Information | 12 tie | 11 tie | 6 tie *** | 9 |
| Vision Care | 12 tie | 12 tie | 6 tie | 8 tie |
| Peer Advocate | NR | 11 tie | NR | NR |
| Medical Specialty Care | NR | 12 tie | NR | 8 tie |
| Interpreter Services | NR | NR | NR | 8 tie |
| Legal services/Immigration/INS Papers Assistance | NR | NR | 6 tie | NR |
| Benefits/Medicare/Disability Assistance | NR | NR | 6 tie | NR |

*Includes Medicaid/Medicare & Ryan White

** Lack of evening/after-hour services

*** Low Orientation to services

Top Ranking Aged/45+PLWH/A Service Needs

1. Food Bank/Nutrition Services
2. Primary Medical Care
3. Housing Assistance
4. Medications
5. Medical Transportation
6. Emergency Financial Assistance/Utility Assistance
7. Psychological Support/Support Groups
8. Mental Health Counseling
9. Health insurance/Co-Pay Assistance
10. Case Management
11. Oral Health Care tied with Employment Assistance
12. Substance Abuse Treatment tied with Health Information tied with Vision care

Top Ranking Aged/45+ PLWH/A Service Uses

1. Primary Medical Care
2. Medical Transportation
3. Case Management
4. Mental Health Counseling
5. Medications
6. Psychosocial Support Groups
7. Health Insurance/Co-Pay Assistance (includes health benefits assistance with Medicaid and Medicare)
8. Substance Abuse Counseling tied with Food Bank/Nutrition Services
9. Oral Health Care
10. Housing Assistance
11. Peer Advocate tied with Health Information
12. Medical Specialty Care tied with EFA and Vision Care

Top Ranking Aged/45+ PLWH/A Service Barriers

1. Medical Transportation
2. Housing Assistance
3. Employment Assistance
4. Emergency Financial/Utility Assistance tied with Food Bank/Nutrition services
5. Health Insurance/Disability Assistance tied with Oral Health care
6. Medications (HIV and non-HIV)
7. Mental Health Counseling tied with lack of evening hours for PMC and Support Groups
8. Case Management tied with Interpreter services, Vision Care & Medical Specialty Care
9. Health Information—Lack of information about services available

Aged/45+ PLWH/A Reasons for Service Barriers

Too many restrictions-Rules and lack of money

Case management not enough

Too many documents and days trying to get help. Grants taken away like Thursdays Child - grant is gone.

Funding and regulations as insurances change - private health plan is not paying for my clinic because it is considered an outpatient hospital visit.

Ineffective listening to client, I have been told due to cutbacks, and I also think a lack of communication, efficiency, incompetence of workers. Workers inexperienced using service providers as stepping stones.

The grant amounts don't cover enough - you have to have extra money yourself

Too many people out there with HIV!

Basically hard to meet all the requirements - not enough extra monies - transportation is awkward and crazy with schedules

Services take too long

Money and services changed about transportation

Because that is how Suffolk County is and it is getting worse.

With all the cutbacks, there is not much to offer me out there.

Sometimes I do not qualify

Because of being illegal immigrant, language barrier, no services available

Transportation can be a problem, but I have a car, I'm lucky.

Maybe not enough funding - less and less round transportation trips

The service I need, root canal, very expensive and not covered

My health is creating problems.

Because once you have HIV, you're too great a risk for health insurance

They cost a lot - used to have here at North Shore but not now. Too high demand too high services.

Because I don't have good transportation. Hard to get out but I can have food delivered if over \$50.

Think this is because I am out of job and have to pay bills but not enough to go around

Top Ranking Aged/45+ PLWH/A Service Gaps

1. Housing Assistance
2. Medical Transportation tied with Food Bank/Nutrition Services
3. Employment Assistance
4. Emergency Financial/Utility Assistance
5. Mental Health Counseling tied with Oral Health Care & lack of evening hours for support groups
6. Immigration Assistance/INS papers tied with Disability/Medicare Assistance & Vision care

Aged/45+ PLWH/A Reasons for Service Gaps

Funds and money. Money cuts and priorities.

Frustration creates anxiety which no one with HIV needs. I face obstacles all the time. I am frustrated by the lack of quality of services LIACC especially.

Rents are too high for me to get - don't have enough in my check

Limited services - aren't realistic

They say because Section 8 and my area I don't qualify for much.

Can't use one service if you have used another

Don't know what to say but struggling with it.

Don't have programs or no longer exist

I am out of town area - RW is too far. I have to travel to medical and RW.

I do not qualify

No services available

Table 5. Aged/45+ PLWH/A Service-Specific Barrier and Gap Reasons

| Service Category | Need Rank | Gap Rank | Barrier Rank | Gap Reasons | Barrier Reasons |
|---|-----------|-----------|--------------|--|---|
| Food Bank/Nutrition services | 1 | 2 tie | 4 tie | Went to WACC for food pantry—there was waiting list, so went to another pantry and can only go every 6 months. Food stamps would be nice. Food assistance/better stocked pantry. | Difficult to get to and use food pantries—bags are heavy/cold out with public transportation. Limited pantry in this area. Really hard to get Ensure supplements; I have to buy it hot off the streets. |
| Primary Medical Care | 2 | NR | 7 tie ** | Lack of evening hours and transportation limits | No evening/after hour's clinics for working people. Sometimes medical is hard to get because of the transportation difficulties. |
| Housing Assistance | 3 | 1 | 2 | Rent assistance. To get Section 8 I had to move to Suffolk County and now I have meaningful transportation problems. | Housing is the hardest to get! The lottery for housing is a problem. HUD won't go to Suffolk, so am limited to Nassau away from family. Waiting for Section 8 for a long time. |
| Medications | 4 | | 6 | Need money for meds. | Because of SSD I have spend-down and have to use ADAP to get meds. It is hard to keep up with my spend-down. |
| Medical Transportation | 5 | 2 tie | 1 | I am still trying to get half fare, but application process is long. Transportation is very hard to get. | Transportation extremely difficult—limited number of trips and limited hours. Can only get 1x per month so changed clinic to be closer to home, but do not feel that this one is as good. |
| Emergency Financial Assistance | 6 | 4 | 4 tie | Extra cash to help me survive—I have a wife and 3 kids to raise. Sometimes I need help but it takes forever. Need telephone. | Need a telephone. Need help with utilities. Need help with finances; need more help on SSD/SSI |
| Psychological Support/Support Groups | 7 | 5 tie ** | 7 tie ** | My job is during the day and there are no groups held at night. No support services in the evening. | Lack of evening resources. |
| Mental Health Counseling | 8 | 5 tie | 7 tie | Grant ran out. | Getting the right counselor can be hard—one you can talk to. Need counseling about my grief. |
| Health Insurance/Co-pay Assistance | 9 | NR | 5 tie | Need red, white and blue card. | Having problems with Medicaid. Need help with hospitalization costs. |
| Case Management | 10 | NR | 8 tie | NA | Need more help with spend-down & knowing what services available. Service orientation low. |
| Oral Health Care | 11 tie | 5 tie | 5 tie | Level of dental care needed is hard to get. | Dental health care hard to get. |
| Employment Assistance | 11 tie | 3 | 3 | Need support getting a steady job. | So many obstacles to employment. If I go to work I fear I'll lose some of my benefits. Could use help figuring this out. |
| Substance Abuse Treatment | 12 tie | NR | NR | NA | |
| Health Information | 12 tie | 6 tie *** | 9 | Just need to know where to go | I don't know what's out there. |
| Vision Care | 12 tie | 6 tie | 8 tie | Eye glasses hard to get and pay for. | Can't find help for eye glasses. |
| Peer Advocate | NR | NR | NR | NA | NA |
| Medical Specialty Care | NR | NR | 8 tie | NA | Need allergist for sinus problems; Need chiropractor for bad back; It would be great to have general medical and medical specialist in the same location. Can't get wheelchair on Medicaid. |
| Interpreter Services | NR | NR | 8 tie | NA | Hard to find services in my primary language |
| Immigration/INS Papers Assistance | NR | 6 tie | NR | Immigration assistance is big—because we cannot go back to our countries and we stay illegally and sick. | NA |
| Medicare/Disability Assistance | NR | 6 tie | NR | NA | Hard to get on social security. I want to be on the blue and white card. Medicaid is terrible. |

Chapter 1: Introduction

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

A comprehensive assessment of the service needs, gaps and barriers of “In Care”¹ Aged 45+ PLWH/A within the Nassau-Suffolk EMA was conducted in the spring of 2009. This assessment of need included an “In Care” survey questionnaire of Aged PLWH/A utilizing the In Care Needs Assessment Client Survey (NACS) tool.

Relevance of the Part A Comprehensive “In Care” Aged PLWH/A 45+ Needs Assessments

The targeted Aged/45+ PLWH/A and their sub-populations have emerged as a major focus of study for the Nassau-Suffolk 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 and support services experienced by the ‘In Care’ Aged PLWH/A (45 years+) within the Nassau-Suffolk EMA.

Aged/45+: PLWH/A, ages 45 years or greater, comprise almost 47% of the total living AIDS population and almost 64% of the total PLWH population in the EMA, evidencing substantial disparity. The aged make up 26% of emergent HIV cases and 37% of emergent AIDS cases. (NYSDOH, 2007)

TABLE 6: AGE GROUP DISTRIBUTION (New AIDS and HIV, PLWH/A), 2007

| Age Group (years) | New AIDS Cases | | New HIV Cases | | PLWA | | PLWH | |
|-------------------|----------------|---------------|---------------|--------------|-------------|-------------|-------------|--------------|
| | 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

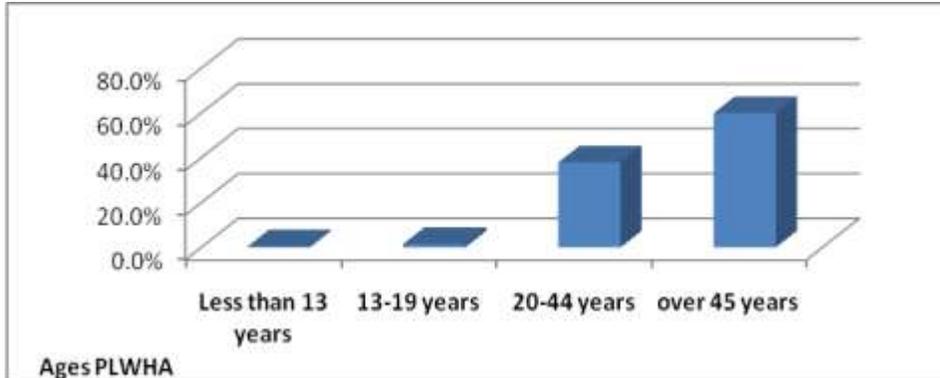
¹ 1) **CD4 – CD4 (T4) or CD4 + CELL COUNT and PERCENT.**

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.

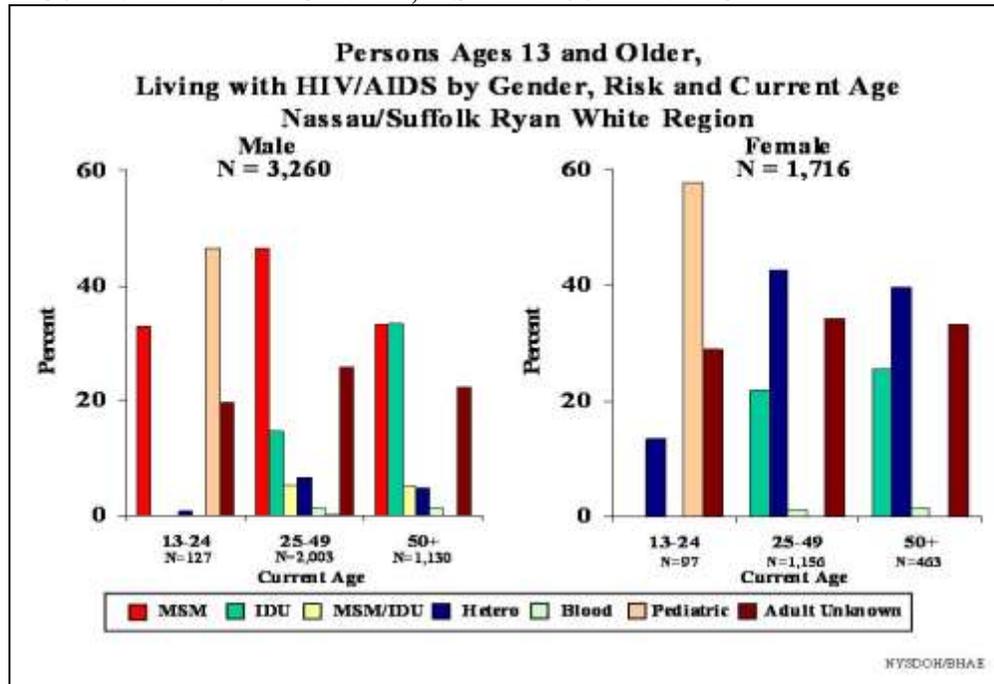
The epidemiologic data clearly reflects that the largest proportion of PLWH/A within the EMA as of 12/31/07 is over 45 years of age (57.66%). The following graph provides a visual representation of the number of PLWH/A in the EMA who are 45 years or greater in age.

FIGURE 2: PLWH/A AGE DISTRIBUTION IN EMA



The Nassau-Suffolk aging PLWH/A risk profile for those Males living with HIV or AIDS, who are currently ages 50+ is primarily comprised of MSM and IDU, as evidenced in Figure 3 below. The aging male PLWH/A profile in the Nassau-Suffolk planning area evidences a smaller Heterosexual risk category than for younger males, ages 25-49 years. Female PLWH/A who are currently 50+ years of age, report their risk exposure mode as primarily Heterosexual, then IDU, with a substantial fraction of those females reporting unknown risk. The 50+ female PLWH/A group reports a greater proportion of IDU than the younger 25-49 year old female PLWH/A, and slightly fewer 50+ females report Heterosexual sex as their risk exposure mode, than their younger PLWH/A counterparts..

FIGURE 3. PLWH/A BY GENDER, RISK AND CURRENT AGE



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

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

The Aged/45+ comprised fully 58% of the PLWH/A population, yet only 46% of the Part A core medical services population in 2007. In contrast, 68% of the support services clients were comprised of 45+ PLWH/A in the 2007 project year. (*NYSDOH and Part A Services, 2007*)

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

| SEVERE NEED GROUP | Percent PLWH/A | Percent in Core Medical Care | Percent in Supportive Care | Percent in any Part A Care |
|--------------------------|-----------------------|-------------------------------------|-----------------------------------|-----------------------------------|
| African Americans | 38% | 30% | 63% | 40% |
| Hispanics | 20% | 15% | 17% | 15% |
| MSM | 29% | 21% | 16% | 19% |
| Women of Color | N/A per NYSDOH | 19% | 42% | 26% |
| IDU | 19% | 13% | 18% | 15% |
| 45+/Aged | 58% | 46% | 68% | 53% |

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.

Approximately 15% of the people with HIV in the US are over the age of 50 (*Centers for Disease Control and Prevention, 2008*). This estimate includes people who were over 50 at the time of their diagnosis, and people with HIV who have aged into this "older" age category.

Nationally, in 2005, persons aged 50 and over accounted for:

- 15% of new HIV/AIDS diagnoses;
- 24% of persons living with HIV/AIDS (increased from 17% in 2001);
- 19% of all AIDS diagnoses;
- 29% of persons living with AIDS; and
- 35% of all deaths of persons with AIDS.

The rates of HIV/AIDS among persons 50 and older were 12 times as high among blacks (51.7/100,000) and 5 times as high among Hispanics (21.4/100,000) compared with Whites (4.2/100,000). (*HIV/AIDS among Persons Aged 50 and Older, CDC HIV/AIDS Facts, February, 2008*)

Aging PLWH/A tend to be diagnosed later in their disease process. In 2005, among HIV-positive older adults, one-half (50%) were diagnosed with HIV and AIDS simultaneously or were diagnosed with AIDS within 1 year of their HIV diagnosis. (Linley L, Hall HI, An Q, et al. *HIV/AIDS diagnosis among persons fifty years and older in 33 states, 2001-2005. National HIV Prevention Conference (abstract B08-1); December 2007. Atlanta, GA.*)

HIV often goes undiagnosed in older adults for several reasons:

- Clinicians may underestimate the risk for HIV among older adults and not discuss HIV transmission or perform testing.
- Common, nonspecific HIV symptoms, such as fatigue, may be mistaken for signs of aging or other conditions.
- Older patients may not perceive themselves as at risk for HIV because of a lack of information on HIV prevention and transmission. (*The Graying of HIV, HRSA CARE Action Newsletter, February 2009*)

A massive number of PLWH/A 45 years and over will begin to confront aging issues in the next decade. The existing knowledge base regarding older PLWH/A is scarce. A review of the literature for those over 45-50 years evidence that aged PLWH/A tend to be diagnosed at a later stage of disease and present to care with a compromised immune system; have increased morbidity and a slower response to antiretroviral therapy (ART); progress more quickly to AIDS, with a slower CD4 cell reconstitution on ART; tend to experience worse treatment side effects, with more drug interactions, in part for their greater number of medications prescribed for other chronic illnesses; and have an increased risk for and early onset of aging conditions. Additionally, the literature supports that aging PLWH/A are aging more quickly, and have higher rates of dementia, depression, with a more limited and fragile support system. The aged PLWH/A evidence limited financial, socioeconomic and emotional support, as compared with their younger counterparts. The aging PLWH/A often do not personalize their risk and have low HIV knowledge/awareness and are not perceived as at-risk by their providers. (*Ryan White Grantee Conference Reports, 2008*)

Project Design for the ‘In Care’ Aged/45+ PLWH/A Needs Assessment Study

The objective of the Aged/45+ PLWH/A ‘In Care’ Needs Assessment Study was to identify the extent and types of service Needs, Uses, Gaps and Barriers among Aged/ 45+ “In Care” PLWH/A in the Nassau-Suffolk EMA service area.

TABLE 8. RYAN WHITE IN CARE POPULATION BY SNG

| Emerging Population | # RW clients served in ‘06 |
|----------------------------|-----------------------------------|
| African Americans | 1,567 |
| Hispanics | 681 |
| MSM | 706 |
| IDU | 581 |
| Women of Color | 997 |
| Aged | 1,624 |
| TOTAL | 3,368 |

The sample for surveying the Aged 'In Care' population was first determined by establishing a 15% participation rate for a representative sampling of the estimated number of PLWH/A in the Nassau-Suffolk EMA. The survey process was designed to target as high level participation as possible among the key emerging aged population of PLWH/A receiving Ryan White Part A funded services (N=15% of 1,624=244). The actual participation rate for 'In Care' 45+ PLWH/A totaled 222 survey participants in the 2008 Needs Assessment process.

Literature Review: Aged/45+ PLWH/A

1) Socioeconomic Disparities owing to Age, Race and Exposure category: National studies of the socioeconomic profile of older adults with HIV, between the ages of 50 and 61 years, (based on the HIV Cost and Services Utilization Study-HCSUS, 1996-and the Health and Retirement Survey) found that older whites with HIV are mostly homosexual men who are more well educated, more often privately insured, and more financially stable than the HIV population as a whole. In contrast, older minorities with HIV possess few economic resources in either absolute or relative terms. (*J Health Care Poor Underserved*, 2005 Feb; 16(1):19-28). A similar study which profiled the socioeconomic circumstances of the middle-aged and older populations living with HIV, (also based on the HIV Cost and Services Utilization Study), indicated that age and exposure category have an impact on socioeconomic well-being. Older gay men (MSM) with HIV/AIDS are a predominantly white population and more likely to have health insurance than their younger counterparts; 38% were employed and 48% reported incomes of more than \$25,000. Older injection drug users (IDU) with HIV/AIDS are a predominantly Black population with a particularly high concentration of disadvantages; only 11% were employed and 74% reported incomes of less than \$10,000. Older IDU reported especially low levels of physical functioning and emotional support in comparison with their younger counterparts, whereas older gay men did not significantly differ from younger gay men in these respects. The authors concluded that characteristics and care needs of the older HIV-positive population are diverse and vary sharply by exposure route. (*J Acquir Immune Defic Syndr*. 2003 Jun 1; 33 Suppl 2:S76-83). The recession and worsening economy are likely to worsen the financial outlook for and further de-stabilize the aging population of PLWH/A.

2) Stigma: Older adults, both as newly infected individuals and as long-term survivors of HIV/AIDS living into older age experience stigma, owing to feelings of rejection, disclosure concerns, stereotyping, and protective silence. Study findings reveal that stigma goes hand-in-hand with depression and stigma was found to be significantly higher in older African Americans, as compared to Whites. (*AIDS Patient Care STDS*. 2007 Oct; 21(10):740-52). Based on the Beck Depression Inventory, 25% of participants in one study reported 'moderate' or 'severe' levels of depression and also reported more HIV-related life-stressor burden, less support from friends, and reduced access to health care and social services due to AIDS-related stigma. (*Aging Mental Health*. 2002 May; 6(2):121-8).

3) Co-morbidities/HIV & Chronic Illness: Nationally, there is a small but growing body of research about 'Aged' PLWH/A and the prevalence of co-morbidities other than HIV/AIDS. In one study, older PLWH/A were significantly less likely to rate their health and well-being as good or excellent, and a significantly larger percentage of older PLWH/A reported additional health conditions (47.2% versus 35.5% in younger PLWH/A), of which the most common was

cardiovascular disease (12.2% of older PLWH/A). Older PLWH/A were markedly less likely to be in contact with services, both those that were HIV-related and those that were not. (*AIDS Patient Care STDS*. 2005 Jul; 19(7):460-5).

Several EMAs have now conducted age-specific needs assessments, and of these, they report anywhere from 4-6 co-morbid conditions compared to 2-3 in the below 45 years of age population. **Fully 80% of the 45+ respondent pool reported that they had been diagnosed and treated for one or more chronic illnesses, other than HIV.** Almost 40% of the 45+ survey participants reported co-morbid mental illness and over 50% report diagnosis and treatment for a substance abuse disorder. Fully 36% had been treated for another sexually transmitted disease.

4) Epidemiology: 'Aged' PLWH/A nationally constitute approximately 15% of the overall infected community. This compares to a figure of 44% of PLWA and 35% of PLWH for 2005. New AIDS cases continue to increase with a 2005 figure of 32%. The 'Aged' group continues to rapidly escalate as the general population ages and incidence among those over 45 years of age rises compared to the general population. Both age bands (under 20 years of age and over 45) show more rapid incidence than the large mid-age band of 21-44 years. The aged differ from the 'young' and mid-age bands in a higher percentage (52%) of AIDS diagnoses versus HIV, MSM constituting the largest group and high-risk heterosexual women rising at the highest rate for the newly diagnosed over 60 years of age. (*CDC, 2008*)

5) Late Diagnosis and Disease Progression: Due to the confounding symptoms of HIV and aging and the overall lack of awareness by general physicians about the risk of HIV due to risky sexual practices and/or drug use among those over 45 years of age, delayed diagnosis upon symptom onset is common among the 'aged'. Concurrent HIV/AIDS diagnoses are far too common. The few studies conducted by other EMAs show that twelve-to-eighteen months transpired on average from symptom onset and attempts to determine condition to an HIV diagnosis. Often the diagnosis was stumbled upon through blood testing for other diseases or was instigated by the individual, not their physician. HIV prevention and education materials focus on youth, creating a distorted impression of who is affected by HIV/AIDS. This 'ageism' is further exacerbated by the reluctance of older adults and their physicians to discuss sexual behaviors and substance use issues.

6) Social Isolation: The profound sense of social isolation reported in other studies was echoed by respondents to the Nassau- Suffolk 'Aged' Needs Assessment. Few groups exist to deal with this specific subpopulation, with senior groups hostile to admission of HIV/AIDS, at a time when support is sorely needed. Few age-specific clinical trials, research programs or education/prevention groups exist for this subgroup. One of the top ranking needs expressed by the 2009 survey participants is the need for more psychosocial support and support groups.

7) Prevention Needs of Older PLWH/A: The aging population of PLWH/A often remain sexually active and/or resume sexual activity after learning their HIV status. Prevention education and counseling performed with older PLWH/A will necessarily need to be adapted to meet the special needs of this population.

Chapter 2: “In Care” Aged/45+ PLWH/A Survey Findings

Overview of the Aged “In Care” 45+ PLWH/A Survey Results

The ‘In Care’ client surveys of Aging PLWH/A (45+) were scheduled over a two-month period in the spring of 2009. The tables below indicate the gender, race/ethnicity, age range, sexual orientation and risk exposure mode of the 222 Aged ‘In Care’ survey respondents.

Demographic and Health Profile of “In Care” 45+ Survey Respondents:

TABLE 9. GENDER OF 45+ PLWH/A SURVEY RESPONDENT GROUP

| Are you? | | |
|--------------------------|------------------|--------------|
| Answer Options | Frequency | Count |
| Male | 55.5% | 122 |
| Female | 44.5% | 98 |
| Transgender | 0.0% | 0 |
| <i>answered question</i> | | 220 |

Among the 2009 Aged/45+ survey respondents, 56% were male and 44% were female. Almost half of the aged respondents were African American (45%); 31% Caucasian; 15% Hispanic; and 7% multiracial/other race (with two of the four ‘other’ reporting Jamaican and Haitian heritage).

TABLE 10. RACE/ETHNICITY OF 45+ PLWH/A RESPONDENTS

| Do you consider yourself? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| African American | 45.0% | 100 |
| American Indian | 1.8% | 4 |
| Asian/Pacific Islander | 0.0% | 0 |
| Caucasian | 30.6% | 68 |
| Hispanic/Latino | 15.3% | 34 |
| Multi-Racial | 5.4% | 12 |
| Other (please specify): Jamaican, Haitian | 1.8% | 4 |
| <i>answered question</i> | | 222 |

TABLE 11. AGE RANGE OF 45+ PLWH/A RESPONDENTS

| What year were you born? | | |
|---------------------------------|------------------|--------------|
| Answer Options | Frequency | Count |
| 45-54 years | 62% | 138 |
| 55-64 years | 35% | 78 |
| 65+ | 3% | 6 |
| <i>answered question</i> | | 222 |

The largest age band among the respondent group (62%) reports their age between 45 and 54 years. Thirty-five percent (35%) reports their age in the range of 55-64 years. Only 3% of the respondents reported their age as 65+.

TABLE 12. SEXUAL ORIENTATION OF AGED 45+ RESPONDENTS

| What is your sexual orientation? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| Gay | 15.3% | 34 |
| Bisexual | 4.5% | 10 |
| Straight | 77.5% | 172 |
| Prefer not to Answer | 1.8% | 4 |
| Other (please specify): "Celibate" | 0.9% | 2 |
| <i>answered question</i> | | 222 |

As evidenced in the table above, over three quarters of the respondent group of 45+ PLWH/A (78%) reports their sexual orientation as heterosexual or 'straight'. Only 15% report a 'gay' sexual orientation, and almost 5% report their sexual orientation as 'bisexual'. As depicted in the table below, two thirds (67%) of all the 45+ PLWH/A respondent group reports Heterosexual sex for their risk exposure mode. The next most frequently reported risk exposure mode, reported by almost ¼ (24%) is injection drug use (IDU); followed by almost 20% who attribute the source of their HIV exposure as MSM risk behavior. A minority of the 45+ PLWH/A respondents report Sex with a Drug user (4%); Sexual Assault (3%); and Transfusion as their HIV transmission mode. Almost 4% report their risk exposure mode as 'unknown'.

TABLE 13. RISK EXPOSURE MODE

| Do you know how you may have acquired HIV/AIDS? (Check all that apply)? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Male sex w/male | 19.8% | 44 |
| Injection Drug Use | 24.3% | 54 |
| Sex with Drug User | 3.6% | 8 |
| Heterosexual Sex | 66.7% | 148 |
| Sexual Assault | 2.7% | 6 |
| Unknown | 3.6% | 8 |
| Transfusion | 8.1% | 18 |
| Other (please specify): Stuck with IDU partner's needle | 0.9% | 2 |
| <i>answered question</i> | | 222 |

Residence and Living Arrangements

A total of 116 (or over half) of the 222 "In Care" 45+ PLWH/A survey participants reported their residence in one of 13 zip codes in the Nassau-Suffolk EMA of the total of 55 different zip codes were reported by the 2009 respondents. (See Table 14 below and on the following page)

TABLE 14: TOP 13 ZIP CODES OF RESIDENCE

| ZIP CODE | COUNTY | Number 45+ Respondents |
|-----------------|--------------------------|---------------------------------------|
| 11413 | Queens, NY | 6 |
| 11550 | Hampstead, Nassau | 30 |
| 11570 | Rockville Centre, Nassau | 6 |
| 11701 | Amityville, Suffolk | 6 |
| 11706 | Bay Shore, Suffolk | 8 |
| 11717 | Brentwood, Suffolk | 9 |

| ZIP CODE | COUNTY | Number 45+ Respondents |
|--------------|-----------------------------|------------------------|
| 11722 | Central Islip, Suffolk | 6 |
| 11735 | Farmingdale, Nassau | 6 |
| 11746 | Huntington Station, Suffolk | 8 |
| 11755 | Lake Grove, Suffolk | 7 |
| 11757 | Lindenhurst, Suffolk | 6 |
| 11772 | Patchogue, Suffolk | 8 |
| 11946 | Hampton Bays, Suffolk | 10 |
| TOTAL | | 116 |

HIV/AIDS Status and Year of Diagnosis

Over half (52%) of the 45+ PLWH/A respondents reports living with HIV and 47% report living with AIDS (with 1% reporting not knowing their HIV/AIDS status). The range of years from initial HIV diagnosis spans from 1981 to 2008, with approximately half of the total HIV diagnoses occurring prior to 1996 and half reported from 1997 to date. Therefore, a substantial number of those whose age is now 45+ most likely were in their late 20's and 30's when initially diagnosed with HIV. Among those 104 PLWH/A who report an AIDS diagnosis, diagnosis dates ranged from 1985 to 2008.

The vast majority of 45+ PLWH/A respondents' reports receiving their HIV/AIDS diagnoses in the State of New York. Only 20 PLWH/A report receiving their HIV diagnosis in a state other than New York, including California, North Carolina, North Dakota, New Jersey, and Pennsylvania. (Four respondents did not answer the question).

Health Insurance Coverage

Almost three quarters (71%) of the Aged/45+ respondents reported Medicaid benefits; another 36% reports Medicare benefits and another 9% reports private insurance. None of the 2009 respondents reported VA benefits. Over 25% report 'ADAP' as their primary form of health insurance. The 'other' benefits were reported as AARP, United Health, ADAP, HIAP or Suffolk Health Plan. (Some Aged PLWH/A claim two forms of insurance, most frequently Medicaid and Medicare benefits.)

TABLE15. CURRENT HEALTH INSURANCE COVERAGE

| Do you currently have health insurance? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Private Health Insurance (Humana, Aetna, etc) | 9.0% | 20 |
| Medicare | 36.0% | 80 |
| Medicaid | 71.2% | 158 |
| ADAP | 25.2% | 56 |
| None | 2.7% | 6 |
| Other (please specify): United Health, Suffolk Health Plan, AARP, ADAP, HIAP | 5.4% | 6 |
| <i>answered question</i> | | 222 |

Last Physician Visit and CD4 and Viral Load Monitoring Visits

As noted below, there were only six of the 2009 PLWH/A who could be categorized as ‘erratically’ In Care and none of the 45+ PLWH/A had a technically ‘Out of Care’ status according to their reports of their most recent HIV Primary Care Physician (PCP) visit. Overall, this “In Care” respondent group evidences an excellent connection to care, with the vast majority evidencing an ideal or satisfactory HIV primary medical care visit pattern. Per client survey reports, one 45+ PLWH/A just returned to care from a lengthy absence, having very recently seen the doctor, and in process of obtaining laboratory testing.

A total of 94% of the Aged/45+ PLWH/A respondent group reports the current active receipt of antiretroviral therapy. Overall, lab monitoring visit patterns reflect the same strong connection to care as for the PCP visit patterns, with the exception of only two 45+ PLWH/A who reported their last viral load test early in 2008 (1/08 and 5/08, respectively).

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

| VISIT TIME FRAME | DOCTOR | CD4 | VIRAL LOAD |
|--|------------|------------------------|------------------------|
| Past 3-4 Months 1/09-3/09 (Ideal “In Care” Status) | 102 | 93 | 93 |
| Past 4-6 Months 10/08-12/08 (Satisfactory “In Care” Status) | 114 | 122 | 120 |
| Past 7-9 Months 7/08-9/08 (Erratically “In Care” Status) | 6 | 6 | 6 |
| Past 10-12 Months 4/08-6/08 (Erratically “In Care” Status- At risk of Unmet Need) | 0 | 0 | 2 |
| TOTAL “In Care” | 222 | 221 | 221 |
| ‘Out of Care’ > One Year (OOC Since 2007 or before) | 0 | 1- just re- entered | 1- just re- entered |
| Did not answer | 0 | 0 | 0 |
| TOTAL ‘Out of Care’ | 0 | 0 | 0 |
| GRAND TOTAL | 222 | 222 | 222 |

The largest proportion of the Aged/45+ respondent group reports the receipt of their HIV primary medical care from North Shore Clinic (approximately 38%). Another 17% reports their primary medical home as Stony Brook, and another 17% reports Nassau University Medical Center as their HIV primary care clinic.

‘Other’ HIV primary care clinics reported by this 45+ respondent group included Brentwood Health Center, Brookhaven, David E. Rogers Center, Elmhurst, Martin Luther King Center,

Patchogue Clinic, Private physicians, Shirley Health Care, South Brookhaven, and Tri-Community Health.

TABLE 17. CLINIC/DOCTOR LOCATION

| What clinic/doctor's office do you go to for your HIV? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| SUNY-Stony Brook | 17.1% | 38 |
| North Shore | 37.8% | 84 |
| Nassau University Medical Center (NUMC) | 17.1% | 38 |
| Other (please specify) | 27.9% | 62 |
| <i>answered question</i> | | 222 |

The 2009 Aged/45+ PLWH/A group of respondents reported the location of their HIV primary care physician as more heavily weighted in Nassau County (56%) with 41% reporting Suffolk County, and only three percent of respondents reporting New York City.

TABLE 18. COUNTY LOCATION OF PCP

| In what County is this doctor located? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| Nassau | 55.5% | 122 |
| Suffolk | 40.9% | 90 |
| New York City | 2.7% | 6 |
| Other (please specify): Not sure of County location | 0.9% | 2 |
| <i>answered question</i> | | 220 |

History of Mental Illness

TABLE 19. HISTORY OF DIAGNOSIS/TREATMENT FOR MENTAL ILLNESS

| Have you ever been diagnosed with or treated for a mental illness? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| Yes | 38.7% | 86 |
| No | 61.3% | 136 |
| <i>answered question</i> | | 222 |

Almost 39% of the Aged/45+ PLWH/A reports having been diagnosed and/or treated for a mental health disorder (compared to 46% of the 2009 MSM participant group). An identical proportion of the 45+ PLWH/A respondents (51%) report a history of diagnosis and/or treatment for a substance abuse disorder, (as compared to the MSM respondent group with 51%).

History of Substance Abuse

TABLE 20. DIAGNOSIS OF OR TREATMENT FOR SUBSTANCE ABUSE DISORDER

| Have you ever been diagnosed with or treated for substance abuse? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Yes | 51.4% | 114 |
| No | 48.6% | 108 |
| <i>answered question</i> | | 222 |

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

As evidenced in the tables below, almost 36% of the Aged/45+ PLWH/A respondents report a previous diagnosis and/or treatment for STDs other than HIV (compared to 40% of the 2009 MSM respondents) and **over 80% reports diagnosis and/or treatment for other chronic illness**, indicating a much higher cost of care ratio among ‘In Care’ Aged/45+ PLWH/A in the EMA.

TABLE 21. DIAGNOSIS AND TREATMENT OF STDs

| Have you ever been diagnosed with or treated for sexually transmitted diseases (STD)? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Yes | 35.5% | 78 |
| No | 62.7% | 138 |
| Don't know | 1.8% | 4 |
| <i>answered question</i> | | 220 |

TABLE 22. DIAGNOSIS AND TREATMENT OF DISEASES OTHER THAN HIV

| Have you ever been diagnosed with or treated for diseases other than HIV? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Yes | 80.2% | 178 |
| No | 19.8% | 44 |
| <i>answered question</i> | | 222 |

History of Homelessness

TABLE 23. CURRENT OR PREVIOUS HOMELESSNESS

| Are you now or have you ever been homeless? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Never | 62.7% | 138 |
| Currently homeless | 0.9% | 2 |
| Been homeless in past 2 years, but not now | 4.5% | 10 |
| Been homeless longer than past 2 years, not now | 31.8% | 70 |
| <i>answered question</i> | | 220 |

As evidenced in the table above, over 37% of the 2009 ‘In Care’ Aged/45+ PLWH/A respondent group reports being currently or previously homeless. For the majority of these PLWH/A, it has been two or more years since their most recent period of homelessness, and only two report current homelessness. However, this finding is indicative of substantial housing instability and supports the finding that housing assistance is viewed as a top priority service need.

Current Living Arrangements

As evidenced in Table 24 below, only 7% of the 2009 45+ PLWH/A respondents are ‘precariously housed, staying with friends or relatives. (See Table 24 on the following page)

TABLE 24. CURRENT LIVING ARRANGEMENTS/PLACE OF RESIDENCE

| Do you currently? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| Own your home | 10.8% | 24 |
| Rent | 78.4% | 174 |
| Live with a Friend/Relative | 7.2% | 16 |
| Stay in a Shelter | 0.0% | 0 |
| Other (please specify): Catholic Charities; Transitional Housing; 'Work for agency that houses me'; Sober living residence | 3.6% | 8 |
| <i>answered question</i> | | 222 |

A total of 52% of all Aged/45+ PLWH/A reports the receipt of some form of housing assistance/rent assistance.

Recent Jail or Prison Stay

Only 2% of the 45+ PLWH/A survey participants reported a recent jail or prison stay in the past six months.

Employment, Education and Income Levels

As indicated below, almost 30% of the Aged/45+ PLWH/A respondent group reports current employment, while 71% are unemployed. Employment Assistance is viewed as a top ranking service Gap and Barrier in the EMA (ranking #3, respectively).

TABLE 25. CURRENT EMPLOYMENT STATUS

| Are you currently employed? | | |
|------------------------------------|------------------|--------------|
| Answer Options | Frequency | Count |
| Yes | 29.1% | 64 |
| No | 70.9% | 156 |
| <i>answered question</i> | | 220 |

The educational levels of the 2009 Aged/45+ PLWH/A tend toward the lower levels, with over half of the respondents, or 55%, reporting a high school diploma or only some high school or grade school education or less. Over 31% report some college level education, with approximately 10% reporting a collage degree. Less than 4% of the Aged respondents report some graduate level education or a graduate level degree.

TABLE 26. HIGHEST LEVEL OF EDUCATION

| What is your highest level of education? | | |
|---|------------------|--------------|
| Answer Options | Frequency | Count |
| Grade school | 0.9% | 2 |
| Some high school | 19.3% | 42 |
| High School degree/GED | 34.9% | 76 |
| Some college | 31.2% | 68 |
| College degree | 10.1% | 22 |
| Some graduate school | 1.8% | 4 |
| Graduate school degree | 1.8% | 4 |
| <i>answered question</i> | | 218 |

TABLE 27. ANNUAL INCOME LEVEL

| What is your approximate yearly income? | | |
|--|------------------|--------------|
| Answer Options | Frequency | Count |
| \$0-\$9,999 | 59.1% | 130 |
| \$10,000 - \$19,999 | 28.2% | 62 |
| \$20,000-\$29,999 | 3.6% | 8 |
| \$30,000 - \$39,999 | 3.6% | 8 |
| \$40,000-\$49,999 | 1.8% | 4 |
| Over \$50,000 | 3.6% | 8 |
| <i>answered question</i> | | 220 |

As indicated above, the Aged/45+ survey respondents report very low levels of income, overall, with the vast majority reporting incomes at or below 200-250% of the federal poverty level. This finding correlates with the high numbers of persons reporting unemployment and/or the receipt of indigent health care benefits, including Medicaid (>71%) and other Ryan White or state assistance. Reported levels of current income reflect an impoverished group of aging PLWH/A, overall.

‘2009 ‘In Care’ Aged/45+Needs Assessment Survey Results

The “In Care” 45+ PLWH/A Needs Assessment Survey results are discussed in order by the frequency and rankings of expressed service needs, service usage, service gaps and service barriers based upon the following definitions:

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

(See Table 28--2009 Aged/ 45+PLWH/A Service Need, Use, Gap, and Barrier Matrix, on the following page)

2009 Aged/ 45+PLWH/A Service Need, Use, Gap, and Barrier Matrix

TABLE 28: 2009 'In Care' AGED/45+ PLWH/A NEED, USE, GAP, & BARRIER MATRIX

| SERVICE CATEGORY | Need Rank | Use Rank | Gap Rank | Barrier Rank |
|------------------------------------|-----------|----------|---------------------------------|---------------------------|
| Food Bank/Nutrition services | 1 | 8 tie | 2 tie | 4 tie |
| Primary Medical Care | 2 | 1 | NR | 7 tie (no evening hours) |
| Housing Assistance | 3 | 10 | 1 | 2 |
| Medications | 4 | 5 | | 6 |
| Medical Transportation | 5 | 2 | 2 tie | 1 |
| Emergency Financial Assistance | 6 | 12 tie | 4 | 4 tie |
| Psychological Support | 7 | 6 | 5 tie (no evening services) | 7 tie (no evening groups) |
| Mental Health Counseling | 8 | 4 | 5 tie | 7 tie |
| Health Insurance/Co-pay Assistance | 9 | 7* | NR | 5 tie |
| Case Management | 10 | 3 | NR | 8 tie |
| Oral Health Care | 11 tie | 9 | 5 tie | 5 tie |
| Employment Assistance | 11 tie | NR | 3 | 3 |
| Substance Abuse Treatment | 12 tie | 8 tie | NR | NR |
| Health Information | 12 tie | 11 tie | 6 tie (orientation to services) | 9 |
| Vision Care | 12 tie | 12 tie | 6 tie | 8 tie |
| Peer Advocate | NR | 11 tie | NR | NR |
| Medical Specialty Care | NR | 12 tie | NR | 8 tie |
| Interpreter Services | NR | NR | NR | 8 tie |
| Immigration/INS Papers Assistance | NR | NR | 6 tie | NR |
| Medicare/Disability Assistance | NR | NR | 6 tie | NR |

Top Ranking Aged/45+PLWH/A Service Needs

1. Food Bank/Nutrition services
2. Primary Medical Care
3. Housing Assistance
4. Medications
5. Medical Transportation
6. Emergency Financial Assistance/Utility Assistance
7. Psychological Support/Support Groups
8. Mental Health Counseling
9. Health insurance/Co-Pay Assistance
10. Case Management
11. Oral Health Care tied with Employment Assistance
12. Substance Abuse Treatment tied with Health Information tied with Vision Care

Top Ranking Aged/45+ PLWH/A Service Uses

1. Primary Medical Care
2. Medical Transportation
3. Case Management
4. Mental Health Counseling
5. Medications
6. Psychosocial Support Groups
7. Health Insurance/Co-Pay Assistance (includes Medicaid and Medicare)
8. Substance Abuse Counseling tied with Food Bank/Nutrition Services
9. Oral Health Care
10. Housing Assistance
11. Peer Advocate tied with Health Information
12. Medical Specialty Care tied with EFA and Vision Care

Top Ranking Aged/45+ PLWH/A Service Gaps

1. Housing Assistance
2. Medical Transportation tied with Food Bank/Nutrition services
3. Employment Assistance
4. Emergency Financial/Utility Assistance
5. Mental Health Counseling tied with Oral Health Care tied with 'lack of evening hours for support groups'
6. Immigration Assistance tied with Disability/Medicare Assistance tied with Vision Care

Aged/45+ Reasons for Service Gaps

Lack of funds and money cuts

Frustration creates anxiety which no one with HIV needs. I face obstacles all the time. I am frustrated by the lack of quality of services LIACC especially.

Rents are too high for me to get - don't have enough in my check

Too many cut backs - RW cut back

They say because Section 8 and my area I don't qualify for much.

Can't use one service if you have used another

Don't know what to say but struggling with it.

Don't have programs or no longer exist

I am out of town area - RW is too far. I have to travel to medical and RW.

I do not qualify

No services available

Top Ranking Aged/45+ PLWH/A Service Barriers

1. Medical Transportation
2. Housing Assistance
3. Employment Assistance
4. Emergency Financial/Utility Assistance tied with Food Bank/Nutrition services
5. Health Insurance/Disability Assistance tied with Oral Health Care
6. Medications (HIV and non-HIV)
7. Mental Health Counseling tied with 'lack of evening hours for PMC and Groups'
8. Case Management tied with Interpreter services, Vision Care & Medical Specialty Care
9. Health Information—'lack of information about services available'

Aged/45+ PLWH/A Reasons for Service Barriers

Too many restrictions

Rules and lack of money

Case management not enough

Too many documents and days trying to get help. Grants taken away like Thursdays Child - grant is gone.

Funding and regulations as insurances change - private health plan is not paying for my clinic because it is considered an outpatient hospital visit.

Ineffective listening to client, I have been told due to cutbacks, and I also think a lack of communication, efficiency, incompetence of workers. Workers inexperienced using service providers as stepping stones.

Limits and funds

The grant amounts don't cover enough - you have to have extra money yourself

When I ask, I am told funding

Too many people out there with HIV!

Basically hard to meet all the requirements - not enough extra monies - transportation is awkward and crazy with schedules

Services take too long

Money and services changed about transportation

Because that is how Suffolk County is and it is getting worse.

With all the cutbacks, there is not much to offer me out there.

Sometimes I do not qualify

Because of being illegal immigrant, language barrier, no services available

Transportation can be a problem, but I have a car, I'm lucky.

Maybe not enough funding - less and less round transportation trips

The service I need, root canal, very expensive and not covered

My health is creating problems.

Because once you have HIV, you're too great a risk

They cost a lot - used to have here at North Shore but not now. Too high demand too high services.

Because I don't have good transportation and I'm just recovering from bad flu. Hard to get out but I can have food delivered if over \$50.

Think this is because I am out of job and have to pay bills but not enough to go around

(See Table 29: Aged/45+ Service-Specific Barrier and Gap Reasons on the following page)

TABLE 29. AGED/45+ SERVICE-SPECIFIC BARRIER AND GAP REASONS

| Service Category | Need Rank | Gap Rank | Barrier Rank | Gap Reasons | Barrier Reasons |
|---|-----------|-----------|--------------|--|---|
| Food Bank/Nutrition services | 1 | 2 tie | 4 tie | Went to WACC for food pantry—there was waiting list, so went to another pantry and can only go every 6 months. Food stamps would be nice. Food assistance/better stocked pantry. | Difficult to get to and use food pantries—bags are heavy/cold out with public transportation. Limited pantry in this area. Really hard to get Ensure supplements; I have to buy it hot off the streets. |
| Primary Medical Care | 2 | NR | 7 tie ** | Lack of evening hours and transportation limits | No evening/after hour's clinics for working people. Sometimes medical is hard to get because of the transportation difficulties. |
| Housing Assistance | 3 | 1 | 2 | Rent assistance. To get Section 8 I had to move to Suffolk County and now I have meaningful transportation problems. | Housing is the hardest to get! The lottery for housing is a problem. HUD won't go to Suffolk, so am limited to Nassau away from family. Waiting for Section 8 for a long time. |
| Medications | 4 | | 6 | Need money for meds. | Because of SSD I have spend-down and have to use ADAP to get meds. It is hard to keep up with my spend-down. |
| Medical Transportation | 5 | 2 tie | 1 | I am still trying to get half fare, but application process is long. Transportation is very hard to get. | Transportation extremely difficult—limited number of trips and limited hours. Can only get 1x per month so changed clinic to be closer to home, but do not feel that this one is as good. |
| Emergency Financial Assistance | 6 | 4 | 4 tie | Extra cash to help me survive—I have a wife and 3 kids to raise. Sometimes I need help but it takes forever. Need telephone. | Need a telephone. Need help with utilities. Need help with finances; need more help on SSD/SSI |
| Psychological Support/Support Groups | 7 | 5 tie ** | 7 tie ** | My job is during the day and there are no groups held at night. No support services in the evening. | Lack of evening resources. |
| Mental Health Counseling | 8 | 5 tie | 7 tie | Grant ran out. | Getting the right counselor can be hard—one you can talk to. Need counseling about my grief. |
| Health Insurance/Co-pay Assistance | 9 | NR | 5 tie | Need red, white and blue card. | Having problems with Medicaid. Need help with hospitalization costs. |
| Case Management | 10 | NR | 8 tie | NA | Need more help with spend-down & knowing what services available. Service orientation low. |
| Oral Health Care | 11 tie | 5 tie | 5 tie | Level of dental care needed is hard to get. | Dental health care hard to get. |
| Employment Assistance | 11 tie | 3 | 3 | Need support getting a steady job. | So many obstacles to employment. If I go to work I fear I'll lose some of my benefits. Could use help figuring this out. |
| Substance Abuse Treatment | 12 tie | NR | NR | NA | |
| Health Information | 12 tie | 6 tie *** | 9 | Just need to know where to go | I don't know what's out there. |
| Vision Care | 12 tie | 6 tie | 8 tie | Eye glasses hard to get and pay for. | Can't find help for eye glasses. |
| Peer Advocate | NR | NR | NR | NA | NA |
| Medical Specialty Care | NR | NR | 8 tie | NA | Need allergist for sinus problems; Need chiropractor for bad back; It would be great to have general medical and medical specialist in the same location. Can't get wheelchair on Medicaid. |
| Interpreter Services | NR | NR | 8 tie | NA | Hard to find services in my primary language |
| Immigration/INS Papers Assistance | NR | 6 tie | NR | Immigration assistance is big—because we cannot go back to our countries and we stay illegally and sick. | NA |
| Medicare/Disability Assistance | NR | 6 tie | NR | NA | Hard to get on social security. I want to be on the blue and white card. Medicaid is terrible. |

CHAPTER 3: Recommendations for Comprehensive Strategic Plan

Special Strategies Directed toward Optimizing Access and Retention in Care

In response to the 2009 needs assessment study findings, the following general recommended strategies may be employed by the Nassau-Suffolk HIV Health Services Planning Council to further strengthen the service delivery system in the Nassau-Suffolk EMA:

Overall Strategies to Enhance Linkage, Engagement & Retention in Care for Aged/45+ PLWH/A:

- Enhancing HIV prevention efforts specifically targeted to the 45+ aging population in the EMA.
- Encouraging routine HIV testing and counseling of persons ages 13-75 years in all health care and clinic settings to promote earlier diagnosis among the aging population
- Cross training of HIV primary medical care clinicians in HIV and gerontology
- Co-locating to the extent possible HIV and general medicine/gerontologic providers and services
- Gradually transforming the care system to achieve chronic disease management (HIV and other chronic illnesses) and patient self sufficiency.
- Striving to reduce the stigma surrounding HIV disease in the service area. HIV-related stigma acts as a barrier to testing and care and prevents disclosure of HIV status, which acts as a serious impediment to preventing/reducing further transmission of HIV disease in the service area.
- Fully assessing aged clients' medical and support needs upon entry into 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, SA and PMC providers to meet the needs of the aging sub-populations
- Ensuring adequacy of social support systems and referrals into appropriate social support groups for the aging PLWH/A populations
- Ensuring that point-of-access HIV testing counselors and case management staff have knowledge of all available resources and how to assist PLWH/A in accessing them
- Aligning planning processes to respond to Service Barriers and Gaps in service delivery system
 - ❖ Service Delivery: Expand Housing and Housing-Related Services
 - ❖ Service Delivery: Expand Medical Transportation assistance services
 - ❖ Service Delivery: Expand Mental Health and Substance Abuse counseling services, and co-locate them with PMC services to the fullest extent possible
 - ❖ Service Delivery: Explore feasibility of expanding employment skills training for part-time jobs whereby PLWH/A could maintain level of Medicare/Medicaid benefits
 - ❖ Service Delivery: Expand/seek additional funding to support the unmet food, housing, transportation and financial assistance needs reported by the 'In Care' Aged/45+PLWH/A

- ❖ Service Delivery: Ensure optimal collaboration among core medical and medical specialty and supportive services providers, co-locating to the extent possible all priority services
- ❖ Service delivery: Expand to the extent possible, access to after-hours/weekends services (both PMC and supportive other services)

Retention of newly diagnosed Aged/45+ persons in HIV primary medical care is essential for providing access to ART that can postpone their further disease progression, and is especially critical for those PLWH/A whose immune systems are already seriously compromised through delayed diagnosis and/or delayed entry into care. Retention in care also has the added benefit of preventing the further transmission of HIV by promoting safer sex practices.

Issue- Specific Recommendations to Enhance Linkage, Engagement & Retention in Care for Aged/45+ PLWH/A:

❖ **Socioeconomic Disparities**

The aging PLWH/A population evidences substantial poverty and marginalization. The success of new drug therapies and the changing demographics of the HIV population necessitate comprehensive supportive services (Housing, EFA, Transportation, etc) and innovative policies that promote labor force participation and continuous access to antiretroviral therapies by the aging/45+ population.

❖ **Co-Morbidities**

With continuously improving antiretroviral therapies, survival following HIV diagnosis has risen dramatically and HIV infection has evolved from an acute disease process to being managed as a chronic medical condition. As treated HIV-infected patients live longer and the number of new HIV diagnoses in older patients rise, clinicians need to be aware of these trends and become familiar with the management of HIV infection in the older patient. As the impact of HIV on older communities continues to increase, HIV medical care providers must become more skilled in gerontologic medicine, so they prepared to provide care to greater numbers of HIV-infected older adults, a substantial minority of whom will present with complex co-morbid physical and mental health conditions.

❖ **Stigma**

HIV stigma should be routinely assessed when working with older, HIV infected clients and interventions should be tailored to the individual experiences of stigma.

❖ **Social Support**

With an increasing number of older people with HIV infection/AIDS, special efforts to create effective and sustainable social support interventions may be particularly beneficial to older persons living with HIV infection.

❖ **Prevention with Aging Positives**

Secondary HIV prevention education and counseling strategies should be tailored to the specific needs of the aging PLWH/A population.

APPENDIX
'In Care' Client Needs Assessment Instrument

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

1. What is your date of birth? _____

2. What is your Zip Code? _____

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

4. What Year were you diagnosed with HIV: _____ unknown

5. What Year were you diagnosed with AIDS: _____ unknown

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

- | | | |
|--|---|---|
| <input type="checkbox"/> Male sex w/male | <input type="checkbox"/> Injection Drug Use | <input type="checkbox"/> Health Care Worker |
| <input type="checkbox"/> Female sex w/female | <input type="checkbox"/> Sex with Drug User | <input type="checkbox"/> Mother w/HIV/AIDS |
| <input type="checkbox"/> Heterosexual Sex | <input type="checkbox"/> Sexual Assault | <input type="checkbox"/> Unknown |
| <input type="checkbox"/> Prison | <input type="checkbox"/> Transfusion | <input type="checkbox"/> Other |

7. Do you currently have health insurance?

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

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

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

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

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

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

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

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

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

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

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

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

19. Are you currently employed? Yes No

20. What is your approximate yearly income? \$0-\$9,999 \$10,000 - \$19,999 \$20,000-\$29,999
 \$30,000 - \$39,999 \$40,000-\$49,999 Over \$50,000

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

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

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

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

25. Are you? Male Female Transgender Other _____

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

30. Who is your HIV Doctor? _____

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

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

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

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

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

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

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

35. Why are these services hard to get?

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

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

37. Why can't you get these services?

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