Comprehensive Service Plan for HIV Services 2009- 2011

Prepared by Houston and Associates for the

Nassau-Suffolk HIV Health Services Planning Council and the
Nassau-Suffolk HIV Care Network

In association with
United Way of Long Island
819 Grand Boulevard, Deer Park, NY 11729
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January 2, 2009

New York State Department of Health – AIDS Institute

United Way
United Way of Long Island

Department of Health and Human Services
HRSA
Health Resources and Services Administration

NASSAU-SUFFOLK HIV HEALTH SERVICES PLANNING COUNCIL
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January 2, 2009

Mr. Kerry Hill, Project Officer
United States Department of Health and Human Services
Health Resources and Services Administration
5600 Fishers Lane
Rockville, MD 20857

Dear Mr. Hill:

I am writing on behalf of the Nassau-Suffolk HIV Health Services Planning Council. We are in concurrence with the attached Comprehensive Service Plan for HIV/AIDS on Long Island, which was completed in December 2008. Members of the Planning Council participated in the development of the Plan and provided input in the process through their expertise in various fields.

The development of the Comprehensive Service Plan was a joint effort of the Planning Council's Strategic Assessment and Planning Committee and the Nassau-Suffolk Ryan White Part B HIV Care Network's Care Coordination Committee. The Committees elected to form a joint ad hoc committee that was charged with developing the Plan. This Committee also included representatives from the Ryan White Part D program (SPARC), the Center for Public Health (AETC), and several other community-based and AIDS services organizations, as well as consumers. I look forward to continued collaboration with these same organizations and individuals to implement the Plan and continue to improve the quality of services throughout our EMA.

The Nassau-Suffolk HIV Health Services Planning Council reviewed the Plan and it was approved by the Planning Council's Executive Committee on January 2, 2009.

Sincerely,

Robert Detor
Chair, Nassau-Suffolk HIV Health Services Planning Council

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January 2, 2009

Maryland M. Toney, MS, Director of Network Initiatives
NYSDOH - AIDS Institute, Bureau of Community Support Services
90 Church Street, 13th fl.
New York, N.Y. 10007

Dear Ms. Toney:

We are writing this letter of concurrence on behalf of the Ryan White Part B Nassau-Suffolk HIV Care Network in support of the 2008 Comprehensive Service Plan for HIV/AIDS in Nassau and Suffolk Counties. Members of the Network participated in the development of the Plan and provided input in the process through their expertise in various fields.

The development of the Comprehensive Service Plan was a joint effort of the Nassau-Suffolk Ryan White Part B HIV Care Network's Care Coordination Committee and the Ryan White Part A Planning Council's Strategic Assessment and Planning Committee. The Committees elected to form a joint ad hoc committee that was charged with developing the Plan. This Committee also included representatives from the Ryan White Part D program (SPARC), the Center for Public Health Education (AETC), and several other community-based and AIDS services organizations, as well as people living with HIV/AIDS. We look forward to the continued collaboration with these planning bodies, service organizations and people living with HIV/AIDS to implement the Plan and continue to identify, develop and improve the quality of HIV services throughout the Nassau Suffolk region.

The Nassau-Suffolk HIV Care Network reviewed the Plan and it was approved by the Executive Committee on January 2, 2009.

Sincerely,

Maria MezzatestaChair,
Nassau Suffolk HIV Care Network

Robert Perez-Sulsona Co-Chair,
Nassau Suffolk HIV Care Network

S P A R C

Suffolk Project for AIDS Resource Coordination

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December 22, 2008

Jackie Mazzeo and Maria Mezzatesta, Co-Chairs
Comprehensive Service Plan Development Ad Hoc
Committee c/o Long Island's United Way
819 Grand Blvd.
Deer Park, NY 11729

Dear Ms. Mazzeo and Ms, Mezzatesta,

We are writing this letter of concurrence with the Comprehensive Service Plan for HIV/AIDS Nassau and Suffolk Counties on behalf of the Suffolk Project for AIDS Resource Coordination (SPARC). Based out of the Pediatric AIDS Center at Stony Brook, SPARC is funded by a Ryan White Part D grant from the HIV/AIDS Bureau of HRSA to improve coordination of services for HIV infected/affected women, children, youth and families in Suffolk.

SPARC staff have been active members of the regional Comprehensive Service Plan Development Committee since 1995 and participated in the development of this Comprehensive Service Plan (CSP), the CSPs completed in 1996, 2002 and 2005, as well as the Addendum completed in 1998. We concur that the CSP accurately reflects the needs of the region and presents a reasonable plan for responding to these needs. SPARC is committed to continuing its work with other regional planning bodies as we implement the CSP.

Sincerely,

Sharon A. Nachman, MD
Division Chief, Pediatric Infectious Diseases
SPARC Project Director

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SPARC Project Coordinator

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Contributors

This document was made possible with funds from the Ryan White HIV/AIDS Treatment Modernization Act of 2006 with additional support of the United Way of Long Island.

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Special thanks to the Joint Ad Hoc Committee and its co-chairs Jackie Mazzeo and Maria Mezzatesta that worked to develop this plan. This committee was comprised of members of the Planning Council's Strategic Assessment and Planning Committee and the HIV Care Network's Care Coordination Committee. See Appendix G for a full listing of committee members.

The completion of this Comprehensive Service Delivery Plan for HIV/AIDS on Long Island could not have been accomplished without the hard work and participation of committee members, agencies who provide HIV/AIDS services in the region and people living with HIV/AIDS who contributed their expertise. Many members contributed on several levels, including participating in discussions and needs assessments, gathering data, analyzing research and completing surveys.

Special thanks to the staff at the United Way of Long Island, which is the lead agency for the Ryan White Part A Nassau-Suffolk HIV Health Services Planning Council and the Ryan White Part B HIV Care Network, and Houston and Associates for the development of this Comprehensive HIV Plan.

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Introduction

This section prepares readers to use this plan effectively. Each reader will have a different reason for using this document. Key audiences are people living with HIV disease in Nassau and Suffolk Counties, New York; New York State Department of Health AIDS Institute; Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services; and the general public. Other audiences include elected officials, various governmental agencies, community-based organizations (including service providers), hospitals, other planning authorities and decision-makers, the public (through the media and directly), and advocacy groups. Every effort has been made to provide a plan that is readable and accessible to each audience.

Representatives from many of these groups assisted in the development of this plan. However, the goals and objectives and the framework for measuring progress contained here reflect decisions of the Nassau-Suffolk HIV Health Services Planning Council and the Nassau-Suffolk HIV Care Network.

The Ryan White HIV/AIDS Treatment Modernization Act of 2006 (usually called "the Ryan White Program") is a Federal law that was first passed by Congress in 1990. In 2006, the Act was reauthorized through 2009 with new requirements (Public Law 109-415). The law provides Federal funds that are used to develop systems of care and to pay for medical and social support services for people living with HIV disease and their families. The Act identifies who can receive this money and describes how the money can be used.

Nassau and Suffolk Counties together comprise an eligible metropolitan area under Part A of the Act, which qualifies it for emergency grant relief funds. Nassau County is the grantee for the Ryan White Program and Suffolk County is a partner by way of the region's Intergovernmental Agreement (IGA) between the two counties. Annually, Ryan White Part A funds are awarded directly to the Nassau County Executive, the designated chief elected official of the region. The Nassau County Public Health Unit serves as the Part A grantee. Both County Health Commissioners serve on the Nassau-Suffolk HIV Health Services Planning Council. Part B of the Act provides additional resources directly to service providers in the region through the New York State Department of Health's AIDS Institute and funds the Nassau-Suffolk HIV Care Network.

The United Way of Long Island serves as the Technical Support and Lead Agency for Ryan White Part A and the Ryan White Part B HIV Care Network by providing fiscal, administrative and programmatic oversight of the Planning Council and Network and by contracting with and monitoring Part A funded service providers.

Part A of the Ryan White Act requires the establishment of an HIV health services planning council. Among other duties, each Ryan White Planning Council must develop a three-year Comprehensive Service Plan. For Part B, the AIDS Institute funds the establishment and maintenance of an HIV Care Network. The HIV Care Network is the local planning body for Part B services in Nassau and Suffolk Counties. Among Network responsibilities is the duty to develop a Service Delivery Plan. This document responds to the planning requirements of both Part A and Part B.

This document will guide planning for Nassau and Suffolk Counties between 2009 and 2011. The plan should be revisited annually and modified as necessary. It is also hoped that other agencies responsible for various aspects of HIV/AIDS services planning, delivery, or funding will use this plan in their own processes.

Key Terms

This document generally uses the term "HIV disease" to describe the entire spectrum of the natural history of the virus, from infection to the clinical definition of AIDS.

The acronym "PLWHA" refers to people living with HIV and AIDS.

See the glossary in Appendix A for other terms and definitions.

Duties of the Nassau-Suffolk HIV Health Services Planning Council under Part A of the Ryan White Treatment Modernization Act of 2006

The Planning Council and its staff must carry out many complex planning tasks. The Ryan White legislation requires planning councils to have members from various groups and organizations. At least one third (33 percent) of the planning council members must be people living with HIV/AIDS who receive Part A services and are "unaffiliated." This refers to consumers who do not have a conflict of interest, meaning they are not staff, consultants, or Board members of Part A-funded agencies. The legislatively mandated responsibilities of the Planning Council are:

- Develop and implement policies and procedures for planning council operations.
- Assess needs.
- Do comprehensive planning.
- Set priorities and allocate resources to service categories, and provide guidance (directives) to the grantee on how best to meet these priorities.
- Help ensure coordination with other Ryan White and other HIV-related services.
- Assess the administrative mechanism.
- Develop standards of care.
- Evaluate program effectiveness.

Duties of the Nassau-Suffolk HIV Care Network under Part B of the Ryan White Treatment Modernization Act of 2006

The mission of the Ryan White Part B HIV Care Networks is to promote a coordinated community response that results in improved access to care and supportive services for those infected with HIV/AIDS. The vision of the Ryan White Part B HIV Care Networks is a comprehensive continuum of high quality services that is responsive to the needs of people infected with HIV/AIDS.

The Care Networks undertake the above mission through the following core activities:

- Promotion of a full complement of HIV/AIDS care and services through the establishment of an active, vibrant, participatory association of local and regional stakeholders.
- Identification of populations and subpopulations of individuals and families with HIV disease.
- Regular assessment of service needs to identify barriers to care and gaps in the service delivery system.
- Identification of emerging issues, especially those with potential impact on the HIV/AIDS service system and the lives of those living with HIV/AIDS.
- Periodic development of a service plan.
- Promotion of consumer involvement to enable HIV-infected individuals to participate in and inform HIV/AIDS policy and program development to assure that the needs of PLWHA are addressed.
- Educational and awareness activities for providers and consumers.
- Clearinghouse for updated regional HIV/AIDS information, including information on available services, local epidemiology, and other data.
- Statewide Coordinated Statement of Need (SCSN): Provision of input to the Ryan White SCSN and participation in SCSN activities.
- Collaboration with the AIDS Institute.

Key Parameters of the Plan

The plan addresses health and human services for people with HIV disease in Nassau and Suffolk Counties, New York.

The plan is a major product of the Nassau-Suffolk HIV Health Services Planning Council and the Nassau-Suffolk HIV Care Network through a joint committee, which used a community-based, evidence-based process to develop it.

Data presenting in this plan reflect the most recently available complete set of data for the region. Annual updates of this plan should use the most recent available data.

The actions in the plan are to occur between January 2009 and December 2011.

The plan can be used by anyone involved in planning, funding, delivering, receiving, or measuring the effectiveness of HIV services.

The plan shows how to monitor and evaluate progress so that changes to the plan can be made along the way. It should be reviewed once a year.

Topics Not Covered in the Plan

Planning issues directly related to HIV prevention and Housing Opportunities for People with AIDS (HOPWA) are not included.

Readers interested in HIV prevention planning are referred to the *2005-2010 New York State Comprehensive HIV Prevention Plan*.

Readers interested in the Part B Statewide Coordinated Statement of Need for New York are referred to the New York State AIDS Institute at http://www.health.state.ny.us.

Executive Summary

The Comprehensive Service Plan for HIV/AIDS Services 2009-2011 addresses health and human services for people with HIV disease in Nassau and Suffolk Counties, Long Island, New York. It can be used by anyone involved in planning, funding, delivering, receiving, or measuring the effectiveness of HIV services.

The Plan's vision is to provide HIV positive individuals in Nassau and Suffolk Counties with a comprehensive, coordinated system of culturally and linguistically appropriate state-of-the-art primary and specialty HIV care and supportive services designed to improve and maintain overall health status and quality of life.

At the time of this writing, those most affected by HIV/AIDS in the EMA are people of color, men who have sex with men, and injection drug users. The majority of people living with HIV/AIDS are over the age of 45, while at the same time the majority of new cases of HIV are among people ages 20 to 44. Meanwhile, the number of people identified with HIV/AIDS is increasing in the region. Racial and ethnic minorities, particularly African Americans and Hispanics, are disproportionally affected.

The overarching goal for the three years covered by this plan is to improve health outcomes and quality of life for people living with HIV disease in Nassau and Suffolk Counties.

The plan includes goals, objectives, and a monitoring and evaluation framework. The goals focus on:

- Increasing the number of HIV-infected individuals who know their HIV status.
- Access to care.
- Maintenance in care, continuity of care, and quality of care.
- The service system as a whole.

Key outcomes resulting from successful completion of the plan are:

- Reduce the AIDS case mortality rate.
- Increase the percentage of people living with HIV and AIDS who report high quality health status.

Who prepared the plan?

Nassau County is the grantee for the Ryan White Part A program and Suffolk County is a partner by way of the region's Intergovernmental Agreement (IGA) between the two counties. Both County Health Commissioners serve on the Nassau-Suffolk HIV Health Services Planning Council.

The plan was prepared jointly by the Nassau-Suffolk HIV Health Services Planning Council and the Nassau-Suffolk HIV Care Network. These planning bodies were supported by Part A grantee staff,

New York State Department of Health AIDS Institute staff, consumers of services, and a team of consultants.

In addition to helping pursue its vision for the people of Long Island with HIV disease, the plan satisfies the Ryan White Act's requirement that Planning Councils develop a comprehensive plan for the organization and delivery of health services that is compatible with any existing State or local plan regarding the provision of health services to individuals with HIV disease. This plan also satisfies the New York State Department of Health AIDS Institute requirement that HIV Care Networks develop a comprehensive service delivery plan. It should be pointed out that the Long Island region is unique in the sense that it has a history of significant collaboration between Ryan White Part A and Part B. Since its inception, the comprehensive service plans have been jointly developed by the Ryan White planning bodies.

The plan covers the period between January 2009 and December 2011. The Plan will be reviewed once a year and updates may be issued. In addition, annual implementation plans will be developed.

How is the plan organized?

The plan consists of four chapters and appendices.

- Chapter 1 deals with the question: Where are we now? It provides an overview of the current system of care. This includes the most recently available information on the HIV/AIDS epidemic in the region and who is most affected, including needs, services, resources, and service gaps.

- Chapter 2 addresses the question: Where do we need to go? The chapter presents the planning principles that were used to develop this plan and the plan's shared vision and values of an ideal system.

- Chapter 3 focuses on: How will we get there? It tells how the system needs to change to assure availability of and accessibility to necessary services. This crucial chapter includes the plan's goals, objectives, and action steps.

- Chapter 4 turns to the question: How will we monitor our progress? Using this chapter as a framework, the region will be able to evaluate progress in meeting its goals. The highlight of this chapter is a set of select indicators and measures.

- Finally, the appendices present a variety of supporting information, such as a glossary, a list of the primary source materials used in developing the plan, and the members of the relevant planning bodies, among other items.

Chapter 1

Where are we now: What is our current system of care?

Description of the EMA

The Nassau-Suffolk Eligible Metropolitan Area (EMA) a bi-county suburban region on Long Island (adjacent to the New York City boroughs of Queens and Brooklyn) that is made up of Nassau and Suffolk Counties. The Nassau-Suffolk region is 100 miles long and an average of 12 miles wide (287 square miles for Nassau and 911 square miles for Suffolk). According to the 2000 Census, the general population of 2.8 million people is primarily White (Nassau County 79%; Suffolk County 85%); followed by the Hispanic population (Nassau County 10%; Suffolk County 11%) and African American population (Nassau County 10%; Suffolk County 7%).

The region's link to the mainland is on its western border, through New York City and its boroughs. The proximity to one of the largest and most diverse cities in the world influences Long Island's population, culture and housing patterns, and brings to it many issues and concerns that are usually found in large urban cities, including HIV/AIDS.

Major issues affecting the Nassau-Suffolk area, including the lack of low-income or affordable housing, inadequate public transportation systems and pockets of poverty within areas of substantial affluence cause concern and directly influence the HIV/AIDS service delivery system of Nassau and Suffolk Counties. Most recently, Nassau and Suffolk County officials announced that the Census Bureau had increased the population for Long Island by approximately 105,000 people. While these new numbers need to be further analyzed for what they imply in the management of people living with HIV and AIDS, they suggest at the least the need for greater funding, more services, and more screening of those with HIV disease.

The EMA has an estimated 10,000 homeless persons, many substance users, a large immigrant population and, cumulatively, more persons with AIDS than any other suburban region in the country. The high rates of AIDS and estimated HIV infection among Blacks, Hispanics and women in the region is consistent with urban areas much larger than the EMA.

In recent years, the region has experienced a significant increase in the number of people living with HIV/AIDS (PLWHA). In the last two years alone, the total number has grown by nearly 7 percent.

The Growing HIV/AIDS Epidemic in Nassau and Suffolk Counties			
	2006	2007	Percent Difference
People living with AIDS	3,488	3,714	↑ 6.47%
People living with HIV (non-AIDS)	1,898	2,039	↑ 7.42%
Total	5,386	5,753	↑ 6.81%

In 2006, a total of 3,488 persons were reported as living with AIDS (PLWA) and 1,898 persons were

reported as living with HIV (PLWH) for a total of 5,386 people living with HIV and AIDS (PLWHA). In 2007, the EMA reports a total of 3,714 people living with AIDS and 2,039 people living with HIV, for a total of 5,753, representing an increase of 7% or 367 PLWHA in the Long Island region. (NYSDOH, 2007).

People of color are especially hard-hit by the HIV/AIDS epidemic. African Americans comprise 10% and 7% of Nassau and Suffolk counties' general populations, respectively, but are disproportionately affected by HIV/AIDS in the region. For example, African Americans represent 36.3% of the newly diagnosed AIDS cases and 33% of emergent HIV cases.

Hispanics on Long Island are also disproportionately affected. While Hispanics represent 10% and 11% of the general populations of Nassau and Suffolk Counties, they make up 28% of the newly diagnosed PLWA and 30% of emergent HIV cases.

Whites living with HIV/AIDS are under-represented compared to the general population of Long Island. Within the EMA, Whites represent approximately 26% of the emergent AIDS and 29% of the HIV incidence and 37.9% of the HIV/AIDS prevalence for the two year period starting January 1, 2006.

As suggested above, the unique geography of Long Island poses barriers to accessing and maintaining HIV care in the region. Mass transportation is limited in either county except for the Long Island Railroad, which is primarily designed to serve commuters traveling from the suburbs into New York City. One interstate highway, I-495, extends from New York City to the East End (Eastern Long Island) but does not reach to the far eastern end of the EMA. Bus routes that run north and south are limited, impeding travel from the north side of the island to the south side of the island without a vehicle. Even for individuals who do have access to a vehicle, travel within the region is challenging. For individuals who are sick, especially those with children or those without a car, transportation poses an ongoing barrier to care.

While the EMA has three hospital-based Designated AIDS Centers (DACs), it is not easy to access them by mass transportation. This is especially true in Suffolk County, the geographically larger of the two counties, with its sole DAC located on the North Shore. In Suffolk, even with a car, travel to the North Shore DAC can take as long as two hours.

In addition to the DACs, the region has several HIV primary care access points. However, given the size of the region, convenient access to care remains an issue. There are a number of services located in one high need community (Hempstead), but for the rest of the EMA, services are geographically dispersed.

In spite of these challenges, the region has been fortunate to have a high level of participation and strong leadership in HIV/AIDS. As a recipient of funds for an AIDS Service Demonstration Project prior to the availability of Ryan White funds, a cooperative spirit, a focus on accurate planning and a dedication to developing a quality system of care has existed regionally for over 15 years. This has enabled the region to provide many of the services needed by HIV positive individuals and to be responsive to the changing needs of the HIV/AIDS community.

The Ryan White Program

In the Long Island region, Ryan White Part A funds are an essential component of the coordinated care system. The Ryan White Part A fiscal year begins each March 1. Needs assessment, planning, and priority setting for Part A funds take into consideration other payers including Medicaid, Medicare, all other Parts of the Ryan White Program including the Minority AIDS Initiative (MAI), the Housing Opportunities for People with AIDS (HOPWA) program[1], Veterans Administration, and all other sources. Policy, planning, and program efforts are made to avoid duplication of services and to ensure that Ryan White Part A funds remain the payer of last resort. See Appendix B for a list of HRSA definitions of eligible Ryan White services.

In 2008, the EMA received $5.3 million in Part A and MAI funding from HRSA. To meet legislative requirements, no less than 75% of the Part A award must be allocated to core medical services. The EMA identified 8 core medical services and 3 support services. MAI funds augment mental health, medical case management, and medical transportation programs. To deliver these services requires 29 separate contracts (21 Part A and 8 MAI) with 13 different health and social service agencies in Nassau and Suffolk Counties.

Nassau Suffolk EMA Ryan White Part A Funding, FY 2008

Priorities	Service Categories	Part A and MAI Funding
Core Services	Mental health Oral health Substance abuse (outpatient recovery readiness) Medical case management, including maintenance in care case and treatment adherence Medical nutrition therapy Health insurance Outpatient/ambulatory medical care State drug reimbursement program (ADAP)	$ 3,396,312
Support Services	Medical transportation Legal services Outreach services	$ 1,126,545
Other[2]	Quality management Administration	$ 798,151
Total		$ 5,321,008

[1] The Nassau Suffolk HOPWA program in 2008-2009 received nearly $1.6 million in Federal funds for non-profit AIDS housing providers for acquisition, rehabilitation, equipment, and furnishings. HOPWA is administered by the United Way of Long Island.

[2] HRSA mandates that 5% of the total regional award be directed towards quality management and 5% be used for administrative cost.

Ryan White Part B funds are allocated to Long Island based on regional recommendations to the New York State Department of Health (NYSDOH) AIDS Institute, which administers the funds. The Part B fiscal year begins every April 1.

In 2008, the AIDS Institute (using a combination of Part B, ADAP, and State funds) provided a total of more than $21.7 million to programs and individuals on Long Island. Approximately $3.2 million was awarded to 27 providers delivering a wide range of services:

- Care coordination
- HIV service coordination
- Housing
- Information and referral
- Legal services
- Mental health
- Nutrition and food
- Outreach
- Partner counseling and referral services
- Permanency planning/legal support
- Support groups
- Transitional case management for parolees/releasees
- Transportation
- Treatment adherence

The State also supports uninsured care programs totaling more than $18.5 million. These funds provide medications directly to people with HIV/AIDS in care, early intervention services, insurance continuation, and home care to residents of Long Island with HIV/AIDS. By far the largest single expenditure is for medications ($17.5 million).

Part C of the Ryan White Program provides direct grants from HRSA to community based primary medical care providers such as community health centers and public clinics. One Part C program operates in the EMA at the Suffolk County Health Services Department.

Part D of the Ryan White Program supports networks of care for women, infants, children, and youth affected by HIV/AIDS. The Part D grantee in the region is the Research Foundation of SUNY at Stony Brook.

Finally, through Part F of the Ryan White Program, two programs receive reimbursement for dental care for people living with HIV/AIDS in the EMA (North Shore University Hospital and Long Island Jewish Medical Center) and one program is funded as part of the New York/New Jersey AIDS Education and Training Center (Center for Public Health Education – Stony Brook University).

Epidemiological Profile [3]

As of 2007, a total of 5,753 people with HIV/AIDS were living in the Nassau-Suffolk EMA (3,714 people living with AIDS and 2,039 people living with HIV), a 7% increase over 2006. [4] The EMA's minority populations are disproportionately impacted representing 74% of the emergent AIDS and 71% of new HIV cases for the two-year period beginning January 1, 2006. The following table represents the HIV/AIDS incidence and prevalence by racial/ethnic categories for the EMA as of December 31, 2007.

[3] This section is adapted from the Nassau-Suffolk EMA's Part A 2009 grant application submitted to HRSA in October 2008.

[4] These numbers do not include an additional 175 people with HIV/AIDS who are prisoners.

Racial and Ethnic Distribution of People Living with HIV/AIDS, 2007								
Race/Ethnic Group	New AIDS Cases		New HIV Cases		People Living with HIV		People Living with AIDS	
	#	%	#	%	#	%	#	%
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

In terms of gender, more than two-thirds of people living with HIV are male. The table below shows the HIV/AIDS incidence and prevalence within the Nassau-Suffolk EMA, by gender as of December 31, 2007.

People Living with HIV and AIDS by Gender, 2007								
Gender	New AIDS Cases		New HIV Cases		People Living with HIV		People Living with AIDS	
	#	% of New AIDS	#	% of New HIV	#	% of PLWH	#	% of PLWA
Male	266	68.91	307	68.07	1,251	61.35	2,553	68.74
Female	120	31.09	144	31.93	788	38.65	1,161	31.26
Total	386	100%	451	100%	2,039	100%	3,714	100%

Source: New York State Department of Health, 2007

The table below represents the EMA's PLWHA distribution by age as of December 31, 2007. 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 PLWHA and 64% of all prevalent AIDS cases in the EMA.

People Living with HIV and AIDS by Age, 2007								
	New AIDS Cases		New HIV Cases		People Living with HIV		People Living with AIDS	
Age Group (years)	#	% of New AIDS	#	% of New HIV	#	% of PLWH	#	% of PLWA
< 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	1,294	34.84
Over 45	143	37.05	117	25.94	947	46.5	2,370	63.81
Total	386	100%	451	100%	2,039	100%	3,714	100%

Source: New York State Department of Health, 2007

The table below depicts the numbers of PLWHA by risk transmission category, and evidences the disproportionate share of men who have sex with men (MSM) and injection drug users (IDU) in the EMA. MSM account for over 28% of the total living cases within the Nassau-Suffolk EMA. The second largest behavioral risk group includes those PLWHA who have a history of intravenous drug use (18.5%). High risk heterosexual behavior accounts for an additional 16.8% of the PLWHA populations within the region.

Transmission Risk for People Living with HIV/AIDS, 2007		
Transmission Risk	Number of PLWHA #	Percentage of PLWHA %
Men who have sex with men (MSM)	1,669	28.1
Injection drug use (IDU) history	1,101	18.5
Heterosexual	996	16.8
MSM/IDU	194	3.3
Other/Unknown	1,557	26.2
Blood transfusion/components	199	3.4
Pediatric Risk	189	3.2

Source: New York State Department of Health, 2007

As shown above, MSM and MSM/IDU risk together comprise nearly one third (31.4%) of all PLWHA, followed by those persons with any IDU risk behavior, who account for nearly one-quarter (21.8%) of all PLWHA in the EMA.

Co-morbid conditions among people living with HIV/AIDS in the EMA add to both the cost and complexity of providing care. A 2007 quality management review of 125 medical charts identified at least eight major co-morbid conditions including Hepatitis B and C as well as PCP (a deadly type of pneumonia if not treated).

Co-Morbid Conditions among a Sample of HIV Primary Medical Care Patients, 2007	
Co-morbid disease or condition	Proportion of population affected
Hepatitis C	20%
Pneumocystis carinii pneumonia (PCP)	11%
Hepatitis B	8%
Hypertension	6%
Syphilis	5%
Diabetes	2.5%
Mycobacterium Avian Complex (MAC)	2.5%
Tuberculosis	2.5%

The incidence and prevalence of sexually transmitted diseases (STD) -- other than HIV -- are another important factor to consider in understanding the extent of the HIV/AIDS epidemic. The *2006 Edition of the Community Need Index and Risk Factor Rates for Nassau and Suffolk Counties* documented that Nassau County's total STD rate for 2006 was 217 per 100,000 population and Suffolk County's STD rate was 186 per 100,000. These rates far exceed the state's median/50th percentile rate of 83 per 100,000. Inmates in the Nassau County Correctional Center made up 15% of the syphilis cases, 2% of the cases of gonorrhea and 36% of the chlamydia cases in 2006.

STD Cases by County, 2007			
STD	Nassau	Suffolk	EMA totals
Chlamydia	2,419	3,193	5,612
Gonorrhea	386	551	937
Early syphilis	64	32	96
Totals	2,869	3,776	6,645

Source: New York State Department of Health, 2007

The 2008 needs assessments of African Americans and Hispanics in care found significant co-morbidity with STDs (39% and 30%, respectively)[5]. The out of care needs assessment reported 100% of respondents had ever been diagnosed with an STD.

Tuberculosis (TB) continues to be reported in the EMA. In 2007, a total of 101 new cases of active TB were reported in the EMA, with cases evenly split between the two counties. People with HIV infection are at a higher risk of developing an acute TB infection (up to 7-10% higher). The incidence of TB in the HIV population is more than 100 times that of the general population. The highest rates of TB are generally found in the homeless, injection drug users, minority populations, and recent immigrants and refugees, as is the case in the Nassau-Suffolk EMA. One of the most

[5] In 2008, the Nassau-Suffolk HIV Health Services Planning Council commissioned an "Out of Care" unmet needs assessment on PLWHA and two "In Care" needs assessments, one on African-Americans and one on Hispanics. Please see primary data sources for reference list of documents.

threatening issues with TB in the HIV-infected population is the potential spread of multi-drug resistant organisms.

Hepatitis C (HCV) is a lifelong infection for the vast majority of persons who acquire it, and a difficult and expensive condition to treat. In 2007, a total of 1,001 new cases of Hepatitis C were reported in the EMA, with nearly 88% of cases occurring in Nassau County. People with HIV, especially injection drug users (IDU) are at risk of being co-infected with HCV. The Centers for Disease Control (CDC) estimate that between 50%-90% of HIV-infected injection drug users are co-infected with HCV. Using the low end of this estimate, a total of 1,300 IDU and MSM/IDU PLWHA in the EMA may be infected with Hepatitis C.

Substance abuse is closely associated with risky behavior that may lead to transmission of STDs and HIV. 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-related hospital discharges in 2006 and Suffolk County documented 148/100,000 cocaine-related hospital discharges during the same time period, as compared to the 50th percentile median rate of 112/100,000 in the state. Opioid-related hospital discharge rates for both 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).

The EMA's 2008 needs assessment data indicate high levels of co-morbidity with HIV and substance abuse, with 55% of African American respondents reporting a history of diagnosis and/or treatment for a substance abuse disorder. Substance use and abuse is a barrier to entry into and retention in HIV primary medical care. The out of care needs assessment survey found that 60% of 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 is yet another serious co-occurring disorder among people affected by HIV/AIDS. Nearly 30,000 people in the general population of the EMA suffer from severe chronic mental health disorders. A chart audit performed at Part A outpatient ambulatory medical care provider sites found that approximately 32% of charts reviewed present with or report depression (23%) or serious mental illness (9%). Co-morbidity with mental illness is high among African Americans in care, with 44% reporting in the 2008 needs assessment survey a history of diagnosis and/or treatment of mental illness. An even greater proportion of the 2008 Hispanic survey respondents report diagnosis or treatment for mental health disorders (57%).

Emerging Populations

In the 2006 New York Statewide Coordinated Statement of Need (SCSN), service needs and barriers were identified for the Nassau-Suffolk region. Housing assistance and transportation are the first two issues discussed. The document also summarizes service needs and barriers for the following specific populations:

- Persons of color
- Mentally ill and chemically addicted (MICA)
- Men who have sex with men (MSM)

- Women
- Homeless
- Adolescents and youth, including those who were perinatally infected
- Immigrants
- Inmates and releasees.

In 2008, the Nassau-Suffolk needs assessment and priority setting process show that the following populations in Nassau and Suffolk Counties continue to be disproportionately affected by HIV/AIDS. These include (alphabetically):

- African Americans
- Hispanics
- Homeless persons
- Immigrant and migrant workers
- Men who have sex with men
- Persons 45 years of age and older
- Persons with histories of incarceration and ex-offenders.
- Persons with histories of substance abuse
- Women of color
- Youth

More information about these and other specific populations appear in the needs assessment section, below.

Description of the Regional Response to the Epidemic

The EMA has established an integrated system of services that maintains the continuum of HIV/AIDS care and facilitates the entry of PLWHA into treatment and care. The region's Comprehensive Plan, a collaborative effort between Ryan White Parts A through Part F and non-Ryan White service providers, guides the region in its efforts to ensure that the continuity of services is maintained. Epidemiologic data is incorporated into this process to ensure that the services within the continuum remain responsive to emerging trends and needs in the region, especially to the underserved, hard to reach, and disproportionately impacted communities.

Formal agreements for primary care services are in effect between the Part A programs and the Suffolk County Department of Health's testing sites, including the site located at the county correctional facility. Two Designated AIDS Centers (DACs) are located in Nassau County (North Shore University Hospital and Nassau University Medical Center). North Shore University Medical Center has referral agreements with all anonymous test sites and clinics in the EMA, and Nassau University Medical Center is part of the corporation that operates the county's health clinics. Nassau County offers confidential testing and also provides testing at the Nassau County correctional facility. One DAC operates in Suffolk County (Stony Brook University Hospital).

New York State Designated AIDS Centers

DACs receive enhanced reimbursement from New York State, which closely monitors the training of staff and the quality of care delivered. The enhanced reimbursement rates ensure that each DAC offers medical case management, substance abuse treatment, mental health services, and either provides or has linkage agreements with oral health services and hospice care.

All DACs: 1) provide inpatient and ambulatory care for adults, adolescents, and children as well as pregnant women; 2) monitor CD4 viral load counts; 3) offer prophylaxis and treatment of opportunistic infections, and combination antiretroviral therapies; 4) adhere to PHS guidelines in treating persons with HIV/AIDS; and 5) have been awarded Part A funds to facilitate the delivery of primary care to PLWHA in the region.

In addition, the region has a network of both medical and critical support services that enhance access to, and retention in, a system of care while addressing quality of life issues.

The region allocated significant FY 2008 funds to medical case management, mental health services, legal services and medical transportation, which are key elements in reducing barriers to accessing and maintaining primary HIV medical care as well as other essential core services. The EMA has mechanisms to assure that the primary HIV medical care is consistent with Public Health Service (PHS) guidelines for the medical care and treatment of people infected with HIV. The other primary elements of the region's continuum of care are described below.

The Nassau-Suffolk EMA has eight (8) providers funded through Ryan White Part B. These funds are allocated based on regional recommendations to the NYSDOH AIDS Institute, which administers the funds. The Part A and Part B planning groups jointly develop and update the Comprehensive Service Plan for the region, thus ensuring that there is no duplication of services through these funding streams.

A Ryan White Part C program is operated by the Suffolk County Department of Health Services. The project is a model project for the detection, diagnosis, and treatment of HIV. The Suffolk County Ryan White Part C program provides comprehensive primary care services at three (3) county health clinics that are located in high need areas as classified by the NYSDOH AIDS Institute's Community Need Index (CNI).

The Ryan White Part D program funded in the region, Suffolk Project for AIDS Resource Coordination (SPARC), participates in the Comprehensive Service Plan development activities by sharing data and information. Ryan White Part D staff actively participates at a number of levels in the Ryan White Part A process, including the Strategic Assessment and Planning (SAP) committee. In addition, an employee of SPARC serves on the Part A Planning Council and another employee serves on the Executive Committee of the Part B HIV Care Network.

The Ryan White Part F program in the region, the Center for Public Health Education (CPHE) is located at Stony Brook University and provides HIV/AIDS education in the Long Island region. Representatives from the CPHE participate in the committee charged with developing the Comprehensive Service Plan and serve on the Planning Council and various Care Network Committees.

Ryan White Parts A, B, C, D and F all actively participate in the development of the Statewide Coordinated Statement of Need (SCSN) by collecting data for use in the process. Additionally, the Consumer Involvement Committee is a joint Ryan White Part A and Part B committee, with representation from Ryan White Part D.

All of the Ryan White Parts work closely together throughout the priority setting and resource allocation process (PSRA). The Parts actively participate in committee and Planning Council deliberations. Through this participation, sharing of data, program information, and the cooperative climate that exists, continuity of care is assured. Duplication of services is minimized and exists only when it is appropriate as a response to the expanding and changing needs of the HIV community. All of these efforts have maximized the number and types of available services and have increased their accessibility. All services are planned and located to meet the needs of the entire geographic region, particularly those of the underserved populations.

Centers for Disease Control and Prevention (CDC): New York receives a total of $62 million in CDC funding to support numerous testing and outreach programs. The Nassau-Suffolk region receives $956,000 in CDC funds ($688,000 from the state and $267,000 directly from CDC).

Medicaid: Of all payer sources and programs outside the Ryan White funded system, Medicaid is the most significant. Ryan White funds are utilized to fill in significant gaps in the care system. The tables below lists the total costs of care and demographic profile for all PLWHA enrolled in Medicaid in the Nassau-Suffolk EMA during FY 2007.

Total Cost of Care for PLWHA Medicaid in EMA, 2007

Category of Service	Total	Regional	State	Federal
Inpatient	$ 15,850,434	$ 3,962,608	$ 3,962,608	$ 7,925,217
Outpatient	23,629,928	5,907,482	5,907,482	11,814,964
Long Term Care	9,695,888	969,588	3,878,355	4,847,944
Case Management	$ 3,421,817	$ 855,454	$ 855,454	$ 1,710,908

Source: NYSDOH, Bureau of HIV Program Review and Systems Development

Profile of PLWHA Served by Medicaid in EMA by Race/Ethnicity and Age, 2007

Age Group	Black	Hispanic	White	Other	Unknown	Total
0-12 years	17	14	6	6	6	49
13-19 years	27	19	17	4	12	79
20-29 years	59	112	49	10	27	257
30-39 years	91	84	54	10	34	273
40-44 years	114	58	98	15	43	328
45-49 years	138	35	89	21	43	326
50-59 years	205	42	133	27	67	474
60+ years	46	17	35	10	15	123
unknown	0	0	0	0	5	5
Total	697	381	481	103	252	1,914

Source: NYSDOH, Bureau of HIV Program Review and Systems Development

State Child Health Insurance Program (SCHIP): New York State offers Child Health Plus to almost all children under age 19. The key eligibility factor is residence; all legal residents and most undocumented immigrants can obtain this medical insurance. Most applying families obtain the insurance at no cost. Some families have a small monthly premium. High income families can obtain the insurance at full cost, approximately $150 per child per month. Children who are Medicaid eligible cannot receive Child Health Plus, they must apply for Medicaid.

Child Health Plus has a comprehensive benefit package very similar to Medicaid, although not offering transportation and imposing some limits on therapies. Full coverage begins in the month following application, without regard to pre-existing conditions. As of August 2008, almost 65,000 children in Nassau/Suffolk received this insurance through the seven insurance carriers active in the region.

Veterans Affairs (VA): The VA Medical Center in the Nassau-Suffolk EMA serves approximately 80 PLWHA through its outpatient primary care clinic, and provides limited dental services and some behavioral health services.

Housing Opportunities for People with AIDS: The United Way of Long Island administers the HOPWA program. Long Island receives $1.6 million annually in HOPWA funds from the Department of Housing and Urban Development (HUD). As of 2007, 50 HOPWA houses had been developed for more than 203 PLWHA and their families on Long Island.

Services for Women and Children: The Supplemental Food Program for Women, Infants and Children (WIC) is administered by the Health and Welfare Council in Nassau County and Suffolk County Department of Health Services and provides WIC vouchers and nutritional services in the EMA. According to the Women, Infants, Children and Youth (WICY) report, the Nassau-Suffolk EMA met all of the target expenditures relative to the 2008-09 guidance for the expenditure of Ryan White Part A funding to serve women, infants, children and youth.

Medicare: An increasing number of PLWHA in the EMA are Medicare eligible. A significant number (13%) of Part A pharmaceutical and ADAP clients are Medicare enrollees. Beginning on January 1, 2006, Medicare beneficiaries who qualified for the full low income subsidy assistance through Medicare Part D were dropped from ADAP and Part A pharmaceutical rolls. Other Medicare beneficiaries were required to enroll in a Medicare Part D plan in order to maintain their ADAP eligibility.

All major racial and ethnic groups are severely impacted by HIV/AIDS in the region. As is the case nationally, racial and ethnic minorities in Nassau and Suffolk Counties carry a heavy and disproportionate burden of the HIV/AIDS incidence and prevalence.

Impact of HIV/AIDS by Racial and Ethnic Group, 2007

Race/Ethnicity	Proportion of Total Population in Nassau County	Proportion of Total Population in Suffolk County	Number of People Living with HIV/AIDS (both Counties)	Percent PLWHA	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 74% of the new AIDS cases. Persons of color make up 62% of all PLWHA 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.

Listed below is a chart that outlines costs (based on the region's top funded core medical services and top funded supportive services) for six special populations.

Average Cost of Care by Select Specific Populations, 2007

Population	Total # Part A Clients 2007	Average Cost of Medical Care	Average Cost Support Services
African Americans	1,230	$ 1,087	$ 1,117
Hispanics	474	1,146	1,161
MSM	587	1,065	1,221
IDU	444	1,066	1,213
Women of Color	801	1,067	1,096
Persons aged 45 and above	1,630	1,028	1,184

The following information describes the unique health and social service needs of select specific populations in the EMA.

African Americans: African Americans carry a high and disproportionate burden of the emergent and prevalent HIV disease in the EMA, comprising a total of 38% of the total PLWHA prevalent

cases. This is particularly true for African American women who represent the largest share of new HIV infections and AIDS cases among women. African Americans represent a higher percentage of the uninsured and under-insured populations; an estimated uninsured rate that is 2.5 times that of the White population in the EMA (*2007 Diversitydata.org*). Uninsured African Americans are three times more likely to lack a consistent source of care (estimated at 20%), compared to those with private or publicly-funded insurance.

Primary barriers to accessing healthcare for African Americans include, but are not limited to, a mistrust of the medical community as a whole, stigma related to both socioeconomic status and the diagnosis of HIV/AIDS, lower education and literacy levels, and a lack of sufficient support systems as a result of homelessness and poverty. African Americans are more likely to be tested later in the course of the disease process than Whites. Late entry into care is known to create a need for more complex and costly care.

Costs of HIV Care Targeting African Americans, 2007

Service Category	Total Cost
Medical Case Management	$ 365,842
Mental Health	222,267
Substance Abuse	85,017
Legal Service	287,828
Transportation	394,570
Total for Part A Core Services	673,127
Total for Part A Non-Core Services	682,399
Total Cost All Services Combined	$ 1,355,526

African Americans comprised 30% of all Part A core medical service clients in 2007. Key services utilized by African Americans include medical transportation, medical case management, legal, and mental health services.

To further explore the care patterns for the African American population, the Planning Council commissioned a needs assessment of African Americans in care. The study data was used for the Ryan White Part A 2009 Priority Setting and Resource Allocation process. Key findings are presented below.

Findings of Needs Assessment of African Americans in Care, 2008

- The African American respondent group is an aging group of PLWHA, with majority of respondents reporting ages in the 45-54 age range. The majority is highly impoverished and largely unemployed (80%).
- Modes of transmission are predominantly heterosexual and IDU.
- Significant proportions, 44% and 55%, respectively, report co-morbidities with mental illness and substance abuse disorders.
- STD co-morbidity is relatively high at 39%, and the reported presence of other chronic diseases is quite high at 55%.
- An extremely high proportion of the African American "In Care" respondents reports current or previous homelessness (47%).
- The majority of the African American respondents have acquired Medicaid or Medicare benefits (76%). The African American respondents report a desire to work but fear that working will lead to a loss of benefits. Many have struggled to reach base-line stability and fear doing anything to jeopardize stable benefits.
- The African American "In Care" survey respondents evidence a greater delay since their last physician/laboratory monitoring visit than the Hispanic "In Care" respondents, indicating a fragile "In Care" status.
- The need for transportation exceeds the monthly rides available, leaving inadequate transportation for pharmacy, food pantry, or other medical appointments outside of primary medical, dental or mental health service visits.

Hispanics: The Hispanic population bears a disproportionate burden of the emergent HIV and AIDS cases in the EMA (29.7% and 27.9%, respectively) and comprises 20% of the total PLWHA prevalent cases within the EMA. The Hispanic population in the EMA has 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. Hispanics who cannot obtain health insurance may stay out of care until it is absolutely necessary, delaying entry into care. It is estimated that roughly 30% of Hispanics lack a steady source of health care. Hispanics demonstrate the highest late to testing and care faction in the EMA with 32.4% of the concurrent HIV/AIDS diagnoses in 2007. Hispanics comprised 15% of the Part A core medical services clients in 2007.

Barriers to accessing care by the Hispanic population include linguistic issues, gender related issues, and stigma related to the diagnosis. 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 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.

Costs of HIV Care Targeting Hispanics, 2007	
Service Category	Total Cost
Medical Case Management	$ 141,145
Mental Health	204,123
Substance Abuse	12,145
Legal Service	92,105
Transportation	95,928
Total for Core Services	*357,414*
Total for Non-Core Services	*188,033*
Total Cost All Services Combined	$ 545,447

To further explore the care patterns of the Hispanic population, the Planning Council commissioned a needs assessment of Hispanics in care. The study was completed in early 2008 with data used for the Ryan White Part A 2009 Priority Setting and Resource Allocation process.

Findings of Needs Assessment of Hispanics In Care, 2008

- Almost half of the Hispanic respondents reports their age in the 35-44 age range (48%), as compared to the older African American "In Care" respondent group. By gender, 47% are Male; 51% Female; and one respondent reports Transgender.
- Modes of transmission include heterosexual risk (66%); followed by MSM risk behavior (18%). 53% report an AIDS diagnosis and 46% report HIV disease only, with many reporting an AIDS diagnosis concurrent with their diagnosis with HIV.
- Few of the Hispanic "In Care" respondents report health insurance benefits (with a substantial number undocumented).
- The majority of the Hispanic "In Care" respondent group reports current employment, despite low education attainment (only 18% finished high school). Roughly 24% of the Hispanic respondent group reports current or previous homelessness. A low proportion (16%) currently receives rental assistance.
- Many Hispanic PLWHA report diagnosis or treatment for mental disorder (57%), but few report a history of substance abuse (11%). Less than 1/3 reports STD co-morbidity (30%) and fewer (28%) report living with another chronic illness other than HIV disease.

Homeless persons: Affordable housing in Nassau and Suffolk Counties is far less available than is needed. The Nassau-Suffolk Coalition for the Homeless estimates that there are approximately 10,000 homeless persons living in the region. Both Nassau and Suffolk Counties recently conducted a point-in-time count of sheltered and unsheltered homeless persons during the last week in January 2007. Nassau County reported 21 sheltered persons with HIV/AIDS; Suffolk County reported 44 sheltered persons with HIV/AIDS.

Homelessness dramatically affects the cost and complexity of providing HIV care in the region. People who are homeless are more likely to be in poorer health and are more likely to be focused on securing safe shelter and meals rather than receiving medical attention or adhering to treatment.

Respondents to the EMA's own needs assessment study of African Americans in care ranked housing first among needed services. This same study reported that 47% of respondents were either homeless or experienced a previous period of homelessness. In addition, the needs assessment found that most respondents reported living assistance check to assistance check, meaning they could easily lose their home due to a medical or other emergency situation.

Immigrant and migrant workers: Since 1980, the Long Island immigrant population has made up more than 16% of the general population, or approximately 465,000 residents. More than half of all immigrants moving to Long Island since 2000 are Latin American. HIV/AIDS service providers, prevention programs and outreach workers report an increasing number of immigrants testing positive. Nationally, the rate of HIV/AIDS is estimated to be as high as ten times greater among immigrant and migrant workers than the national average. Local providers also report difficulty engaging and maintaining this population in care. Fear of deportation keeps many immigrants, especially those who are undocumented, from seeking medical attention or any interaction with government agencies. Other problems are lack of insurance, a lack of culturally competent care, and inflexible work schedules that conflict with available hours for medical appointments.

Men who have sex with men: MSM comprised 36% of emergent HIV cases and 29% of emergent AIDS cases in the EMA in 2007 and represent 29% of the HIV/AIDS prevalent cases reported within the EMA during the same time period *(NYSDOH, 2007).* When combined with MSM/IDU risk, the role of MSM increases to over 32% of all PLWHA. In addition, the anecdotally reported abuse of alcohol and illicit drugs remains prevalent among this population, leading to an increase in risky sexual behaviors. Magnifying the problem is the belief among some MSM that having sex with virally suppressed partners is safe. In addition, some studies have shown increased rates of mental health problems, such as mood disorders, among the MSM population. Young MSM, especially those of minority races or ethnicities are at high risk for HIV infection. Not having seen firsthand the toll of AIDS in the early years of the epidemic, young MSM may be less motivated to practice safer sex. MSM comprised 26% of the Part A core medical service clients in 2007.

To further explore the care patterns among MSM, the Planning Council has commissioned an assessment of needs among MSM in care. The study will be completed in early 2009 with data used for the Ryan White Part A 2010 Priority Setting and Resource Allocation process.

Costs of HIV Care Targeting MSM, 2007	
Service Category	Total Cost
Medical Case Management	$ 251,466
Mental Health	175,395
Substance Abuse	36,436
Legal Service	106,908
Transportation	78,733
Total for Part A Core Services	463,297
Total for Part A Non-Core Services	185,641
Total Cost All Services Combined	$ 648,938

Persons 45 years of age and older: Individuals who are 45 years of age and older account for 58% of the PLWHA cases within the EMA. PLWHA 45 years+ accounted for 21% of the emergent HIV and 37% of the emergent AIDS in 2007.

The treatment and care of older PLWHA 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. Persons aged 45 and above comprised 46% of the Part A core medical services population in 2007, however only 29% of the entire aging PLWHA population participated in Part A services during 2007 *(NYSDOH and Part A Services, 2007).*

To further explore the care patterns of people with HIV/AIDS over age 45, the Planning Council commissioned an assessment of needs of persons over age 45 in care. The study will be completed in 2009, the results of which will be utilized for the Ryan White Part A 2010 Priority Setting and Resource Allocation process.

Costs of HIV Care Targeting Persons Aged 45+, 2007	
Service Category	Total Cost
Medical Case Management	$ 610,008
Mental Health	291,820
Substance Abuse	93,114
Legal Service	411,183
Transportation	372,851
Total for Part A Core Svc	994,942
Total for Part A Non-Core Svc	784,034
Total Cost All Services Combined	$ 1,778,976

Persons with histories of incarceration and ex-offenders: People who are incarcerated are more than three times more likely to be living with HIV/AIDS than the general population. It is also estimated that up to 25 percent of people living with HIV in the United States have spent time in a correctional facility. According to the Department of Justice's most recent report on HIV in prisons, New York State reported the largest number of male HIV positive inmates and the second largest number of female HIV positive inmates. The Nassau Suffolk region reported 175 persons diagnosed with HIV/AIDS in a correctional facility at time of diagnosis through December 2007. Of particular concern is the apparent lack of pre-release planning for HIV positive inmates. It is essential that those exiting the correctional system are linked to medical services in order to continue their treatment once they return to the community.

Persons with histories of substance abuse: Injection drug users account for 3% of the emergent HIV cases and 8% of the emergent AIDS cases in 2007, but IDU accounts for 19% of the PLWHA prevalent cases within the EMA. When IDU risk is considered along with MSM/IDU data, the IDU prevalence increases to 22.5%. Some studies show that the IDU population has 10-20 times higher rates of illness and death than the non-IDU population. In addition, intravenous drug use can cause significant and serious medical problems, such as hypertension, cardiomyopathy, abscesses from dirty needles, dental deterioration, neurologic disorders, renal problems, psychiatric issues, and most commonly, Hepatitis C. Treatment for acute and chronic Hepatitis C produces significant cost and complexity of care issues for the EMA. IDU represented 13% of all Part A core medical service clients in 2007.

Women of color: In 2007, women with HIV/AIDS comprised 32% of emergent HIV cases and 31% of emergent AIDS cases. Women account for almost 39% of living HIV cases and over 31% of living AIDS cases. In particular, Black women accounted for the largest share of new HIV cases and AIDS cases in the region. In 2006, in the Nassau-Suffolk EMA, Black women living with HIV/AIDS totaled 815 compared to 444 White women and 241 Hispanic women. Research indicates women tend to seek out health care services at a higher rate than men. However, women tend to be diagnosed later. In addition, women often present with higher rates of asthma, diabetes, cardiovascular disease, and hypertension. Women of color represented 19% of all Part A core medical service clients in 2007.

Costs of HIV Care Targeting IDU, 2007

Service Category	Total Cost
Medical Case Management	$ 171,970
Mental Health	72,577
Substance Abuse	44,533
Legal Service	118,421
Transportation	91,403
Total for Part A Core Services	289,080
Total for Part A Non-Core Services	209.824
Total Cost All Services Combined	$ 498,904

To further explore the care patterns among women of color, the Planning Council commissioned an assessment of needs of women of color in care. The study will be completed in 2009, the results of which will be utilized for the Ryan White Part A 2010 Priority Setting and Resource Allocation process

Costs of HIV Care Targeting Women of Color, 2007

Service Category	Total Cost
Medical Case Management	$ 227,131
Mental Health	161,786
Substance Abuse	32,388
Legal Service	172,697
Transportation	272,398
Total for Part A Core Services	421,305
Total for Part A Non-Core Services	445,095
Total Cost All Services Combined	$ 866,400

Youth: In 2008, the CDC reported 34% of new HIV infections in the United States were among adolescents and young adults between the ages of 13-29, representing the highest infection rate of any other age group. While the aged population is clearly overrepresented in the Long Island region, service providers have begun expressing increasing concern over the number of young people testing positive in the region. At the end of 2007, 15 new cases of HIV were reported among youth aged 13 – 19 in the EMA.

Need for Primary Medical Care and other Core Medical Services

As evidenced in the following table below, consistent disparities exist 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 PLWHA, but represent only 30% of those Part A core medical clients during 2007. Utilization of supportive services, particularly among African Americans, women of color, and people over the age of 45 exceeds their relative participation in core medical services.

Specific Populations of PLWHA Served by Part A, 2007				
Severe Need Group	Percent PLWHA	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	Not available	19%	42%	26%
IDU	19%	13%	18%	15%
45 years+	58%	46%	68%	53%

In 2008, the HIV Care Network conducted a survey to assess the regional services priorities for the Nassau Suffolk region. The survey was conducted online in October and November 2008. The survey was distributed to 388 Network members to complete and provide an assessment of the service needs of PLWHA's in the Long Island Region. Of the survey respondents, 68% service providers, 32% people living with HIV/AIDS and 34% were racial /ethnic minority group.

The purpose of the survey was to review and rank the priorities for the HIV Service Delivery Plan and to identify emerging needs for the New York State Department of Health, Ryan White Part B funding, on behalf of the Nassau-Suffolk region. The following results below are broken into Core Medical services and Support services. Survey participants were asked to rank the two categories priorities in order of importance to them from 1 to 5, with 1 being the most important.

Core Medical Services

1. Outpatient/Ambulatory Medical Care (Health Service): Provision of professional diagnostic and therapist services rendered by physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting.

2. Mental Health Services for HIV Positive Persons: Psychological and Psychiatric treatment and counseling services, including individual and group counseling, provided by mental health professionals licensed by the NYS Department of Education and the Board of Regents to practice within the boundaries and scope of their respective profession.

3. Substance Abuse Services-Outpatient: Provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting rendered by a physician or under the supervision of a physician, or by the qualified personal.

4. Medical Nutrition Therapy: Provided by a licensed registered dietitian outside of a primary care visit and includes the provision of nutritional supplements.

5. Medical Case Management (Including Treatment Adherence): A range of client-centered services that link clients with health care, psychosocial, and other services.

Support Services [6]

1. Housing Services: Provision of short-term assistance to support emergency, temporary or transitional housing to enable an individual or family to gain or maintain medical care.

2. Referral for Health Care/Supportive Services: The act of directing a client to service in person or through phone, written, or other types of communication. Referrals may be made within the non-medical case management system, by professional case managers, informally through support staff, or as part of an outreach program.

3. Food Bank/Home-Delivered Meals: Provision of actual food or meals. It does not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item. Includes vouchers to purchase food.

4. Rehabilitation Services: Services provided by a licensed or authorized professional in accordance with an individualized plan of care intended to improve or maintain a client's quality of life and optimal capacity for self-care. Services include physical and occupational therapy, speech pathology, and low-vision training.

5. Case Management (non-medical): Includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed support services.

Service Gaps

Service gaps are an ongoing challenge. In the 2006 New York Statewide Coordinated Statement of Need, service needs and barriers were identified for the Nassau-Suffolk region. Housing assistance and transportation are the first two issues discussed. These were followed by case management, emergency financial assistance, substance abuse and alcohol treatment/counseling services, dental services, mental health services, and mental health support groups.

[6] Defined as services needed to achieve outcomes that affect the HIV-related clinical status of a person with HIV/AIDS.

During 2008, new studies were completed to assess the needs of African Americans in care, Hispanics in care, and people with HIV who are out of care. (See Appendix E for more detailed findings from these studies.) Service gaps were identified by the researchers, used in the priority setting and resource allocations process, and are summarized below. Another important survey of consumers was completed in 2007. Service gaps identified at the time in that survey are also described. Finally, service gaps identified in 2008 through community meetings and other activities are also summarized.

The key results of the three 2008 needs assessments can be compared because the same researchers used similar methods and analytical approaches. The table below compares the rankings of top service gaps for each of the groups.

Service Gap Ranking African Americans in Care, Hispanics in Care, and Persons Out of Care, 2008			
Service Category	African Americans in Care	Hispanics in Care	Persons Out of Care
Medical transportation	2 (tie)	3 (tie)	1
Health insurance	6	7	2
Housing services	1	5	3
Medical case management	-	-	4
Mental health services	10	-	5
Food bank, meals	4 (tie)	2	6
Financial assistance	2 (tie)	3 (tie)	7
Medications	7 (tie)	-	8
Primary medical care	4 (tie)	9	-
Health education, information and referral	9	-	-
Employment skills, job training	7 (tie)	6	-
Rental assistance	-	1	-
Immigration papers, documentation	-	8	-

The top ranking service gaps reported in the 2008 African American PLWHA Needs Assessment study include:1) Housing Services; 2) Medical Transportation tied with Emergency Financial Assistance; 4) Food Bank tied with Primary Medical Care; 6) Health Insurance; 7) Employment Skills Training tied with Medications; 9) Health Education/Information & Referral; and 10) Mental Health services.

The 2008 Hispanic Needs Assessment survey results evidence a high degree of similarity to the African American survey results with regard to the service gap rankings. The Hispanic PLWHA ranked service gaps in the following order: 1) rental assistance; 2) food bank; 3) medical transportation tied with emergency financial assistance; 5) housing services; 6) employment/skills training; 7) health insurance; 8) immigration/documentation assistance; and 9) primary medical care.

The 2008 Out of Care Unmet Needs Assessment survey identified service delivery challenges, gaps in services, and barriers to care. The top service gaps were: 1) medical transportation, 2) health insurance, 3) housing services, 4) medical case management, 5) mental health services, 6) food bank, 7) financial assistance, 8) primary medical care and medications (tied), 9) employment/job skills training and legal services (tied), 10) support groups, 11) immigration protection/assistance.

The Long Island HIV/AIDS 2007 Consumer Survey describes the top services identified as most needed by people living with HIV/AIDS in Nassau and Suffolk Counties.

Respondents were asked to indicate their needs for service and ability to receive services at a doctor's office or clinic for HIV-related problems during the past six months. The data is provided in the table below. The majority (83.5%) reported that they needed medical care and received it.

Need for Primary Medical Care Among Surveyed Consumers of HIV/AIDS Services, 2007

Response	Number	Percent
Did not need medical care for HIV	6	5.8%
Needed medical care and received it	86	83.5%
Needed and received medical care, but needed more than what was available	11	10.7%
Needed medical care, but could not get it	0	0
Total respondents	103	100%

Respondents were also asked to indicate their needs and services other than primary care and their ability to receive these services during the past six months. A comprehensive listing of various types of services was provided on the survey, and most people were asked to respond with one of six choices for each service:

- Needed and received this
- Received this, but needed more than what was available
- Needed this, but could not get it
- Needed this, but did not seek it
- Did not need this

Top Ranked Services Identified by Surveyed Consumers as "Needed and Received This" (Need Met), 2003 – 2007

2007	2005	2003
Medications	Dental care and medications (tied)	Medications
Dental care	Eye care	Dental care
Eye care	Ambulatory/outpatient care	Case management
Case management	Case management and mental health (tied)	Eye care
Ambulatory/outpatient care	N/A	N/A

Top Ranked Services Identified by Surveyed Consumers as "Received this Service, but Needed More" (Need Partially Met), 2003 - 2007		
2007	2005	2003
Client advocacy, Transportation (tied)	Case Management	Case Management, Information about services (tied)
Case management, Information about services (tied)	Transportation	Client advocacy
Mental health services, Help with housing (tied)	Information about services	Help with housing
Legal services, Emergency medical care (tied)	Money for rent	Food bank/voucher

Top Ranked Services Identified by Surveyed Consumer as "Needed this Service, but Could Not Get It" (Unmet Need), 2003 - 2007		
2007	2005	2003
Complementary Services	Complementary Therapies	Money for Utilities
Food Bank	Money for Rent	Help with Housing
Help with Housing, Money for Rent (tied)	Money for Utilities	Complementary Therapies, Food Bank/Food Voucher (tied)
Money for Utilities	Help with Housing	Money for Rent
Legal Services, Meals Brought to My Home (tied)	N/A	N/A

Top Ranked Services Identified by Surveyed Consumer as "Need this Service, but Did Not Seek It" (Unmet Need), 2003 - 2007		
2007	2005	2003
Complementary therapies	Complementary therapies	Complementary therapies
Dental care, Money for utilities (tied)	Eye care	Support group
Nutritional counseling	Nutritional counseling, Support group (tied)	Nutritional counseling
Mental health services, Support groups, Money for rent (tied)	Client advocacy	Eye care

Four community meetings were held in July 2008 to discuss Ryan White Part A HIV/AIDS services in the region. In addition, a conference call was convened for individuals who were unable to attend the community meetings.

The purpose of these meetings was to have people infected and affected by HIV/AIDS (consumers), service providers, case managers and medical personnel share with the Planning Council's Strategic Assessment and Planning Committee the types of HIV/AIDS services needed

on Long Island. The information gathered was used in the priority setting process and comprehensive service plan.

The meetings were held in both Nassau and Suffolk Counties and two meetings were conducted in Spanish. Individuals received supermarket vouchers for their participation.

Results from the community forums also shed light on gaps in services. The community forum ranking of services most important to PLWHA was: 1) legal services, 2) medical transportation, 3) ADAP, 4) emergency financial assistance, 5) mental health services, 6) outpatient/ambulatory medical care, 7) food bank, 8) health education, 9) medical nutritional therapy, 10) psychosocial support, 11) non-medical case management, 12) housing and outreach (tied), 13) substance abuse services, early intervention services, child care services, and rehabilitation services (tied), 14) referrals and health insurance (tied).

Community forum participants also reported on needed services that are not being provided: alternative medicine/therapies, housing assistance, emergency financial assistance, education, and a range of other supportive services.

The Long Island Minority AIDS Coalition submitted recommendations for HIV/AIDS services that addressed gaps in care: transportation; mental health services; services that address co-occurring disorders of HIV/AIDS, substance abuse, and mental illness; parity between mental health services reimbursement and medical care reimbursement (particularly for Medicaid/Medicare), ocular care, home health care, and services facilitating the transition from adolescent to adult medical care.

Finally, the Comprehensive Service Plan Joint Ad Hoc Committee reviewed the gaps presented in the 2006 Plan. The Committee found that in 2008, many of the same gaps still exist, including:

- Lack of evening and weekend appointments for medical and supportive services.
- Lack of low income housing that is suitable for HIV-positive individuals and families.
- Lack of substance abuse services that can accommodate mothers and children.
- Lack of housing for individuals pursuing recovery from substance abuse.
- Access to services for HIV-positive mentally ill chemical abusers.
- Lack of services for undocumented individuals.
- Lack of adequate public transportation, especially in Suffolk County.
- Lack of services for affected family members.
- Lack of support groups specifically for HIV-positive youth in Nassau County.
- Inadequate availability of needle exchange programs.
- Inadequate availability of services for individuals who do not speak or read English.
- Lack of bi-lingual staff.
- Inadequate availability of primary medical care services providing culturally competent and appropriate services to the gay community.
- Lack of services targeting recently incarcerated persons.
- Lack of services targeting persons older than age 45.

Unmet Need Estimate

Estimation methods: The NYSDOH has determined that there were 5,928 PLWHA in the Nassau-Suffolk EMA (including prisoners) as of December 31, 2007. A total of 3,467 of these PLWHA were identified as Medicaid/ADAP eligible. Medicaid/ADAP served 2,366 of the identified Medicaid/ ADAP eligible PLWHA representing 68% of the total Medicaid/ADAP met need. When determining the met need for the other payor mix population, the percentage of met need from the Medicaid and ADAP data (68%) was assumed for the total other payor recipients (2,190) to arrive at the met need number (1,495). Additionally, 1,926 PLWHA have been identified statewide by the VA. Using data submitted to HRSA by the VA it was determined that Statewide VA met need is 1,705. Nassau-Suffolk represents 4.96% of statewide PLWHA. Therefore applying this percentage to the statewide VA met need; the met need for Long Island is estimated at 84.61 PLWHA. The Veterans Administration (VA) provided care to an estimated 2.0% of the HIV/AIDS population in the EMA.

2008 Unmet Need Framework				
Input	Value	Data Source		
Population Sizes				
Number of PLWHA as of 12/31/2007	5,928	Jurisdiction specific surveillance data, includes prisoners		
People living with AIDS (64%)	*3,821*			
People living with HIV (36%)	*2,107*			
Care Patterns (Met Need) [7]				Total population
Medicaid / ADAP (FFY07)	2,366	Total Medicaid / ADAP met need		3,467
People living with AIDS (64%)	*1,536*			*2,034*
People living with HIV (36%)	*830*			*1,433*
Veteran's Administration (FY03 HRSA Data Run)	84	Total VA met need		95
People living with AIDS (64%)	*54*			*61*
People living with HIV (36%)	*30*			*33*
Corrections (Epi Data)	119	Total Corrections met need		175
People living with AIDS (64%)	*76*			*107*
People living with HIV (36%)	*42*			*68*
Other Payors	1,494	Total Other Payor met need		2,190
People living with AIDS (64%)	*963*			*1,411*
People living with HIV (36%)	*531*			*778*
Total	4,064	68.57%	Total Met Need	5,928
People living with AIDS (64%)	*2,631*	*68.86%*	*AIDS Met Need*	*3,614*
People living with HIV (36%)	*1,433*	*68.05%*	*HIV Met Need*	*2,313*
Calculated Result (Unmet Need)				
Number of PLWHA not in care	1,863	31.43%	Total Unmet Need	
People living with AIDS (64%)	*1,189*	*31.14%*	*AIDS Unmet Need*	
People living with HIV (36%)	*673*	*31.95%*	*HIV+ Unmet Need*	

Source: New York State Department of Health, 2008

[7] Number of people living with HIV/AIDS in care.

According to the Nassau-Suffolk EMA's Unmet Need Assessment, there are 1,863 PLWHA who are aware and out of care. Of those, 31.14% are AIDS aware but out of care; and 31.95% are HIV aware but out of care. To further explore the barriers to care for the Out of Care population, the Nassau-Suffolk HIV Health Services Planning Council conducted an Out of Care Needs Assessment in early 2008. The data was used for the 2009 Priority Setting and Resource Allocation process. Additionally, outcomes from the 2008 Out of Care Needs Assessment were incorporated into the EMA's Standard of Care development process.

Determination of the demographics and locations of persons who know their HIV/AIDS status and are not in care: The 2008 Study of Unmet Need, based on 2007 data, revealed that 31.43% of all PLWHA were 'Out of Care' (n=1,863). Through assessments of PLWHA needs, barriers to accessing and maintaining medical care and treatment can be addressed, thereby increasing the likelihood of returning to care and treatment services.

Based upon an analysis of the 2008 "Out of Care"(OOC) needs assessment findings, the populations most likely to be out of care are male and female heterosexuals and White MSM, MSM of color and IDU. There is no current location information (i.e. zip code or county of residence) available for the entire OOC population. According to the 2008 Out of Care needs assessment survey, the majority of OOC respondents (63%) report their residence in one of 11 major zip codes, including 11550-Hempstead, Nassau (15); 11520-Freeport, Nassau (6); 11717-Brentwood, Suffolk (5); 11901-Riverhead, Suffolk (5);11798-Wyandanch, Suffolk (5); 11704-West Babylon, Suffolk (4); 11722-Patchogue, Suffolk (4); 11553-Uniondale, Nassau (4);11969-Southampton, Suffolk (4); 11003-Elmont, Nassau (4); and 11763-Medford, Suffolk (4).

Gaps in Care

The Long Island region completed three needs assessments in 2008 which examined pressing questions regarding the HIV/AIDS epidemic on Long Island. Respondents in each of the three needs assessments (Out of Care; African American In Care; and Hispanic In Care) were asked to rank gaps in care in the region. Below are the top 10 gaps in care according to those who participated in the needs assessments:

Top Ranking Service Gaps Among Persons Out of Care, African American In Care, and Hispanics In Care, 2008

Service Category Description	Out of Care Respondents Gap Rank	African American In Care Respondents Gap Rank	Hispanic In Care Respondents Gap Rank
Medical Transportation	1	2 tie	3 tie
Health Insurance	2	6	7
Housing Services	3	1	5
Medical Case Management	4	N/A	N/A
Mental Health Services	5	10	N/A
Food Bank/Quality Food	6	4 tie	2
Financial Assistance	7	2 tie	3 tie
Medications	8	7 tie	N/A

Top Ranking Service Gaps Among Persons Out of Care, African American In Care, and Hispanics In Care, 2008			
Service Category Description	Out of Care Respondents Gap Rank	African American In Care Respondents Gap Rank	Hispanic In Care Respondents Gap Rank
Primary Medical Care	N/A	4 tie	9
Health Education/Information & Referral	N/A	9	N/A
Employment Skills/Training	N/A	7 tie	6
Rental Assistance	N/A	N/A	1
Immigration Papers/ Documentation	N/A	N/A	8

Reflecting these local results are rankings from a targeted community survey for supportive services. The survey was conducted statewide by the AIDS Institute. Both providers and consumers were surveyed. Among 15 Long Island providers who participated in the survey, the ranking of supportive service gaps are:

1 - Medical Transportation
2 - Case Management
3 - Health Education
4 - Treatment Adherence
5 - Psychosocial Support
6 - Linguistic Services
7 - Child Care

Prevention Needs

An individual's introduction to the HIV care system often occurs at testing sites, making them a vital point of access to primary HIV medical care. A network of anonymous HIV counseling and testing sites are operated by the NYSDOH AIDS Institute in both Nassau and Suffolk counties. Other types of facilities, including community health centers, offer confidential testing throughout the EMA. In addition, three community based organizations operate mobile vans that offer rapid HIV testing in high need communities.

Once identified, every attempt is made to immediately connect newly HIV infected individuals into the service system. Clients are provided linkages and referrals to regional providers that provide primary medical care, case management, and critical supportive services that promote retention in care and treatment. The integration of case management services with HIV counseling and testing sites, is an ideal mechanism for maximizing the opportunities to engage the newly infected and hard to reach populations into the HIV system of primary medical care.

Description of the Current Continuum of Care

The region enjoys an integrated continuum of care focused on getting people into treatment and ensuring that they remain in treatment.

The first component of this continuum is the network of anonymous and confidential HIV counseling and testing sites, as described in the prevention section above. These sites are key elements in facilitating access to care. For many individuals, these sites are the initial point of contact with the HIV care system in the region. Anonymous test sites serve as distribution points for information regarding regional HIV-specific medical and support services. In addition to anonymous testing sites, there are a variety of other facilities, including community health centers that offer confidential testing throughout the region. In addition, three community based organizations operate mobile vans that offer rapid HIV testing in high need communities. During post-test counseling, all testing sites provide information on resources and prevention (including a discussion about partner notification) to all clients. For persons who are HIV infected, referrals are made to regional providers that provide primary medical care, case management, and critical support services that promote retention in care and treatment services. The integration of case management services with HIV counseling and testing sites, is an ideal mechanism for maximizing opportunities to engage the newly infected and hard to reach populations into the HIV system of primary medical care.

Formal referral agreements have been established between these entry points and primary medical care providers. For example, in Suffolk County there are written referral agreements between Part A funded programs and the Suffolk County Department of Health's testing sites, including the site located at the county correctional facility. In Nassau County, one Designated AIDS Center (DAC) (North Shore University Hospital) has written referral agreements with all anonymous testing sites and clinics in the region. The other DAC in Nassau County (Nassau University Medical Center) is part of the same public benefits corporation that operates the county's health clinics. Nassau County offers confidential testing and also provides testing at the Nassau County correctional facility. Thus, all testing and counseling sites and early-intervention services are linked to primary medical care services in the region.

With respect to primary medical care services for the treatment of HIV infection in the region, the region has developed mechanisms to assure that care is consistent with Public Health Service (PHS) guidelines. In New York State, a system of Designated AIDS Centers (DACs) has been developed and implemented by the NYSDOH AIDS Institute. The state provides enhanced reimbursement at these sites and closely monitors the programmatic aspects of the care delivery system, the training of staff, the quality of care provided and other factors. The enhanced reimbursement ensures that each DAC offers case management, substance abuse treatment, mental health services and either provides or has linkages with oral health care services and hospice care. In the Nassau-Suffolk region, there are three Designated AIDS Centers.

In Nassau, there are Designated AIDS Centers at North Shore University Hospital and Nassau University Medical Center. In Suffolk, Stony Brook University Hospital is a DAC. All three DACs provide acute and clinic based care for adults, adolescents and pediatric cases in addition to providing care to pregnant women to reduce perinatal HIV transmission.

Resource Inventory

The table below summarizes the number of organizations providing services accessible to people living with HIV in the Nassau and Suffolk Counties. Note that financing for these programs is from a wide range of sources, including government, private philanthropy, individual giving, and volunteer support. Further, many agencies provide multiple services and some offer services in multiple locations. Contact information for many of the providers in the table below can be found in Appendix C. For more detailed information, see *The Nassau-Suffolk HIV/AIDS Resource Guide*, published regularly by the Nassau-Suffolk HIV Care Network.

Summary of Organizations Providing Services Accessible to People Living with HIV/AIDS in Nassau and Suffolk Counties	
Service	# of Providers
Benefits and financial assistance	22
Case management	13
Counseling	18
Dental care	9
Domestic violence programs	6
Education and prevention	27
Food and nutrition	11
Gay, lesbian, bisexual, and transgender services	9
HIV counseling and testing	10
Home health care	66
Hospital services [8]	22
Hospice care	9
Housing (residential/community based)	9
Housing related services	7
Legal assistance	10
Mental health care	11
Multicultural services	17
Partner notification programs	2
Pediatric services	5
Prescription drugs [9]	5
Primary medical care	11
Residential health care	3
Substance abuse services	23
Support groups	18
Transportation	17
Treatment education	6
Women's services	15
Youth and adolescent services	19

[8] Includes three Designated AIDS Center hospitals.
[9] Includes the State AIDS Drug Assistance Program.

Profile of the Ryan White Program

The table below shows service providers funded the various Ryan White Parts on Long Island.

Nassau-Suffolk Ryan White Funded Providers, 2008				
Service Funded Providers	Ryan White Part A	Ryan White Part B	Ryan White Part C	Ryan White Part D
North Shore University Hospital	▪ Ambulatory/Out-patient Medical Care ▪ Medical Case Management	▪ Counseling - Supportive/ Individual ▪ HIV Health Education/Risk Reduction ▪ Medical Care Coordination ▪ Mental Health		
New York State AIDS Institute	▪ ADAP			
Suffolk County Department of Health Services	▪ Medical Case Management ▪ Oral Health Care	▪ Ambulatory Health Care ▪ Case Management	▪ Early Intervention Services for HIV Disease	
Southampton Hospital	▪ Mental Health Services			
FEGS	▪ Substance Abuse Services – Outpatient ▪ Medical Case Management (Maintenance In Care) ▪ Mental Health Services	▪ Mental Health ▪ Transportation ▪ Supportive/ Individual Counseling ▪ Care Coordination ▪ HIV Health Education & Risk		

Nassau-Suffolk Ryan White Funded Providers, 2008				
Service Funded Providers	Ryan White Part A	Ryan White Part B	Ryan White Part C	Ryan White Part D
		Reduction ▪ Support Group		
Catholic Charities	▪ Oral Health Care			
Research Foundation of SUNY Stony Brook*	▪ Medical Case Management ▪ Mental Health Services ▪ Medical Nutrition Services	▪ Ambulatory Health Care ▪ Case Management ▪ Medical Care Coordination ▪ Mental Health		▪ Comprehensive Medical Care ▪ Linkage to Care Coordination ▪ HIV Counseling and Testing ▪ Transportation ▪ Respite ▪ Referral Tracking ▪ Advocacy ▪ Women's Care Coordination ▪ Youth Clinic ▪ Oral Health Initiative
Nassau-Suffolk Law Services	▪ Health Insurance ▪ Legal Services			
Circulo de la Hispanidad –	▪ Medical Transportation			

Nassau-Suffolk Ryan White Funded Providers, 2008				
Service Funded Providers	Ryan White Part A	Ryan White Part B	Ryan White Part C	Ryan White Part D
Nassau				
Economic Opportunity Council of Suffolk, Inc.-Suffolk	▪ Medical Transportation	▪ Transportation		
Long Island Association for AIDS Care (LIAAC)	▪ Outreach	▪ Case Management ▪ Nutrition/Meals		
Hispanic Counseling Center	▪ Mental Health Services			
Nassau University Medical Center	▪ Medical Case Management			
Long Island Jewish Medical Center		▪ Ambulatory Health Care ▪ Case Management ▪ Treatment Adherence ▪ Medical Care Coordination		
United Way of Long Island		▪ HIV Service Coordination		

* Research Foundation of SUNY Stony Brook also receives Part F funding for clinical training.

Barriers to Care

Funding data presented above, helps to understand what services are being delivered. Additional information on service needs and barriers to receiving them is necessary to more specifically describe the gaps in services available to people with HIV/AIDS. The results of the primary data collection activities undertaken to develop funding priorities in 2008 included consumer surveys and community forums. The findings reveal top service needs, how to improve HIV services, and barriers or obstacles to HIV services.

Consistently, transportation and lack of stable and affordable housing are the primary barriers to HIV/AIDS care in the Nassau-Suffolk region.

Other important service needs and barriers are:

- Homelessness, unstable, and inadequate housing
- Lack of substance abuse treatment
- Lack of mental health services
- Lack of care coordination
- Lack of treatment adherence services
- Lack of transportation to support groups
- Transition to Medicaid managed care, which may create temporary or even permanent access barriers to care
- Lack of availability of primary medical care providers with sufficient cultural competence
- Lack of information on available services and resources needed by people living with HIV/AIDS
- Lack of adequate insurance coverage for young adults
- The changing fiscal environment in government and the private sector
- Lack of consistent formularies across different health care plans
- Rising cost of co-payments

Chapter 2

Where do we need to go: What is our vision of an ideal system?

The planning process began with the adoption of principles of planning, a vision statement, and statement of values.

Principles of planning

- Is consumer/client-focused.
- Is evidenced-based.
- Describes historically under-served populations, those with severe needs, those not in care.
- Emphasizes outcomes over processes.
- Is realistic in terms of time, resources, and personnel.
- Envisions a complete continuum of care.
- Encourages coordination and collaboration.
- Effectively informs those responsible for allocations decisions.
- Informs HRSA, the AIDS Institute, and other public and private sectors involved in health care for people living with HIV/AIDS in Nassau and Suffolk Counties of the unique nature of the epidemic here.
- Is used to measure system performance and adjusted as needed but at least annually.
- Is expressed in words and graphics that are easy to comprehend.

Vision statement

Our shared vision is to provide HIV positive individuals in Nassau and Suffolk Counties with a comprehensive, coordinated system of culturally and linguistically appropriate state-of-the-art primary and specialty HIV care and supportive services designed to improve and maintain overall health status and quality of life.

Shared values

1. Services should be planned and established based on extensive needs assessment with the target populations.
2. There should be easy entry into care from many points within and outside of the system.
3. The care should be of high quality, culturally competent, cost effective, and accessible (e.g., available at hours and locations that accommodate the needs of the people served and accompanied by childcare when necessary).
4. There should be stable funding for good services, but agencies should be accountable for maintaining the quality of their services and adapting to changes in the disease and/or the populations served.
5. Seamless transitions between providers (which can be accompanied by provisions of co-located services within or between agencies) and among all agencies should occur to ensure coordinated services without regard to "turf issues" or politics.
6. As a society, we should address co-factors associated with HIV disease such as poverty, hunger, homelessness, poor quality education, inequities in incarceration, substance abuse, mental illness, stigma, and discrimination. We should also work to eliminate disparities based on race, geography, class, gender, or sexual orientation.
7. As a region, we should continue to address barriers to accessing care and maintaining care, including the lack of quality housing that is affordable and the lack of adequate public transportation.
8. As a region, we should support both primary and secondary HIV prevention on the local level to promote healthy behavior and work with the media to influence cultural norms on a societal level.

Access to care

Access is a shorthand term used for a broad set of concerns that center on the degree to which individuals and groups are able to obtain needed services from the health care system. Access to health care can be defined as the timely use of personal health services to achieve the best possible health outcomes. [10]

[10] Source: Access to Health Care in America, Institute of Medicine, 1993.

Key points of entry

When Congress reauthorized the CARE Act in 2000, it included new requirements intended to expand the number of people receiving services through certain sections of the law. These were carried forward in the 2006 reauthorization.

Agencies funded under Part A and Part B of the Act are required to maintain relationships and linkages with key points of entry to the local health care system. The goal is to reach individuals who are either newly diagnosed with HIV or who know their HIV status but are not in care.

The region requires contractors establish a system to comply with HRSA requirements concerning appropriate referral relationships that are designed to ensure that individuals who are newly diagnosed with HIV have early access to medical care.

Key points of entry are defined as locations where persons with HIV disease can be identified, referred, and maintained in health care and related supportive services. Such locations include emergency rooms, substance abuse treatment programs, detoxification centers, adult and juvenile detention facilities, sexually transmitted disease clinics, HIV counseling and testing sites, mental health programs, and homeless shelters.

Early intervention services

HRSA defines early intervention services as counseling, testing, and referral activities designed to bring HIV-positive individuals into the local HIV continuum of care. The goal is to decrease the number of under-served individuals with HIV/AIDS while increasing their access to the local continuum of care by providing:

- Test results that identify HIV status at an earlier stage of their disease,
- Information on living with HIV disease and managing therapeutic regimens,
- Counseling on modifying behaviors that compromise one's own or another's health status,
- Referrals to appropriate prevention and risk reduction programs and to primary care or case management for those testing positive, and
- Referrals to prevention programs for high risk individuals who test negative.

Effective linkages [11]

The aim of forming referral linkages is to connect people living with HIV and AIDS to services they need. Linkages are vital to creating a coordinated system of care. People with HIV and AIDS, Ryan White providers, and key points of entry each benefit from linkages.

[11] Source: Opening Doors: A Guide for Building Effective Linkages between CARE Act Funded Providers and Key Points of Entry to Health Care, CAEAR Coalition Foundation, 2003.

For people with HIV and AIDS, effective linkages between point-of-entry agencies and Ryan White providers can help clients to:

- Receive critical health and social services,
- Improve health status,
- Enhance quality of life, and
- Lengthen life.

For Ryan White providers, effective linkages can:

- Clarify responsibility among Ryan White providers and other service agencies,
- Foster successful, system-wide service coordination,
- Ensure that the referral process endures through staff turn-over,
- Generate new relationships with the linked organizations,
- Help the monitoring system for both providers and their partners,
- Facilitate continuity of care among multiple providers for individual clients, and
- Maximize CARE Act funds by identifying primary payers.

For point-of-entry agencies, formal linkages with Ryan White enable them to:

- Focus on their primary mission while still ensuring that people with HIV and AIDS get the services they need.
- Create partnerships and collaborations that broaden agencies' ability to serve their communities and their clients while enhancing their profile in the community.

Barriers [12]

Three primary types of barriers to health care exist: structural, financial, and personal and cultural barriers.

- Structural barriers are impediments to care directly related to number, type, concentration, location, or organizational configuration of care providers.

[12] Source: Access to Health Care in America, Institute of Medicine, 1993.

- Financial barriers may restrict access either by inhibiting the ability to pay for needed services or by discouraging providers from treating persons of limited means.

- Personal and cultural barriers may inhibit people who need medical attention or services from seeking it, or once they obtain care, from being able to adhere to recommended treatment guidelines.

Barriers interact in complicated ways. The simple presence or absence of a barrier does not guarantee that one can predict whether services can be obtained.

Effectiveness of Ryan White services [13]

The Ryan White Program requires that services be provided in a manner that is coordinated, cost effective, and ensures that Part A funds are the payer of last resort for HIV/AIDS services.

Cost effectiveness includes two interrelated dimensions: outcomes and costs. To be effective, Ryan White Programs should accomplish positive results, and do so at a reasonable cost. Cost effective programs do not necessarily lead to cost savings, although they do provide good value for the money.

Services are cost effective when:

- The unit cost is reasonable and acceptable relative to the benefits and outcomes received.

- The service can be provided less expensively than other similar services but with an equal or better outcome.

- The service provides an additional benefit worth the additional cost.

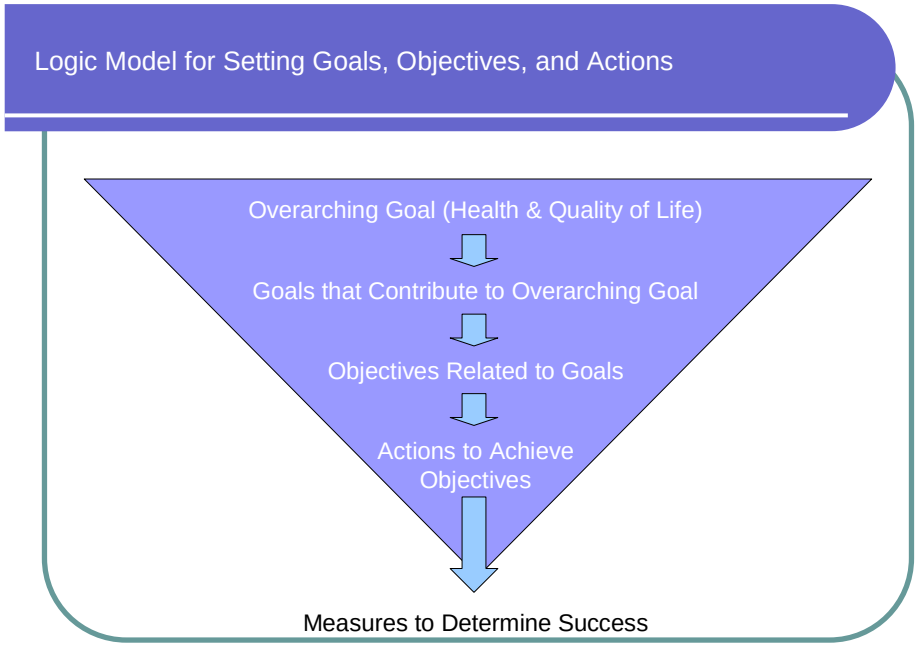
Impact evaluation and cost effectiveness analysis are challenging. With respect to impact evaluation, determining outcomes is always complex. In the context of Ryan White services, outcomes measures that can serve as indicators or standards of care are in development.

On the cost effectiveness side, calculating unit cost – the cost per service unit – or per-client cost is also quite challenging because most Part A resources support service delivery programs rather than specific clients.

[13] Source: Ryan White CARE Act Title I Manual, Health Resources and Services Administration, 2002.

Logic model

The planning process to develop the 2009 Comprehensive Plan for Nassau-Suffolk made use of the logic model shown below to guide the development of goals, objectives related to goals, and actions to achieve the objectives.



Key outcomes resulting from successful completion of the plan

- Reduce the AIDS case mortality rate.
- Increase the percentage of people living with HIV and AIDS who report high quality health care.

Chapter 3.

How will we get there: How does our system need to change to assure availability of and accessibility to core services?

This section presents the goals and objectives for the service system for 2009-2011. Also included are action steps. Chapter 4 presents the framework for monitoring and evaluating these objectives.

Overarching Goal 2009 – 2011

To improve the health outcomes and quality of life for people living with HIV disease in Nassau and Suffolk Counties.

Supporting goals focus on:

- Increasing the number of HIV-infected individuals who know their HIV status.
- Access to care.
- Maintenance in care, continuity of care, and quality of care.
- The service system as a whole.

Readers are urged to keep in mind that:

- Goals are broad and embrace a 3-year period.
- Objectives are proxy measures for goal attainment.
- Together, goals and objectives provide a road map for the region to annually set priorities and determine resource allocations for the Ryan White Program.
- Measurement is necessary to consider when implementing action steps. Readers are urged to refer frequently to Chapter 4 of this plan for details on the measures for each of the objectives presented on the following pages.

How to use this chapter

The plan consists of four broad goals and objectives. Action steps are listed for each of the objectives, along with information on the time frame for action. Justification for the objective is also indicated.

The Comprehensive Services Plan covers the timeframe from January 1, 2009- December 31, 2011. All three planning years vary according to funding. The Ryan White funding year does not coincide with the calendar year. Some goals may overlap.

Year 1 = 2009-2010 Year 2 = 2010-2011 Year 3 = 2011-2012

Note that action steps and corresponding year of action which are specific to the HIV Care Network are in *italics.* The measure for all Network action steps should answer the question: to what extent was the action achieved?

Goal 1 Increase the number of HIV-infected individuals who know their HIV status.			
Objectives	Action Steps	Measures	Year
1A. Expand testing at key points of entry into health and human service systems accessed by at-risk populations. *At-risk populations include African Americans, Hispanics, men who have sex with men, injection drug users, women of color, pregnant women, and infants, children, and youth.*	▪ Describe characteristics and needs of at-risk populations known to delay testing. ▪ Identify service barriers and gaps in counseling, testing, and linkage to services for at-risk populations. ▪ Identify and promote service delivery models to enable counseling, testing, and linkage to care. ▪ *Promote public relations 'get tested' and 'get treatment' campaigns targeted towards high risk populations.*	▪ Number of individuals who do not know their status as reflected by the number of persons who test positive for HIV in a year. ▪ Percentage of people who are diagnosed with HIV and AIDS concurrently.	▪ Year 1 ▪ Year 2 ▪ Year 2 & Year 3 ▪ *Year 2*

Examples of evidence to justify the objective
▪ At-risk populations, especially racial and ethnic minorities in Nassau-Suffolk carry a heavy and disproportionate burden of HIV/AIDS incidence and prevalence in the region. ▪ African Americans are more likely to be tested later in the course of the disease process than whites. ▪ Hispanics demonstrate the highest late to testing and care fraction in the EMA. ▪ When combined with MSM/IDU risk, the role of MSM increases to over 32% of all PLWHA in the region. ▪ IDUs account for nearly one-fifth of prevalent HIV/AIDS cases in the region. ▪ In 2007, women with HIV/AIDS comprised nearly one-third of emergent HIV and AIDS cases. ▪ Women tend to be diagnosed later than men. ▪ The majority of people living with HIV/AIDS are over the age of 45, while at the same time the majority of new cases of HIV are among people ages 20 to 44. ▪ At the end of 2007, 15 new cases of HIV were reported among youth aged 13-19 in the EMA.

Goal 2 Increase the number of HIV-positive individuals who access care.			
Objectives	Action Steps	Measures	Year
2A. Ensure that programs serving as key points of entry into health and human service systems provide effective linkages to core medical care and other necessary support services for people living with HIV/AIDS.	▪ Describe the extent to which at-risk populations have access to care. ▪ Describe the characteristics and needs of at-risk populations known to delay entry into care. ▪ Identify gaps in services among at-risk populations seeking access to care. ▪ Identify mechanisms and resources to address gaps in access to care. [14] ▪ Allocate resources to address gaps that impede access to care. ▪ *Facilitate training of providers on linkages.*	▪ Percentage of newly diagnosed clients who have not entered HIV care within 90 days of testing HIV-positive. ▪ Percentage of newly diagnosed clients who have entered HIV care within 90 days of testing HIV-positive.	▪ Year 1 ▪ Year 1 ▪ Annually ▪ Year 2 & Year 3 ▪ Annually ▪ *Annually*
2B. Reduce barriers to timely receipt of HIV care experienced by HIV-positive individuals.	▪ Describe the barriers and gaps to timely receipt of HIV care experienced by HIV-positive individuals. ▪ Identify and promote mechanisms to address barriers and gaps to timely receipt of care. [15] ▪ Allocate resources to address barriers to timely receipt of HIV care.	▪ Percentage of needs assessment survey respondents reporting one logistical barrier to getting needed care.	▪ Year 1 ▪ Annually ▪ Annually

[14] Examples include information dissemination, organizational capacity building, and special consumer and provider meetings.

[15] Examples include co-location of services and language translation.

Goal 2 Increase the number of HIV-positive individuals who access care.			
Objectives	Action Steps	Measures	Year
	▪ *Collaborate with the Planning Council to identify barriers and gaps.* ▪ *Promote mechanisms to address barriers and gaps.*		▪ Year 1 ▪ *Annually*

Examples of evidence to justify the objectives
▪ An estimated 1,863 PLWHA in the region are not in care, which is nearly one-third (31%) of the total number of PLWHA on Long Island. ▪ Populations most likely to be out of care are male and female heterosexuals, White MSM, MSM of color, and IDUs. ▪ Accessing the three Designated AIDS Centers by public transportation in the region is difficult. ▪ Service sites are dispersed over a large geographic area. ▪ One-third of out of care needs assessment respondents delayed care longer than 52 weeks. ▪ More than half (60%) of respondents to the region's out of care needs assessment survey reported regularly using alcohol or drugs (or both), and nearly one third (27%) admit to previous to IDU. ▪ Significant proportions of specific populations such as African Americans and Hispanics report co-morbidities that are barriers to care such as mental illness and substance abuse disorders. ▪ More than 10% of consumers surveyed in 2007 reported that while they needed and received medical care, they needed more than what was available.

Goal 3 Increase the proportion of people living with HIV/AIDS who are maintained in quality HIV care once they enter the service system.			
Objectives	Action Steps	Measures	Year
3A. Ensure the availability of high quality core medical care and other necessary support services for people living with HIV/AIDS.	▪ Identify populations experiencing barriers and gaps in care. ▪ Identify service delivery strategies and program models to address barriers and gaps in care. ▪ Allocate resource to address barriers and gaps in care. ▪ *Update and publish in hard copy and online the region's Resource Directory.*	▪ Percentage of needs assessment survey respondents reporting a need for services who are <u>not</u> receiving the service or services. ▪ Percentage of needs assessment survey respondents reporting a need for services who are receiving the service or services.	▪ Year 1 ▪ Year 2 & Year 3 ▪ Annually ▪ *Year 1*
3B. Enhance coordination of care among providers of services to people living with HIV/AIDS.	▪ Identify strategies to coordinate and promote care among providers delivering services to the same clients. ▪ *Conduct regular Network meetings to facilitate coordination of care among providers* ▪ *Continue to engage PLWHA through Network activities such as Community Liaison Outreach Program.*	▪ Improvements in coordination between specific types of providers. [16]	Year 2 & Year 3 ▪ *Annually* ▪ *Annually*
3C. Implement mechanisms to identify and re-engage people living with HIV/AIDS who	▪ Identify those who drop out of care or are at-risk of dropping out of care.	▪ Increase in the number of people living with HIV/AIDS who are re-engaged	▪ Annually

[16] Examples include coordination between case managers and other health service providers and between providers of mental health and primary care.

Goal 3 Increase the proportion of people living with HIV/AIDS who are maintained in quality HIV care once they enter the service system.			
Objectives	Action Steps	Measures	Year
are out of care.	▪ Develop strategies to re-engage those who drop out of care. ▪ Allocate resources necessary to support mechanisms to identify and re-engage people living with HIV/AIDS who are out of care.	in care.	▪ Annually ▪ Annually
3D. Ensure that HIV services meet or exceed quality standards set by the quality management program.	▪ Gather and analyze data on quality of care and services. ▪ Identify gaps in quality of care and services. ▪ Maintain a quality management program that meets or exceeds HRSA and AIDS Institute expectations. ▪ *Participate in the region's quality management activities.* ▪ *Survey consumers on needs and satisfaction.*	▪ Percentage of patients with viral load and CD4 counts in all review periods. ▪ Percentage of needs assessment survey respondents who meet AIDS Institute criteria for appropriate medical care such as number of medical care visits and knowledge of CD4 counts.	▪ Annually ▪ Annually ▪ Annually ▪ *Annually* ▪ *Annually*

Examples of evidence to justify the objectives
▪ While more than two-thirds (69%) of all PLWHA in the region are estimated to be in HIV care, the remainder (31%) are out of care. ▪ Transportation and housing are two of the most frequently unmet or partially met needs of people living with HIV. ▪ Transportation is insufficient for pharmacy, food pantry, and other appointments outside of primary medical care, dental care, or mental health visits. ▪ Numerous co-morbid conditions, including Hepatitis and tuberculosis, have been documented

Examples of evidence to justify the objectives

among PLWHA in care in region. Co-morbid conditions increase both the cost and complexity of providing HIV care.

- Nearly one third of PLWHA in care in the region are diagnosed with depression (23%) or serious mental illness (9%).
- African Americans in care report a greater delay since their most recent physician/laboratory monitoring visit than their Hispanic counterparts.
- Large proportions of African Americans and Hispanics in care report current or previous homelessness.
- Few of the respondents to the Hispanic needs assessment report having health insurance, and a substantial number are undocumented.

Goal 4 Ensure the continuum of HIV/AIDS services is integrated, effective, and comprehensive.			
Objectives	Action Steps	Measures	Year
4A. Ensure that the HIV/AIDS service system is integrated to the fullest extent possible.	▪ Identify the extent to which service elements are integrated. ▪ Develop and promote strategies to enhance service system integration. ▪ *Promote the integration of services among Network providers.* ▪ *Implement the region's service delivery plan.*	▪ Increased number of network participants. ▪ Increase in network integration-related activities completed. ▪ Increase in the number and quality of formal inter-agency agreements addressing service integration.	▪ Annually ▪ Annually ▪ *Annually* ▪ *Annually*
4B. Address the capacity and infrastructure barriers and gaps in the system of HIV/AIDS care.	▪ Identify and describe the capacity characteristics and needs in the system of care. ▪ Identify and describe the infrastructure characteristics and needs in the system of care. ▪ *Identify and promote mechanisms to address capacity and infrastructure gaps in the system of care.* [17]	▪ Extent to which actions steps were accomplished.	▪ Year 1 ▪ Annually ▪ *Annually*
4C. Evaluate the cost effectiveness and outcomes effectiveness of services, service categories, and the system of HIV/AIDS	▪ Identify which elements of the service system to evaluate in terms of cost and impact effectiveness. ▪ Describe the scope and	▪ Extent to which actions steps were accomplished.	▪ Annually ▪ Year 2 & Year

[17] Examples include provider training on cultural competency and appropriateness and provider retention.

Goal 4 Ensure the continuum of HIV/AIDS services is integrated, effective, and comprehensive.			
Objectives	Action Steps	Measures	Year
care.	methods of these evaluations. ▪ Allocate resources to conduct the evaluations. ▪ Apply the results of the evaluations to planning and priority setting. ▪ *Collaborate with the Planning Council on evaluation activities.*		3 ▪ Annually ▪ Annually ▪ *Annually*

Implementing the Plan

The Planning Council and HIV Care Network will use this plan to assist them in fulfilling their duties between 2009 and 2011.

Implementation of the plan's goals and objectives primarily will require the involvement of:

- The Planning Council
- The HIV Care Network
- United Way of Long Island
- Providers funded by Part A and Part B of the Ryan White Program
- Providers funded by other Parts of the Ryan White Program

Collaborating external partners include:

- Ryan White Part C, Part D, and Part F providers in the region
- HIV/AIDS Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services
- New York State Department of Health AIDS Institute.
- Nassau County Department of Health
- Suffolk County Department of Health Services
- Providers of Services to PLWHA not funded by Ryan White (such as Substance Abuse Treatment providers, non- AIDS Service Organizations, HIV Counseling and Testing Programs, Homeless Shelters and other key points of entry into care)

Plan Update and Renewal Process

This document will guide planning for Nassau and Suffolk Counties between 2009 and 2011. The plan should be revisited annually and its objectives and action steps modified as necessary. It is also hoped that other agencies responsible for various aspects of HIV/AIDS services planning, delivery, or funding will use this plan in their own processes.

In addition to its ongoing quality management activities, the Planning Council and HIV Care Network will use the framework in Chapter 4 to monitor and evaluate the extent to which the goals and objectives have been achieved. The results of these point-in-time reviews will provide the region with a reliable source of information to better understand the quality and reach of the Plan.

Chapter 4

How will we monitor our progress: How will we evaluate our progress in meeting our short- and long-term goals?

This chapter presents a framework for monitoring and evaluation. In preparing the monitoring component, the Planning Council and Network seek to:

- Provide a mechanism by which the Planning Council and Network can measure progress toward achievement of the plan's goals and objectives and develop an annual work plan of activities.
- Identify areas for data collection to assist the Planning Council in allocating Part A funds for evaluation related activities.
- Provide direction to the process of targeting, measuring, and achieving outcomes of services supported by Part A and Part B funds in 2009, 2010, and 2011.

Context for Monitoring and Evaluation

Performance monitoring and evaluation activities are vital to pursuing the EMA's vision. However, monitoring does not occur in a vacuum. A number of factors need to be taken into consideration when judging performance over time.

The changing environment: It is difficult to know for certain how recent or future changes in entitlement and immigration laws, primary payer benefits, as well as clinical advances, will affect people with HIV disease. Stability of future levels of discretionary Federal funding for HIV/AIDS and other necessary services is uncertain. These uncertainties affect planning and priority setting, and also complicate the selection of performance indicators and measures. As more information becomes available to the region, the appropriate indicators (and their measures) can be refined.

Data-related limitations. Several types of data limitations affect the region's ability to monitor plan performance. These include:

- Inadequate baseline or comparison data against which to judge performance.
- Historically, monitoring and evaluation of Ryan White services has primarily involved process evaluation (e.g., Were intended activities completed?) versus outcome evaluation (e.g., Were desired programmatic outcomes achieved?). Meanwhile, HRSA and other funders increasingly emphasize the need to collect client-level data and analyze outcomes data.

Important Monitoring and Evaluation Terms

An **indicator** is a statement that defines success for a given objective. Indicators are indirect or partial measures of a complex situation, but if measured sequentially over time they can indicate direction and magnitude of change and serve to compare different areas or groups of people at the same moment in time.

A **measure** is a specific factor or variable that can be measured to indicate progress in achieving an objective.

Selecting Performance Measures

The framework for monitoring this plan is outcomes-oriented. Toward that end, and bearing in mind the data limitations outlined previously, the following prioritized list of outcome selection criteria were used to determine measures.

Outcome Selection Criteria

Criteria	Related Questions
Measures defensible from a technical perspective.	▪ In terms of validity: Does this indicator truly measure what it was intended to measure? ▪ In terms of reliability: To what extent is this measure likely to yield consistent results over time? ▪ Is the entire population being measured or a sample? If a sample, is there reason to believe it is representative? ▪ Is the sample size large enough to be acceptable from a statistical perspective?
Measures where a strong argument can be made that the outcome is the result of, or at least strongly influenced by, Ryan White resources or other regional initiatives.	▪ Is the "causal model" linking the region's activities to programmatic outcomes credible? ▪ Are there major factors that contribute to this outcome that have little or nothing to do with Part A/Part B funding and/or other regional activities? ▪ Is it possible to compare the results for individuals receiving Part A/Part B services to the results for individuals not receiving Part A/Part B services?
Measures for which needed data are already available on a routine basis, or can easily be made available on a routine basis with little cost and/or minimal effort.	▪ If data are already being collected: How frequently? Is funding for data collection secure for the next three years? How long does it take for results to be made available? ▪ If data are not already being collected: How expensive and difficult would it be to implement data collection? How likely is it that funding for data collection will be available for the next three years? How long would it take for results to be made available?
Priority will be given be to measures in the following order:	▪ Is there an alternative measure available from a higher category that could be used to determine success?

Outcome Selection Criteria	
Criteria	Related Questions
▪ Outcome measures (for example, improved health) ▪ Input or output measures (for example, number of individuals who enter a service) ▪ Process measures (for example, completion of a planned action item)	

Data Sources Used to Monitor Plan Performance

Data sources cited in the monitoring and evaluation plan are listed below. Note that each of these data sources has strengths and limitations. In several instances, changes in data collection methodologies and the data collected are expected to occur in the future. Possible new data sources and areas for data coordination include the AIDS Institute's HIV Quality Management Program (see box below), ADAP, needs assessment data, epidemiological data, Medicaid data, and client-level service utilization data. These changes may require that the region revisit and potentially modify the framework for comprehensive plan monitoring at some point in the future.

- HIV surveillance data, AIDS surveillance data, ADAP data, Medicaid data from New York State
- Centers for Disease Control and Prevention
- Nassau-Suffolk client-level and quality management data
- Planning Council and Network meeting minutes and other documentation

Monitoring the Plan

The framework for monitoring the plan, outlined below, reiterates each goal and objective presented in Chapter 3. For most objectives, the following information is included in the framework:

- A measure, which is a specific factor or variable that can be measured to indicate progress in achieving the objective.
- Baseline data, which states the status of the measure at the beginning of the plan. Baselines are being developed by an ad hoc committee comprised of members representing the Strategic Assessment and Planning Committee, Quality Management Committee, and Care Coordination Committee.
- Indicator of progress, which is a statement defining what constitutes success for a given measure.
- The data source for the measure and any other reference information necessary to better understand the measure.
- In some instances, quantifiable data are not available to measure the success of an objective; in such cases "process measures" are used instead. Process measures ask the question, "Did the Planning Council/Network complete the tasks it set for itself?"

When process measures are used to indicate plan success, the action steps listed in Chapter 3 are repeated in the monitoring plan. Because success is measured by action step completion, baselines are not relevant.

Key Results

As noted in Chapter 3, the region identified an overarching goal to improve the health outcomes and quality of life for people living with HIV disease in Nassau and Suffolk Counties.

Two key results can measure the EMA's success in achieving this overarching goal. These measures are listed below along with their current status:

- Reduce the AIDS case mortality rate.

  According to the New York State Department of Health, the AIDS case mortality rate for Nassau was 2.3 per 100,000 and was 2.4 per 100,000 population for Suffolk Counties in 2007.

- Increase the percentage of people living with HIV and AIDS who report high quality health care.

Monitoring Framework

Goal 1: Increase the number of HIV-infected individuals who know their HIV status.

Objective 1A: Expand testing at key points of entry into the health care system accessed by at-risk populations.

Measure #1: Number of individuals who do not know their status as reflected by the number of persons who test positive for HIV in a year.

Baseline: To be determined. [18]

Indicator of Progress: Decrease in the number of individuals who do not know their status.

Date Sources/Reference Information: New York State Department of Health.

Measure #2: Percentage of people who are diagnosed with HIV and AIDS concurrently.

Baseline: To be determined.

Indicator of Progress: Decrease in the number of individuals who are concurrently diagnosed.

Date Sources/Reference Information: New York State Department of Health.

[18] Baselines are being developed by an ad hoc committee comprised of members representing the Strategic Assessment and Planning Committee, Quality Management Committee, and Care Coordination Committee.

Goal 2: Increase the number of HIV-positive individuals who access care.

Objective 2A: Ensure that programs serving as key points of entry into the health and human service systems provide effective linkages to core medical care and other necessary support services for people living with HIV/AIDS.

Measure: Percentage of newly diagnosed clients who have not entered HIV care within 90 days of testing HIV-positive.

Baseline: To be determined.

Indicator of Progress: Decline in the percentage of new diagnosed clients who have not entered care within 90 days of testing HIV-positive.

Date Source/Reference Information: Client-level data.

Measure: Percentage of newly diagnosed clients who have entered HIV care within 90 days of testing HIV-positive.

Baseline: To be determined.

Indicator of Progress: Increase in the percentage of new diagnosed clients who have not entered care within 90 days of testing HIV-positive.

Date Source/Reference Information: Client-level data.

Objective 2B: Reduce barriers to timely receipt of HIV care experienced by HIV-positive individuals.

Measure: Percentage of needs assessment survey respondents reporting one logistical barrier to getting needed care.

Baseline: To be determined.

Indicator of Progress: Decrease in the percentage of those reporting a delay or not getting needed assistance.

Date Source/Reference Information: Needs assessment surveys.

Goal 3: Increase the proportion of people living with HIV/AIDS who are maintained in quality HIV care once they enter the service system.

Objective 3A: Ensure the availability of core medical care and other necessary services for people living with HIV/AIDS.

Measure #1: Percentage of needs assessment survey respondents reporting a need for services who are not receiving the service or services.

Baselines: To be determined.

Indicator of Progress: Decrease in existing service gaps.

Data Source/Reference Information: Needs assessment surveys.

Measure #2: Percentage of needs assessment survey respondents reporting a need for services who are receiving the service or services.

Baselines: To be determined.

Indicator of Progress: Increase in met need for services.

Data Source/Reference Information: Needs assessment surveys.

Objective 3B: Ensure coordination of care among providers of services to people living with HIV/AIDS.

Measure: Improvements in coordination between specific types of providers.

Baselines: To be determined.

Indicator of Progress: Increased coordination identified.

Data Source/Reference Information: Quality Management Program.

Objective 3C: Implement mechanisms to identify and re-engage people living with HIV/AIDS who are lost to care.

Measure #1: Increase in the number of people living with HIV/AIDS who are re-engaged in care.

Baseline: To be determined.

Indicator of Progress: Decrease in the percentage of clients who were not seen for medical appointments during a 6 month period.

Date Source/Reference Information: Quality Management Program/Client Level Data.

Objective 3D: Ensure that HIV services meet or exceed quality standards set by the quality management program.

Measure #1: Percentage of patients with viral load and CD4 counts in all review periods.

Baseline: To be determined.

Indicator of Progress: Increase in clinical monitoring testing.

Date Source/Reference Information: Quality Management Program.

Measure #2: Percentage of needs assessment survey respondents who meet AIDS Institute criteria for appropriate medical care such as number of medical care visits and knowledge of CD4 counts.

Baseline: To be determined.

Indicator of Progress: Increased percentage that meet AIDS Institute standards of care.

Date Source/Reference Information: Quality Management Program.

Goal 4: Ensure the continuum of HIV/AIDS services is integrated, effective, and comprehensive.

Objective 4A: Ensure that the HIV/AIDS services system is integrated to the fullest extent possible.

Measure #1: Increased number of network participants.

Baseline: To be determined.

Indicator of Progress: Increased number of network participants.

Date Source/Reference Information: Network documents and survey data.

Measure #2: Increase in network integration-related activities completed.

Baseline: To be determined.

Indicator of Progress: Increased number of network integration-related activities.

Date Source/Reference Information: Network documents and survey data.

Measure #3: Increase in the number and quality of formal inter-agency agreements addressing service integration.

Baseline: To be determined.

Indicator of Progress: Increased number and quality of formal inter-agency agreements.

Date Source/Reference Information: Network documents and survey data.

Objective 4B: Address the capacity and infrastructure barriers and gaps in the system of HIV/AIDS care.

Process Measures: Were the action steps accomplished?

Objective 4C: Evaluate the cost effectiveness and outcome effectiveness of services, service categories, and the system of HIV/AIDS care.

Process Measures: Were the action steps accomplished?

Primary Data Sources

1. African American 'In Care' PLWHA Needs Assessment in the Nassau Suffolk EMA: 2008 Report of Findings. Prepared by Collaborative Research LLC. May 2008.

2. Comprehensive Service Plan for HIV/AIDS in Nassau and Suffolk Counties. January 2006.

3. Hispanic 'In Care' PLWHA Needs Assessment in the Nassau Suffolk EMA: 2008 Report of Findings. Prepared by Collaborative Research LLC. May 2008.

4. Long Island HIV/AIDS 2007 Online Consumer Survey Results. Nassau-Suffolk HIV Health Services Planning Council.

5. Nassau-Suffolk EMA FY 2009 Ryan White Part A Application.

6. 'Out of Care' Unmet Needs Assessment of Persons Living with HIV/AIDS in the Nassau Suffolk EMA: 2008 Report of Findings. Prepared by Collaborative Research LLC. May 2008.

7. Quality Improvement 2007 Site Visit Final Report, Nassau-Suffolk TGA. Prepared by Collaborative Research LLC.

8. Quality Management Report. Prepared by Collaborative Research LLC. July-August 2008.

9. Ryan White CARE Act 2006 Statewide Coordinated Statement of Need and Comprehensive Plan. New York State Department of Health, AIDS Institute. February 2006.

Appendix A
Glossary

ADAP: AIDS Drug Assistance Program

Barriers: Impediments in access to care, including structural (availability, how organized, transportation), financial (insurance coverage, reimbursement levels, public support), and personal (acceptability, cultural, language, attitudes, education/income).

Cohort: A group of individuals participating in a research study over time who join the study at the same time and are periodically re-surveyed or re-examined at the same time.

Designated AIDS Center (DAC): A health facility providing comprehensive inpatient and outpatient services delivered by a multi-disciplinary team of clinical and support service professionals led by an HIV specialist, for persons infected with HIV and organized under a single AIDS Center administrator and medical director. DACs are qualified by the State of New York.

Disparities: Differences, primarily in longer-term health outcomes, between different populations or geographic regions.

EMA: Eligible Metropolitan Area

Gaps: A perceived (qualitative) or measurable lack of availability or appropriateness of services or concrete needs.

Goal: A measureable statement of the desired long-term, global impact of the program.

Health Resources and Services Administration (HRSA): An agency of the U.S. Department of Health and Human Services which administers the Ryan White Program through its HIV/AIDS Bureau (HAB).

IDU: Injection drug user.

Incidence: The number of new cases that occur during a specific period of time. For example, 2007 incidence is the total number of people diagnosed in calendar year 2007.

MSM: Men who have sex with men.

Objective: A specific, measureable statement of the desired immediate or direct outcomes of the program.

Outcomes: Defined as longer-term outcomes, such as improved health status, versus intermediate outcomes, such as service utilization rates. Client satisfaction and service quality measures are also included in this category.

Overcoming barriers: Strategies, usually programmatic, that could potentially help to overcome barriers.

PLWHA: People living with HIV/AIDS.

Prevalence: The total number of people currently living with HIV or AIDS. For example, 1999 AIDS prevalence is the number of individuals who were diagnosed with AIDS through December 1999 still living at that time.

Qualitative data: Descriptive information usually presented in narrative form. Qualitative data can help illuminate what is happening, as well as describe how or why something is occurring.

Quantitative data: Numbers that can be statistically analyzed and are used to describe what, who, when, how many, or how much in relation to a question or issue.

Service utilization: Qualitative or quantitative data that describes the service utilization patterns of a population.

Special needs: Broad descriptions of the population and its unique cultural and/or service needs.

Statewide Coordinated Statement of Need (SCSN): A provision of the Ryan White Act requiring each State to publish a statewide summary of service needs across the spectrum of care for HIV positive persons and to develop a comprehensive plan. The current SCSN for New York (2006) is available at http://www.health.state.ny.us/diseases/aids/reports/scsn/index.htm.

Targeted services: Services that exist within the continuum of care in order to meet the unique needs of this population.

Appendix B
Ryan White Program Service Definitions

Part A Core Services

AIDS Drug Assistance Program (ADAP) is a State administered program authorized under Part B of the Ryan White Program that provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance, Medicaid or Medicare. According to NYSDOH, the ADAP Formulary of drugs includes anti-retroviral, anti-neoplastic, and opportunistic infection therapies, and prophylaxis for pneumocystic carinii pneumonia (PCP). New drugs are added to the formulary based upon the changing clinical profile of the epidemic and the most recent clinical trials data.

Health Insurance is the provision of financial assistance for eligible individuals living with HIV to maintain a continuity of health insurance or to receive medical benefits under a health insurance program. This includes premium payments, risk pools, co-payments, and deductibles.

Medical Nutrition Therapy is provided by a licensed registered dietitian outside of a primary care visit and includes the provision of nutritional supplements. Medical nutrition therapy provided by someone other than a licensed/registered dietitian should be recorded under psychosocial support services.

Medical Case Management is a range of client-centered services that link clients with health care, psychosocial, and other services. The coordination and follow-up of medical treatments is a component of medical case management. These services ensure timely and coordinated access to medically appropriate levels of health and support services and continuity of care, through ongoing assessment of the client's and other key family members' needs and personal support systems. Medical case management includes the provision of treatment adherence counseling to ensure readiness for, and adherence to, complex HIV/AIDS treatments. Key activities include (1) initial assessment of service needs; (2) development of a comprehensive, individualized service plan; (3) coordination of services required to implement the plan; (4) client monitoring to assess the efficacy of the plan; and (5) periodic re-evaluation and adaptation of the plan as necessary over the life of the client. It includes client-specific advocacy and/or review of utilization of services. This includes all types of case management including face-to-face, phone contact, and any other forms of communication. Medical case management includes treatment adherence.

Mental Health Services are psychological and psychiatric treatment and counseling services offered to individuals with a diagnosed mental illness, conducted in a group or individual setting, and provided by a mental health professional licensed or authorized within the State to render such services. This typically includes psychiatrists, psychologists, and licensed clinical social workers.

Oral Health Care includes diagnostic, preventive, and therapeutic services provided by general dental practitioners, dental specialists, dental hygienists and auxiliaries and other trained primary care providers.

Outpatient/Ambulatory Health Services is the provision of professional diagnostic and therapeutic services rendered by a physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting. Settings include clinics, medical offices, and mobile vans where clients generally do not stay overnight. Emergency room services are not outpatient settings. Services includes diagnostic testing, early intervention and risk assessment, preventive care and screening, practitioner examination, medical history taking, diagnosis and treatment of common physical and mental conditions, prescribing and managing medication therapy, education and counseling on health issues, well-baby care, continuing care and management of chronic conditions, and referral to and provision of specialty care (includes all medical subspecialties). *Primary medical care* for the treatment of HIV infection includes the provision of care that is consistent with the Public Health Service's guidelines. Such care must include access antiretroviral and other drug therapies, including prophylaxis and treatment of opportunistic infections and combination antiretroviral therapies.

Substance Abuse Services (outpatient) is the provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting, rendered by a physician or under the supervision of a physician, or by other qualified personnel.

Part A Support Services

Legal services are the provision of services to individuals with respect to powers of attorney, do-not-resuscitate orders and interventions necessary to ensure access to eligible benefits, including discrimination or breach of confidentiality litigation as it relates to services eligible for funding under the Ryan White Program. It does not include any legal service that arrange for guardianship or adoption of children after the death of their normal caregiver.

Medical transportation services include conveyance services provided, directly or through voucher, to a client so that he or she may access health care services.

Outreach services are programs that have as their principal purpose identification of people with unknown HIV disease or those who know their status so that they may become aware of, and may be enrolled in care and treatment services (i.e., case finding), not HIV counseling and testing nor HIV prevention education. These services may target high-risk communities or individuals. Outreach programs must be planned and delivered in coordination with local HIV prevention outreach programs to avoid duplication of effort; be targeted to populations known through local epidemiologic data to be at a disproportionate risk for HIV infection; be conducted at times and in places where there is a high probability that individuals with HIV infection will be reached; and be designed with quantified program reporting that will accommodate local effectiveness evaluation.

Part B Core Medical Services

Medical Case Management (Including Treatment Adherence): A range of client-centered services that link clients with health care, psychosocial, and other services.

Medical Nutrition Therapy: Provided by a licensed registered dietitian outside of a primary care visit and includes the provisions of nutritional supplements.

Mental Health Services for HIV Positive Persons: Psychological and psychiatric treatment and counseling services, including individual and group counseling, provided by mental health professionals licensed by the NYS Department of Education and the Board of Regents to practice within the boundaries and scope of their respective profession.

Outpatient/Ambulatory Medical Care (Health Service): Provision of professional diagnostic and therapist services rendered by physician, physician's assistant, clinical nurse specialist, or nurse practitioner in an outpatient setting.

Substance Abuse Services-Outpatient: Is the provision of medical or other treatment and/or counseling to address substance abuse problems (i.e., alcohol and/or legal and illegal drugs) in an outpatient setting, rendered by a physician or under the supervision of a physician, or by the qualified personal.

Part B Supportive Services

Case Management: Includes the provision of advice and assistance in obtaining medical, social, community, legal, financial, and other needed support services.

Child Care Services: Provision of care for the children of clients who are HIV positive while the clients attend medical or other appointments or Ryan White Program-related meetings, groups, or training. Note: This does not include child care while a client is at work.

Emergency Financial Assistance: Provision of short-term payments to agencies or establishment of voucher programs to assist with emergency expenses related to essential utilities, housing, food (including groceries, food vouchers, and food stamps), and medication when other resources are not available.

Food Bank/Home-Delivered Meals: Provision of actual food or meals. It dose not include finances to purchase food or meals. The provision of essential household supplies such as hygiene items and household cleaning supplies should be included in this item. Includes vouchers to purchase food.

Health Education/Risk Reduction: Provision of services that educate clients with HIV, including the provision of information about medical and psychosocial support services and counseling to help clients with HIV improve their health status, and education about HIV transmission and how to reduce the risk of HIV transmission.

Housing Services: Provision of short-term assistance to support emergency, temporary or transitional housing to enable an individual or family to gain or maintain medical care.

Linguistics Services: Provision of interpretation and translation services.

Medical Transportation Services: Includes, conveyance services provided, Directly or through voucher, to a client so that he or she may access health care services.

Appendix C
Consumer Service Providers in the Nassau Suffolk Region

Below is a list (as of December 2008) of consumer service sites in Nassau and Suffolk Counties where the following are available:

- General Medical Care
- Medical Care: Designated AIDS Centers
- HIV Case Management
- Partner Notification

General Medical Care

Apple/A Program Planned For Life Enrichment
220 Veterans Hwy
Hauppauge, NY 11788
(631) 979-0922
HIV Primary Care Medicaid Program

Brookhaven Memorial Hospital Medical Center
101 Hospital Rd
Patchogue, NY 11772
(631) 654-7100
HIV Primary Care Medicaid Program

Family Residences and Essential Enterprises, Inc.
120 Plant St
Hauppauge, NY 11788
(631) 851-3810

Franklin Hospital Medical Center
900 Franklin Ave
Valley Stream, NY 11580
(516) 256-6000

Huntington Hospital Dolan Family Health Center
284 Pulaski Rd
Green Lawn, NY 11740
(631) 425-5242

Long Island Jewish Medical Center
270-05 76 Ave
New Hyde Park, NY 11040
(718) 470-7764
HIV Primary Care Medicaid Program

Long Island Jewish Medical Center
410 Lakeville Rd Suite 108
New Hyde Park, NY 11040
(516) 465-5360

Nassau Health Care Corporation
2201 Hempstead Tpke
East Meadow, NY 11554
(516) 572-0123

Nassau Health Care Corporation
Community Health Center
490 Main St
Freeport, NY 11520
(516) 572-3100

Nassau University Medical Center
2201 Hempstead Tpke
East Meadow, NY 11554
(516) 572-6505
HIV Primary Care Medicaid Program

North Shore University Hospital
300 Community Dr
Manhasset, NY 11030
(516) 562-4188
HIV Primary Care Medicaid Program

North Shore University Hospital Glen Cove
101 St Andrews Ln
Glen Cove, NY 11542
(516) 674-7580
HIV Primary Care Medicaid Program

Planned Parenthood of Nassau County, Inc.
540 Fulton St
Hempstead, NY 11550
(516) 483-3193

SUNY Stony Brook
(Research Foundation of SUNY)
University Hospital Pediatric Program
HSC-T11/SUNY Stony Brook
Stony Brook, NY 11794
(631) 444-8227

Southampton Hospital
240 Meeting House Ln
Southampton, NY 11968
(631) 726-8555
HIV Primary Care Medicaid Program

Suffolk County Department of Health
225 Rabro Dr East
Hauppague, NY 11788
(516) 853-3000
HIV Primary Care Medicaid Program

Suffolk County Department of Health Services
Tri-Community Health Center
1080 Sunrise Hwy
Amityville, NY 11701
(631) 854-1000

Suffolk County Department of Health Services
Martin Luther King Jr. Health Center
1556 Straight Path
Wyandanch, NY 11798
(631) 854-1700

Suffolk County Department of Health Services
Brentwood Family Health Center
1869 Brentwood Rd
Brentwood, NY 11717
(631) 853-3400

Suffolk County Department of Health Services
Riverhead Health Center/County Center
300 Center Dr
Riverhead, NY 11901
(631) 852-1800

Suffolk County Department of Health Services
North Brookhaven Family Health Center
3600 Rte 112
Coram, NY 11727
(631) 854-2301

Suffolk County Department of Health Services
Central Islip Health Center
45 West Suffolk Ave
Central Islip, NY 11722
(631) 853-2710

University Hospital at Stony Brook
AIDS Center
Stony Brook, NY 11794
(631) 444-1667
HIV Primary Care Medicaid Program

Medical Care: Designated AIDS Centers

Nassau University Medical Center
2201 Hempstead Tpke
East Meadow, NY 11554
(516) 572-6505

North Shore University Hospital
300 Community Dr
Manhasset, NY 11030
(516) 562-4188

University Hospital at Stony Brook
AIDS Center
Stony Brook, NY 11794
(631) 444-1667
HIV Primary Care Medicaid Program

HIV Case Management

Circulo de la Hispanidad, Inc.
91 North Franklin St Suite 200
Hempstead, NY 11550
(516) 292-2499

Economic Opportunity Council of Suffolk, Inc.
25 Fourth Ave Suite 106
Bay Shore, NY 11706
(631) 968-8000

Five Towns Community Center, Inc.
175 Fulton Ave
Hempstead, NY 11550
(516) 505-9177

Long Island Association for AIDS Care, Inc. (LIAAC)
60 Adams Ave
Hauppauge, NY 11788
(631) 385-2451

Options for Community Living, Inc.
1 Helen Keller Way 4th Fl, Suite 402
Hempstead, NY 11550
(516) 481-6300

Options for Community Living, Inc.
202 East Main St Suite 7
Smithtown, NY 11787
(631) 361-9020

Suffolk County Department of Health Services
Tri-Community Health Center
1080 Sunrise Hwy
Amityville, NY 11701
(631) 854-1000

Partner Notification

Family and Children's Association
126 North Franklin St.
Hempstead, NY 11550
(516) 486-7200

Daytop Village, Inc.
Suffolk Outreach
2075 New York Ave
Huntington Station, NY 11746
(631) 351-7112
Must Be Medicaid Eligible

Long Island Jewish Methadone Maintenance Treatment Program
270-05 76th Ave PB6
New Hyde Park, NY 11040
(718) 470-8940

Nassau County Correctional in collaboration with Nassau County Department of Mental Health Chemical Dependency & Developmental Disabilities Services
100 Carmen Ave
East Meadow, NY 11554
(516) 572-3620
Bilingual Staff (English/Spanish)

Source: http://www.health.state.ny.us/diseases/aids/resources/resource_directory/

Appendix D
HIV Care Network Survey Instruments

Nassau Suffolk HIV Care Network Consumer Involvement Committee 2008 Survey

The NYSDOH AIDS Institute requires that the HIV Care Network conduct quality assurance activities to assess and evaluate the effectiveness of its committees annually. The tool below was used to survey members of the Consumer Involvement Committee.

MEMBER INFORMATION

Name: _____

Address: _____

_____

Phone:_____ Fax:_____

Email:_____

THE CONSUMER INVOLVEMENT COMMITTEE MISSION IS TO PROMOTE CONSUMER INVOLVEMENT BY INCREASING AND RETAINING THE PROPORTION OF CONSUMERS ACTIVELY PARTICIPATING ON THE NETWORK FOR THE PURPOSE OF INFORMING HIV/AIDS POLICY, SHARING THE REALITIES OF LIVING WITH HIV/AIDS, IDENTIFYING GAPS IN SERVICES AND EFFECTING CHANGE.

COMMITTEE STRUCTURE

1. Does the Consumer Involvement Committee provide an opportunity for you to participate in committee activities? Such as: health fairs, legislative visits, etc…

_____ YES _____ NO

2. If no, what can be done to encourage your participation and what would you like? (Please fill in your answer below)

_____

_____

3. Is the location of the Consumer Involvement Committee meetings acceptable?

_____ YES _____ NO

If not, please explain below:

_____

_____

4. Are the meeting times acceptable?

   _____ YES _____ NO

   If not, please explain below:

   _____

   _____

METHOD OF COMMUNICATION

1. Do you currently receive materials and information?

   _____ YES _____ NO

2. Are the minutes of the Consumer Involvement Committee meetings generally timely and accurate?

   _____ YES _____ NO

COMMITTEE MEETINGS

In the space below, please indicate if there are other issues that should be discussed at Consumer Involvement Committee meetings. Please indicate if a different format for committee meetings would better meet your needs.

_____

_____

_____

THE EXECUTIVE COMMITTEE IS THE GOVERNING BODY OF THE NASSAU-SUFFOLK HIV CARE NETWORK AND PROVIDES SUPPORT AND GUIDANCE TO ALL OTHER STANDING AND AD HOC COMMITTEES.

1. Do you think that there is enough input from the Executive Committee into your committee? _____YES _____NO (If no, please complete ques#2)
2. If you have ideas on how the Executive Committee can assist the Consumer Involvement Committee, please let us know below:

_____

_____

Nassau Suffolk HIV Care Network Policy Advisory Education Committee 2008 Survey

The NYSDOH AIDS Institute requires that the HIV Care Network conduct quality assurance activities to assess and evaluate the effectiveness of its committees annually. The tool below was used to survey members of the Policy Advisory Education Committee.

MEMBER INFORMATION (*Optional*)

Name: _____

Title/Organization:_____

Address: _____

_____

Phone:_____ Fax:_____

THE POLICY ADVISORY/ EDUCATION COMMITTEE MISSION IS INFORM STAKEHOLDERS (GOVERNMENT AND COMMUNITY) OF REGIONAL NEEDS AND EMERGING ISSUES RELATED TO HIV/AIDS, IDENTIFYING GAPS IN SERVICES AND EFFECTING CHANGE.

COMMITTEE STRUCTURE

1. Does the Policy Advisory Education Committee provide adequate opportunities for you to participate?

_____ YES _____ NO

2. If not, what additional opportunities would you like? (Please fill in your answer below)

_____

_____

3. Is the location of the Policy Advisory Education Committee meetings acceptable?

_____ YES _____ NO

If not, please explain below:

_____

_____

5. Are the meeting times acceptable?

_____ YES _____ NO

If not, please explain below:

_____

_____

METHOD OF COMMUNICATION

3. Do you currently receive sufficient materials and information?

   _____ YES _____ NO

4. Are the minutes of the Policy Advisory Education Committee meetings generally timely and accurate?

   _____ YES _____ NO

COMMITTEE MEETINGS

In the space below, please indicate if there are other issues that should be discussed at Policy Advisory Education Committee meetings. Please indicate if a different format for committee meetings would better meet your needs.

_____

_____

_____

THE EXECUTIVE COMMITTEE IS THE GOVERNING BODY OF THE NASSAU-SUFFOLK HIV CARE NETWORK AND PROVIDES SUPPORT AND GUIDANCE TO ALL OTHER STANDING AND AD HOC COMMITTEES.

3. Do you think that there is enough input from the Executive Committee into your Policy Advisory/Education Committee? _____YES _____NO

4. If you have ideas about how the Executive Committee can assist the Policy Advisory Education Committee, please let us know below:

_____

_____

_____

Nassau Suffolk HIV Care Network Care Coordination Committee 2008 Survey

The NYSDOH AIDS Institute requires that the HIV Care Network conduct quality assurance activities to assess and evaluate the effectiveness of its committees annually. The tool below was used to survey members of the Care Coordination Committee.

MEMBER INFORMATION (*Optional*)

Name: _____

Title/Organization:_____

Address: _____

_____

Phone:_____ Fax:_____

THE CARE COORDINATION COMMITTEE MISSION IS TO REDUCE BARRIERS TO SERVICES BY ASSESSING SERVICE NEEDS, IDENTIFYING BARRIERS TO CARE, GAPS IN SERVICES, EMERGING ISSUES AND POPULATIONS EXPERIENCING DISPARITIES IN ACCESS AND SERVICES, PROPOSE SOLUTIONS AND IMPLEMENT STRATEGIES TO COORDINATE COMMUNITY RESOURCES, IDENTIFYING NEW RESOURCES AND ADDRESS RETENTION IN CARE AND HEALTH OUTCOMES.

COMMITTEE STRUCTURE

1. Does the Care Coordination Committee provide adequate opportunities for you to participate?

_____ YES _____ NO

2. If not, what additional opportunities would you like? (Please fill in your answer below)

_____

_____

3. Is the location of the Care Coordination Committee meetings acceptable?

_____ YES _____ NO

If not, please explain below:

_____

_____

6. Are the meeting times acceptable?

_____ YES _____ NO

If not, please explain below:

_____

_____

METHOD OF COMMUNICATION

5. Do you currently receive sufficient materials and information?

   _____ YES _____ NO

6. Are the minutes of the Care Coordination Committee meetings generally timely and accurate?

   _____ YES _____ NO

COMMITTEE MEETINGS

In the space below, please indicate if there are other issues that should be discussed at Care Coordination Committee meetings. Please indicate if a different format for committee meetings would better meet your needs.

_____

_____

_____

THE EXECUTIVE COMMITTEE IS THE GOVERNING BODY OF THE NASSAU-SUFFOLK HIV CARE NETWORK AND PROVIDES SUPPORT AND GUIDANCE TO ALL OTHER STANDING AND AD HOC COMMITTEES.

5. Do you think that there is enough input from the Executive Committee into your committee? _____YES _____NO

6. If you have ideas about how the Executive Committee can assist the Care Coordination Committee, please let us know below:

_____

_____

Appendix E
Specific Population Needs and Gaps Identified in 2008

African American "In Care" PLWHA Needs and Service Gaps, 2008

Service Category	Need Rank	Gap Rank	Typical Reasons
Housing	1	1	Problems covering 1st month's rent when relocating from out of area or prison; no assistance for non-homeless or working PLWHA. More people are testing positive but funding and services are being cut.
Quality Food - Meals and Food Boxes	2 tie	4 tie	Food stamps & vouchers limited or unavailable; "qualify for food assistance but no way to get there".
Medical Transportation	2 tie	2 tie	Medical transportation service is unreliable; need help to find a car; limited # and range of rides- monthly medical appointments often exceed max # of rides (especially with additional diseases), no rides to grocery store, food pantry or pharmacy; no rides across county lines limits choice of providers.
Emergency Financial Assistance	4	2 tie	Should not lose coverage when you start working; no national or local political prioritization for funding; little to no assistance available for "working poor"; public assistance barely covering basic needs.
Medications	5	7 tie	Limited transportation to doctor, no transportation to pharmacy; confusing Medicaid spend-down fosters lapses in medication; need new, more tolerable & affordable meds; many medications not covered.
Primary Medical Care	6 tie	4 tie	"Many people are living with HIV but not going to the doctor. We need outreach to people who are scared or on the down-low"; transportation is an issue (limited # per month, limited range; hard to obtain after-hour & emergency appointments).
Health Education/ Information & Referral	6 tie	9	Programs to help obtain GED would be helpful; need workshops; need better info for newly diagnosed; clients still face discrimination & ignorance in the workplace/community.
Employment / Skills Training	10 tie	7 tie	"Would like skills training and job, but afraid I will lose assistance if I begin working again"; housing crisis affects working poor with HIV.
Mental Health	13	10	Use FEGS, Hispanic Counseling Center (Part A providers) no outreach efforts educating public on benefits of mental health care; still stigma attached with care.
Health Insurance	14	6	"I worked for 20+ years and now that I need help I can't get it!"; overly complicated system is discouraging and leads to frustration, stress and lack of trust in health care service plan; "been denied and don't know where to go".

Hispanic "In Care" PLWHA Needs and Service Gaps, 2008			
Service Category	Need Rank	Gap Rank	Typical Reasons
Rental Assistance	9	1	Most claim ineligible for rental assistance or Section 8 because of immigration / documentation status; expressed extreme need for rent assistance; "Housing assistance does not exist for me".
Food Bank Buenos Para alguien comidia (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 but no way to get there".
Medical Transportation- transporte masculino; transportation medio; público	2 tie	3 tie	"I don't know how to request services" because of documentation / immigration status; language barriers; lack of funding; "really need a car but seems impossible"; limited # and range of rides- exceed max # of rides (especially with additional diseases), need metro cards + travel vouchers.
Financial Assistance- aoudad / asistencia; dinero	10	3 tie	No emergency funds; Many don't qualify for assistance because of immigration and/or documentation status.
Housing services Vivendi femenino; tecnología cubierta femenino	8	5	"Because I don't make very much money at my job-"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 PLWHA to remain active; needs ideas for disabled; "need more services geared towards making clients independent."
Health Insurance Seguro	6	7	Most are ineligible due to immigration status; 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	4	9	"I'm new and am figuring out where to go"; lack of mobile health units providing range of services to all in need and lacking transportation; transportation is an issue (limited range + # per month, limited range (ie: won't cross county lines).

Appendix F
HIV Planning Bodies in Nassau Suffolk

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

The Nassau-Suffolk HIV Health Services Planning Council is a 43 member planning group. The purpose of the Planning Council is to provide effective planning for the area and promote the development of HIV services, which meet identified needs of HIV positive individuals. The Planning Council sets the priorities for Ryan White Part A funding in Nassau and Suffolk Counties.

The roles and responsibilities of the Planning Council are:

- To establish priorities for the allocation of funds within the Eligible Metropolitan Area (EMA), including how best to meet each priority and any additional factors that the grantee should consider in allocating funds, based on the documented needs of the HIV-infected population, the cost and outcome effectiveness of proposed strategies and interventions, the priorities of the HIV-infected communities for whom the services are intended and the availability of other governmental and non-governmental resources.

- To develop a comprehensive service plan for the organization and delivery of Ryan White Part A services that is compatible with existing State or local plans regarding the provision of health services to individuals with HIV disease.

- To assess the efficiency of the administrative mechanism in rapidly allocating funds to the areas of greatest need within the eligible area and, at the discretion of the Planning Council, assess the effectiveness, either directly or through contractual arrangements, of the services offered in meeting the identified needs.

- To participate in the development of the Statewide Coordinated Statement of Need (SCSN) initiated by the State public health agency responsible for administering grants under Part B.

- To establish methods for obtaining input on community needs and priorities, which may include public meetings, conducting focus groups and convening ad-hoc panels.

The Planning Council meets four to six times a year at 9:30 a.m. for two hours on a weekday. Meetings are held in western Suffolk, near the border connecting Nassau and Suffolk Counties. Each member must serve on at least one committee of the Planning Council. Committees meet six to eight times a year on a weekday.

Involvement of People Living with HIV/AIDS on the Council

The involvement of individuals who are HIV positive is an essential part of the Planning Council as they bring the consumer perspective to the planning process. By joining the Council and its committees, these individuals are given a voice in the process that determines what Part A

services are appropriate and needed in the Long Island region. It is a requirement that 33% of the entire Council membership be members of the infected and affected community who are non-conflicted. In order to be considered non-conflicted, an individual must meet the following criteria: 1) persons who are receiving HIV-related services from Part A providers; 2) persons who are not officers, employees or consultants to any providers receiving Part A funds and 3) persons who reflect the demographics of the population of individuals with HIV disease in the Long Island region.

Confidentiality is a very important part of Planning Council membership. At least two HIV positive members of the Planning Council must publicly disclose their status as required by the government. It is not mandatory for an HIV positive individual to disclose his or her HIV status at a Planning Council or committee meeting. However, in important situations where decisions are being made that may affect a large number of individuals with HIV/AIDS other Planning Council members may take recommendations more seriously if the individual is known to be a consumer. Most HIV positive members of the Council may be willing to make their status known within the Planning Council or in certain committee meetings with the understanding that the Council will not make this information available to the general public.

The Planning Council has a Consumer Involvement subcommittee, which provides input to the planning process and recommendations to the Planning Council in an anonymous setting. This subcommittee was set up as a way for HIV positive individuals and caregivers to exchange information and participate in the decisions being made about the needs of people living with HIV/AIDS in the Long Island region. The Consumer Involvement subcommittee works to educate and empower its members regarding HIV/AIDS services offered in the region and how to advocate for themselves.

Nassau-Suffolk HIV Care Network
Ryan White Program Part B

The Nassau-Suffolk HIV Care Network is a broad coalition of people infected or affected by HIV/AIDS, providers and community members whose goal is to ensure that HIV/AIDS services are available, accessible and appropriate for the individuals and families who need them in Nassau and Suffolk Counties. The Ryan White Part B HIV Care Network mission is to promote a coordinated community response that results in improved access to care and supportive services for those infected with HIV /AIDS.

The Network sends out a monthly mailing with information about events that are taking place and groups that are meeting in the region. About four times a year, Network Meetings are held on topics of importance and interest to the members.

The goals of the Network are accomplished primarily through the Standing and Ad Hoc committees and include:

Ensuring that HIV/AIDS services are available, accessible and appropriate for individuals and families who need them in Nassau and Suffolk Counties, and

Maintaining at least 25% representation from PLWHA in all levels of Network membership.

Committees

Under their Bylaws, both the Part A Planning Council and the Part B Care Network are required to have standing or ad hoc committees. The Consumer Involvement Subcommittee is a joint committee of Part A and Part B in the EMA. Below is a description of each committee:

Strategic Assessment and Planning Committee (Part A)
This committee oversees the needs assessment process by establishing and reviewing data and discussing ways to collect data on HIV/AIDS in the region. The committee also develops estimates of the HIV/AIDS population and their service needs. This information is used to recommend priorities for the region and guide the development of the comprehensive service plan. In addition, the committee is responsible for approving the amount of funding designated for each priority by the Finance Subcommittee.

Finance Subcommittee (Part A)
This subcommittee reports to the Strategic Assessment and Planning (SAP) Committee and is responsible for the allocation of funds to the priorities established by the SAP Committee.

Quality Assurance and Membership Committee (Part A)
This committee is responsible for evaluating how well services meet community needs; identifying, reviewing and recommending members to the Planning Council (based upon the Ryan White legislation's mandated membership requirements); managing the established Council grievance process; and conducting an annual assessment of the administrative mechanism in the region. The Committee also works closely with the Consumer Involvement Subcommittee to increase participation and involvement of affected people and communities in Planning Council activities.

Executive Committee (Part A)
This committee handles all administrative functions associated with internal management and budget review, grant application, reporting and oversight, coordination with other HIV consortia, planning and coordinating bodies; and procedures for Council record keeping and functions. This Committee also annually reviews the Council's Bylaws and reviews and evaluates the annual grant application and the Minority AIDS Initiative Application grant application.

Executive Committee (Part B)
The Executive Committee is responsible for the overall leadership, direction, and committee oversight of the Network and exercises a degree of decision-making authority.

Consumer Involvement Committee *(Joint Committee, Part A and B)*
This committee is a standing committee of the Ryan White Part B HIV Care Network and joint committee with the Nassau-Suffolk HIV Health Services Planning Council (reporting to the Quality Assurance & Membership Committee of the Planning Council). It addresses issues affecting people living with HIV/AIDS from a consumer point of view and provides feedback to the various Part A and Part B committees. The ultimate goal of this committee is to promote consumer involvement in the region, provide a venue for consumers to share the realities of living with HIV and AIDS, identify gaps in services, raise community awareness, and provide a mechanism where

consumers can participate in the development of policies to and other strategies to address their needs.

Care Coordination Committee (Part B)
The ultimate goal of this committee is to reduce barriers to services using a cooperative approach and to translate consumer input into action. This committee identifies underserved and disenfranchised populations and sub-populations, develops strategies to assess HIV service delivery and develops universal practices.

Policy Advisory/Education Committee (Part B)
The ultimate goal of this committee is to inform legislative, government and community leaders at the local and state levels of regional needs and emerging issues related to HIV/AIDS and to promote a coordinated response to address these issues.

Suffolk Project for AIDS Resource Coordination
Ryan White Part D

The Suffolk Project for AIDS Resource Coordination (SPARC) is based out of the Pediatric AIDS Center at Stony Brook and funded by a Ryan White Part D grant from HRSA. SPARC works to ensure that all HIV infected/affected women, children youth and families in Suffolk County are engaged and retained in a comprehensive, coordinated system of family-centered, culturally and linguistically appropriate, state-of-the-art primary and specialty care in order to ultimately improve their overall health status and quality of life. SPARC has formed a consortium to bring together HIV service providers and consumers with agencies serving women, children, youth and families in Suffolk. The SPARC Consortium works to improve coordination of services, identify unmet needs of HIV infected/affected families and develop collaborative programs to meet them. SPARC also works closely with the Nassau-Suffolk HIV Health Services Planning Council and the Nassau-Suffolk HIV Care Network to ensure coordinated needs assessment, planning and advocacy efforts.

SPARC's Linkage to Care Coordination program provides short-term intensive interventions with HIV+ individuals who are either newly diagnosed or previously diagnosed but not in care in order to successfully link them with medical care and case management services. SPARC's Women's Care Coordination Team works with HIV+ OB/GYN patients at Stony Brook to ensure that they are engaged and retained in care and are linked to other needed services in the community. SPARC's youth clinic offers primary and specialty medical care for HIV+ youth, HIV testing, screening for sexually transmitted diseases and pregnancy testing both on-site at Stony Brook and off-site at Stony Brook's Islip Primary Care clinic. SPARC's project advocate coordinates the activities of SPARC's Youth Advisory Committee and develops life-skills trainings for HIV+ youth as well as family development workshops for HIV infected/affected families.

SPARC's respite program is designed to enable a caretaker to access needed services or take a much-needed break. SPARC's transportation program is designed to provide clients with access to services provided by participating agencies. To be eligible for SPARC respite and/or transportation services, an HIV infected/affected individual must live in Suffolk County and be a client of an agency that is currently participating in the program.

Center for Public Health Education
Ryan White Program Part F

The Center for Public Health Education (CPHE), located at Stony Brook University, has been providing HIV/AIDS education in the Long Island region for more than twenty years. The program plays a pivotal role in ensuring that information on HIV/AIDS treatments and clinical practice guidelines are widely disseminated to health and human service professionals in the region. The CPHE is a Local Performance Site (LPS) of the NY/NJ AIDS Education and Training Center (AETC) which is funded under Part F of the Ryan White Treatment Modernization Act. A multi-disciplinary staff provides on-site trainings in all aspects of HIV/AIDS education.

The CPHE is also funded as a Regional Training Center (RTC) and a Center of Expertise (COE) by the NYSDOH AIDS Institute. Forty different courses are offered to care providers under these initiatives.

Nassau County HIV Commission

The mission of the HIV Commission of Nassau County is to advocate for the resources to halt the spread of HIV infection, promote the availability of services, create an environment of compassion for the HIV community through education and to serve as an advisor to the Board of Health. The Commission is charged with controlling the spread of HIV infection and identifying resources necessary to provide health care and supportive services for those already infected.

Suffolk County HIV Commission

The Suffolk County HIV Commission, under the auspices of the Suffolk County Department of Health Services strides to combat HIV/AIDS in Suffolk County. The HIV Commission uses a “Push, Pull and Support” strategy to make a difference: the strategy is to "push" information out to the public, to "pull" the public in for education and testing and to "support" agencies and community programs. They also work with school districts to update their HIV and AIDS curricula and support county-wide educational programs that publicize prevention and diagnostic screening and testing.

Appendix G
Nassau-Suffolk Planning Council and Care Network Members

Planning Council Members

The Nassau-Suffolk HIV Health Services Planning Council is a 43 member planning body that strives to reflect the local HIV/AIDS epidemic and is representative of the membership categories put forth in the Ryan White Treatment Modernization Act of 2006. Members of the Planning Council include, but are not limited to, health care providers, social service agencies, housing providers and mental health providers. In addition, approximately 40% of Planning Council members represent infected/affected communities, exceeding the federal requirement that 33% of the Planning Council is comprised of consumers.

Wendy Abt
Martina Arce
Gail Barouh, Ph.D
Maria Torroella Carney, M.D.
Humayun Chaudhry, D.O
James Colson
Robert Detor, Chair
Nancy Duncan
Robert Edwards
Adrian Fassett
Rick Greco
Letitia Hawkins
Sandra Johnson
Maria Kuriloff
Teresa Maestre
Catherine Martens
Jackie Mazzeo
Joseph McGowan, M.D.
Denise Messier
Christine Mirabelli
Beverly Mobley
Michael Moore
Victoria Osk, Esq.
Marissa Polanco
Teri Rhett-Williams
Stephen Sebor
Traci Shelton
Jane Sholkoff
Sabina Steiner
Margaret Sukhram, Ed.D
Katelin Thomas
Kevin Urban
Michael Wade Vice-Chair

HIV Care Network

The Nassau-Suffolk HIV Care Network has a membership of 394 community members who are working towards promoting a coordinated community response that will result in improved access to care and supportive services for people living with HIV/AIDS. Current members of the Network include: HIV/AIDS service providers (such as primary care, mental health, case management), faith based communities, social service agencies, substance abuse providers, nutrition and housing service providers, health centers, community based organizations, youth, woman, people living with HIV/AIDS and their caregivers. There are currently 194 participating agencies and 86 consumer members in the Network.

Executive Committee Members:

Wendy Abt
Martina Arce
Ilvan Arroyo
Patricia Bartik
Arthur Brown
Debra Brown
Celia Burghi
Natalie Cruz
Nancy Duncan
Christine Hunter
Anthony Marmo
Barbara Martens
Catherine Martens
Jackie Mazzeo
Kevin McHugh
Maria Mezzatesta,Co-Chair
Jose Wilson Montoya
Robert Perez-Sulsona, Co-Chair
Leah Topek-Walker
Ed Weingarten
Jean Wright

Lists current as of December 2008.

The development of this Comprehensive Service Delivery Plan was a joint effort of the Planning Council's Strategic Assessment and Planning Committee and the HIV Care Network's Care Coordination Committee. The Committees elected to form a Joint Ad Hoc Committee to focus on the Plan's development.

Members of the committees are as follows:

Joint Ad Hoc Comprehensive Service Plan Committee Members:

Laura DiClementi
Rose Guercia, M.D.
Marie Leger
Barbara Martens
Catherine Martens
Jackie Mazzeo, Part A Co-Chair
Maria Mezzatesta, Part B Co-Chair
Robert O'Donnell
Joseph Pirone
Sabina Steiner
Margaret Sukhram, Ed.D.
Robert Perez-Sulsona
Katelin Thomas
Virginia Walsh
Vicki White
Jennifer Wood
Schamiqua Young

Part A Strategic Assessment and Planning Committee Members:

Wendy Abt
Gail Barouh, Ph.D.
James Colson
Robert Detor
Adrian Fassett
Catherine Martens, Vice Co-Chair
Jackie Mazzeo, Chair
Joseph McGowan, M.D.
Maria Mezzatesta
Victoria Osk, Esq.
Sabina Steiner
Margaret Sukhram, Ed.D., Vice Co-Chair
Katelin Thomas
Michael Wade
Vicki White

Part B Care Coordination Committee Members:

Wendy Abt, Co-Chair
Sarine L. Allen
Keith L. Anderson
Jennifer Baldwin
Patricia Bartik
Tanya Benitez
Cherie Blae
Mary Brite
Debra Brown, Esq., Co-Chair
Louise Bungert
Chantay Coleman
Mary Carroll Connelly
Rev. Theresa Cooper
Allison Covino
Elizabeth Degrocco
Delia Deguzman
Leslie Dewrance-Doucet
Tere Dickson, M.D.
Laura DiClementi
Michael Dixon
Jennifer Fazio
Patricia Fulton
Christine Gabriele
Jennifer Giardini
Jeffrey Giordano
Susan Gnoffo
Jack Hoffmann
Mary Jane Hudson
Christine Hunter
Dorothy Jackson
Pat Kubis
Hannah Kugelman
Angela Lampe
Teresa Maestre
Kevin T McHugh
Kerin Marczak
Daniel Matos
Jackie Mazzeo
Joseph A Melendez
Maria Mezzatesta, Co-Chair
Dorthea Moore
Celia Neira-Burghi
Senda J. Newman
Carol O'Neil
Ada Ortiz
Robert Perez-Sulsona
Mildred Rivera
Eileen Rubin
Felix M Ruiz
Francine Schwarz
Melissa Shikora
Jane Sholkoff
Susanne Smoller
Sabina Steiner
Lynda V. Strecker
William Terenzi
Steven Thalmann
Vanessa Thidemann
Katelin Thomas
Virginia Walsh
Jennifer Wood
Jean Wright