RYAN WHITE CARE ACT
2006
STATEWIDE COORDINATED STATEMENT OF NEED
AND
COMPREHENSIVE PLAN

New York State Department of Health
AIDS Institute
February 2006

NEW YORK STATE DEPARTMENT OF HEALTH
AIDS INSTITUTE
STATEWIDE COORDINATED STATEMENT OF NEED (SCSN)
AND
COMPREHENSIVE PLAN

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SECTION I:
EXECUTIVE SUMMARY

The 2006 Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan (CP) summarizes HIV-related service needs and barriers across New York State, and presents goals and strategies for its evolving HIV service continuum. This document, an update of the SCSN/CP submitted in 2001, has been prepared in accordance with the legislative mandate in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and accompanying guidelines issued by the federal Health Resources and Services Administration (HRSA).

A multi-step process was employed to prepare this document. A comprehensive review was conducted of HIV local and regional needs assessments, as well as planning, policy, program and evaluation documents prepared since 1999, that relate to the design, delivery, coordination and integration of HIV care and services. The AIDS Institute sent an announcement requesting such documents to a mailing list of about 600, including representatives and agencies involved with all Titles of the CARE Act, service providers, consumer groups and advisory bodies, other government agencies, staff, advocates and other interested parties. More than 150 documents were received; each was reviewed using a checklist developed to capture service needs, barriers, subpopulations and other issues addressed in the source documents.

Additional steps involved the aggregation of epidemiological data and other information that directly affects HIV service delivery planning and implementation. Data from the State Health Department Bureau of HIV/AIDS Epidemiology and many other sources was compiled, analyzed and summarized. Key environmental considerations that impact the HIV/AIDS epidemic and emerging trends are presented, as well as an overview of special populations that require focused attention relative to HIV planning, priority setting and resource allocation in New York State.

All of the above information is summarized and organized in separate Sections of the SCSN, as outlined in the Table of Contents. Most information is presented for New York State as a whole, for New York City as a whole, and then by borough and by Ryan White CARE Network region for the rest of the State. The Comprehensive Plan was prepared based on the data and information gathered through the SCSN process, and on-going strategic planning processes informed by formal advisory and coordinating bodies, and by various workgroups of Persons Living with HIV and AIDS (PLWHA) and providers.

The final steps of the process encompassed broad distribution of the draft document to more than 1,400 agencies and individuals, along with an invitation to attend one of seven community forums, held during the Fall of 2005, where the draft document was discussed and additional advice obtained on current needs and trends before the document was finalized. Input from the community forums and written comments received were incorporated into the final 2006 SCSN and Comprehensive Plan. This input validated the most commonly identified needs listed below, underscored special populations in need of

focused attention, and offered insight on region and borough-specific needs to make the document more complete.

The needs identified in this document are premised on the epidemiological profile of New York State, which has 17 percent of all persons living with AIDS, but only 7 percent of the nation's population. New York's AIDS case rate of 34.8 per 100,000 is more than double the U.S. average of 15.2 per 100,000. Persons of color represent the overwhelming majority of persons living with AIDS in New York State — 77 percent.

Section VII of this document contains comprehensive summaries of needs across the State and by region. The needs most commonly identified for HIV infected persons can be broadly summarized in the following ten broad categories:

- Comprehensive Health Care, integrating Primary Care (for HIV, STDs, Hepatitis, and TB), Medication Assistance, Treatment Adherence Support, and Specialty Care for all persons including those who are uninsured or underinsured
- Dental Care
- Housing and Related Support Services
- Substance/Alcohol Abuse-Related Services
- Mental Health Services
- Linguistically and Culturally Competent Services in all settings
- Targeted Outreach for purposes of providing HIV Testing, Casefinding, Linkage with Care, and Primary Prevention
- Case Management and Supportive Services that enable linkage with and retention in care, and compliance with medication regimens, emphasizing in particular: transportation, food/nutrition services, legal assistance, entitlements/benefits assistance, family support, peer education and support
- Service Delivery Models that meet patient needs, such as evening and weekend hours, co-located services, neighborhood service sites, mobile medical vans, and improved service integration and coordination
- HIV Prevention, Health Education and Clinical Education to raise awareness, build skills, eliminate stigma and discrimination, improve consumer health literacy, ensure high quality care and services, and prevent further transmission of HIV

The Comprehensive Plan, contained in Section VIII of this document, includes broad goals, principles and strategies for engaging and retaining all HIV infected persons in early, high quality care and services. In general, the goals address the need to: 1) ensure that HIV positive persons learn their HIV status and enter care early by promoting strategies to reach high risk persons, communities of color, and special populations; 2) improve health outcomes by ensuring access to high quality, culturally competent health and dental care for all persons living with HIV/AIDS; and 3) ensure access to life-saving medications, mental health services, and substance and alcohol abuse counseling and treatment. The goals also address the need for the appropriate level of case management and an array of supportive services that enable persons living with HIV/AIDS to seek treatment, remain in care, and adhere to complex medication regimens.

Key strategies for achieving the above goals are presented by describing program initiatives that have recently been designed and implemented in response to changes in the epidemic, analyses of HIV/AIDS data, clinical advances and new testing technologies. The program initiatives are grouped into four key areas: 1) Enhancing access to and availability of HIV testing; 2) Outreach, casefinding and engagement in care and services; 3) Enhancing direct services; and 4) Promoting Consumer/Provider Communication and Prevention with HIV Positive Persons.

The Comprehensive Plan also describes numerous strategies to enhance quality of care and monitor progress in meeting short- and long-term goals and objectives. These strategies include the AIDS Institute Quality Management and Improvement Initiative, special evaluation studies, the contract monitoring process, and expanded laboratory reporting requirements.

SECTION II:
PURPOSE OF LEGISLATIVELY REQUIRED SCSN AND COMPREHENSIVE PLAN

A. Statewide Coordinated Statement of Need (SCSN) – Legislative Requirements and Purpose

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act Amendments of 1996 require CARE Act grantees to conduct activities to enhance coordination across CARE Act programs by mandating participation in the development of a Statewide Coordinated Statement of Need (SCSN). Legislative language requires further that the Title II grantee develop the SCSN and that grantees under all Titles participate in the SCSN process. In addition, applicants for CARE Act funds are required to submit evidence that the proposed program is consistent with the SCSN.

According to the federal Health Resources and Services Administration (HRSA), the purpose of the SCSN is to provide a collaborative mechanism to identify and address significant HIV care issues related to the needs of people living with HIV/AIDS (PLWHA), and to maximize coordination, integration and effective linkages across CARE Act Titles related to such issues.

As the Ryan White Title II grantee, the New York State Department of Health AIDS Institute (NYSDOH AI) is responsible for the preparation of the SCSN document based on HRSA guidelines. Such guidelines were updated and issued in April 2005. HRSA encourages the use of the SCSN for statewide HIV/AIDS planning, and each state has the flexibility to adapt the SCSN preparation process to its particular circumstances. The guidelines state that the SCSN is not intended to replace local program planning and priority setting. Grantees under all Titles of the CARE Act must participate through a representative process.

The outcome of the SCSN process is a written document that summarizes needs and service barriers across the state. HRSA guidelines indicate that the SCSN must reflect, without replicating, a discussion of existing needs assessments and should include a brief overview of epidemiological data, existing quantitative and qualitative information, emerging trends/issues affecting HIV care and services delivery in the State, and cross-cutting issues. In addition, the guidelines state that the SCSN should include broad goals, but these goals should not be prioritized.

This document has been prepared based on those guidelines and will be submitted to HRSA by January 31, 2006, the prescribed due date. This is the third SCSN prepared by the NYSDOH AI; previous versions were submitted in 1998 and 2001.

B. Comprehensive Plan – Legislative Requirement and Purpose

The Ryan White CARE Act Amendments of 2000 requires Title II grantees (States) to develop and implement a comprehensive plan, including a description of HIV-related services in the State, available resources, epidemiological data, service needs, goals and strategies. The original HRSA guidelines relating to this legislative requirement indicate that comprehensive planning should result in a road map for the incremental development of a

system of care over the long term. The guidelines state further that the plan should address disparities in HIV care, access and services among affected subpopulations and historically underserved communities, and the needs of those who know their HIV status and are not in care, as well as the needs of those who are currently in the care system.

The updated HRSA comprehensive plan guidelines issued in July 2005 provide an outline of topics to be covered in the plan. Many of the topics are the same as those required to be addressed as part of the SCSN. Therefore, to eliminate duplication, in both the process of providing input and in preparation of the final document, New York State has combined the SCSN and Comprehensive Plan into one document. This approach allows for the preparation of a broad document that describes service needs and barriers on multiple levels (statewide, New York City-wide, by borough and by multi-county Ryan White CARE Network region), drawing from local and regional needs assessments, planning and evaluation documents. This statewide summary of needs and barriers forms the basis of goals, strategies, and priority-setting that are part of the statewide Comprehensive Plan included as Section VIII of this document.

It is also important to note that the NYSDOH AI fosters a dynamic SCSN and planning process to assure that priority-setting and resource allocation are guided by the most current data, emerging trends, scientific advances, annual budget appropriations and other changes affecting individuals and health care systems. As those variables change, the comprehensive plan and resulting program implementation must be adjusted to reflect progress and other realities.

SECTION III:
DESCRIPTION OF THE 2006 SCSN PROCESS

This Section describes the resources utilized and the steps taken to complete the 2006 version of the Statewide Coordinated Statement of Need (SCSN).

Overview of the Process

A six-step process, described below, was used to gather information, extract relevant data, obtain additional input, and complete the document.

Step One: Solicit documents, review and extract information that identifies local and regional service needs, and barriers to care and service.

This step entailed a comprehensive review of HIV local and regional needs assessments, as well as planning, policy, program and evaluation documents prepared since 1999, that relate to the delivery, coordination and integration of HIV care and services. The AIDS Institute sent an announcement requesting such documents to: Title I EMAs and Planning Council members, Title II CARE Networks and grantees, Title III and IV grantees, SPNS grantees, AETC representatives, dental reimbursement program providers, persons living with HIV/AIDS, health and human service providers holding contracts with the AIDS Institute, local health units and other governmental agencies, AIDS Institute staff, advocates and other interested parties.

In total, over 150 source documents were received, are listed and briefly described in Appendix A. These documents varied in content and format, ranging from regional needs assessments and service plans, articles published in medical and scientific journals, research and evaluation reports, cohort study reports, epidemiological profiles, regional gaps analyses, focus group reports, survey results, letters, and excerpts from grant applications. While the CARE Act mandate for the SCSN focuses on collaboration among the Titles relating to the needs of persons living with HIV and AIDS, all identified needs, including prevention and concerns regarding relevant policy issues, are summarized in this document.

Other documents reviewed include resource materials such as new treatment guidelines, materials related to health care financing and managed care for HIV infected persons, and general background information on the Ryan White CARE Act.

Each document was reviewed using a checklist developed to capture needs, barriers, subpopulations, policy and other related issues. A database was created to aggregate this information which, along with illustrative narrative from the source documents, forms the basis of Section VII of this document. The service needs, barriers and affected subpopulations are presented for the State as a whole, for New York City as a whole, and then by borough and by Ryan White CARE Network region for the rest of the State. The information for each geographic area is presented in slightly different formats since it reflects the nature of the source documents from that region. For example, some source documents identify service needs by subpopulation, while others present a menu of service needs across all subpopulations.

Step Two: Summarize HIV/AIDS epidemiological data.

The Bureau of HIV/AIDS Epidemiology (BHAE) of the NYS Department of Health produced graphic and tabular data on reported HIV and AIDS cases and persons living with HIV and AIDS, which are presented in Section IV of this document. This data highlights variables such as mode of transmission, race/ethnicity, gender, and age, and displays trend data on cases and deaths. The information is presented on a statewide basis, for the City of New York, by borough and by region outside of New York City.

Other comparative and interpretive data is presented throughout the document to characterize the nature of the epidemic across the State. In addition to BHAE, the sources of this data include reports issued by the federal Centers for the Disease Control and Prevention (CDC), the New York City Department of Health and Mental Hygiene HIV Epidemiology Program, the Kaiser Family Foundation website, and epidemiological profiles included in various source documents.

Step Three: Summarize environmental considerations, emerging trends and special populations.

Key environmental considerations and emerging trends that impact the HIV/AIDS epidemic are summarized in Section V of this document. While not an exhaustive list, the issues discussed in this section are cross-cutting and must be considered in the planning and implementation process:

- Growing Service Demands and New Mandates in an Era of Level and Decreasing Resources
- Medicaid Reform
- Continuing Disproportionate Impact of the Epidemic on Communities of Color, particularly among Blacks and Hispanics
- HIV Case Reporting
- Emerging High Risk, Underserved Subpopulations and Changing Service Needs
- Rapid Testing, Treatment Adherence and Resistance Testing
- Stigma and Discrimination
- Changes in Medicaid and Medicare Coverage of HIV Care
- Debate regarding “Medicalization” of Ryan White CARE Act-Funded Services
- Impact of Ryan White Reauthorization on New York State

Section VI of the document provides an overview of the following special populations that require focused attention based on the profile of the epidemic in New York State. Within each of these populations, persons of color, primarily Blacks and Hispanics, represent the overwhelming majority of reported cases and of persons living with HIV and AIDS:

- Substance and Alcohol Users
- Women
- Men Who Have Sex with Men
- Children and Families
- Adolescents and Young Adults

- Homeless Persons
- Immigrants
- Inmates and Releasees from Criminal Justice Settings
- Mentally Ill, and Mentally Ill and Chemically Addicted Persons
- Migrant Workers
- Persons Aged 50 and Over
- Lesbians and Transgender Persons

Step Four: Summarize findings and prepare the SCSN and Comprehensive Plan document.

The information gathered in the first three steps was organized and summarized in the respective Sections of this document noted above. An attempt was made to present the most up-to-date information in a clear, easy-to-access format. The document is drawn almost in total from the source documents listed in the Appendix and other sources noted in this Section; it is not footnoted but specific references to documents are indicated when appropriate.

The Comprehensive Plan, contained in Section VIII of this document, was prepared by the AIDS Institute based on the information and data described above, and on-going strategic planning processes that are informed by various workgroups of PLWHAs and providers, as well as formal advisory and coordinating bodies, including the Ryan White Title II CARE Networks and Title I Planning Councils, the Statewide AIDS Services Delivery Consortium (SASDC), the State AIDS Advisory Council, the Advisory Committees for the HIV Uninsured Care Program, and the Prevention Planning Group.

Sections I through VIII of this document constitute the draft updated 2006 SCSN and Comprehensive Plan as it was presented for review and comment by the public.

Step Five: Distribute the draft document and conduct community forums.

The draft document was broadly distributed to more than 1,400 agencies and individuals, including all categories noted above under Step One, along with an invitation to attend one of seven community forums where the draft document was discussed and additional input obtained before the document was finalized. The forums were held across the state and provided the opportunity to discuss issues related to service needs, barriers, coordination and integration of care. The goal of the forums was to assure broad input on the draft document so that it accurately represents current needs, issues and concerns.

Step Six: Incorporate findings and distribute the 2006 SCSN and Comprehensive Plan.

The final step in the process was the incorporation of comments and recommendations from the community forums to produce the final 2006 SCSN and Comprehensive Plan. The final document was submitted to HRSA and broadly disseminated statewide.

SECTION IV:
HIV/AIDS EPIDEMIOLOGY

New York's HIV/AIDS Epidemic Compared to the National Epidemic

It is important to highlight key facts about New York's epidemic in relation to the rest of the country:

- New York State has 7 percent of the nation's population, but 17 percent of all persons living with AIDS, the highest percentage of any state.
- New York's AIDS case rate of 34.8 per 100,000 is more than double the U.S. average of 15.2 per 100,000.
- New York State accounted for 33 percent of HIV cases reported to the Centers for Disease Control and Prevention in 2002. (Note: States with code-based and name-to-code surveillance systems, including California, are not included by CDC in the national dataset.)
- New York State's epidemic overwhelmingly affects persons of color: 77 percent of persons living with AIDS are persons of color - 45 percent Black, 31 percent Hispanic, one percent Asian/Pacific Islander, and less than one percent Native American (confirmed cases through December 2004). Approximately 58 percent of cumulative AIDS cases nationally are among persons of color.
- New York State has both urban and rural epidemics. This is illustrated by the fact that even if New York City cases are excluded, New York State ranks 5th among all states in cumulative AIDS cases and 7th in terms of living AIDS cases nationally.

HIV/AIDS Data by Region and Borough

The tables and graphs in this Section provide an overview of the HIV/AIDS epidemic by geographic area in New York State. This SCSN includes HIV case data for the first time since New York State initiated HIV case reporting by law as of June 1, 2000. The tables and graphs were produced by the Bureau of HIV/AIDS Epidemiology (BHAE) of the New York State Department of Health. Data presented in this Section are generated from information collected and maintained by BHAE and the HIV Surveillance and Epidemiology Unit of the New York City Department of Health and Mental Hygiene. The data, based on a special run of cases reported through December 2004 regardless of diagnosis date, is presented in tabular and graphic formats to assist the reader with interpretation, comparisons and viewing trends.

Data is provided for each of the following geographic areas:

- New York State
- New York City
- Boroughs of New York City:
  - Bronx
  - Brooklyn
  - Manhattan

    - Queens
    - Staten Island
- Upstate (New York State excluding New York City - - Ryan White Regions Outside of New York City):
    - Albany (Northeastern)
    - Binghamton Tri-County
    - Buffalo (Western)
    - Lower Hudson
    - Mid-Hudson
    - Nassau/Suffolk
    - Rochester (Finger Lakes)
    - Syracuse

Uniform tables and graphs, based on data reported through December 2004 regardless of diagnosis date, are provided for each of the above geographic areas as follows:

- **Figure 1:** Provides the number of persons living with HIV and with AIDS and cumulative AIDS cases by Borough, by United Hospital Fund Neighborhoods in NYC, by Ryan White Region outside of NYC, and by County.

  Data is also provided from the New York State Comprehensive Newborn Screening Program regarding HIV seroprevalence among women giving birth in 2002.

- **Figure 2:** A line graph that depicts trends from 1983 to 2004 for AIDS Cases, Persons Living with HIV and AIDS, and Deaths.

- **Figure 3:** Three pie charts comparing the racial/ethnic composition of the general population (U.S. Census 2000) with newly diagnosed HIV cases (2001-2003) and persons living with HIV/AIDS (reported through December 2004).

- **Figure 4:** A bar graph showing males living with HIV/AIDS by race/ethnicity and by transmission category.

- **Figure 5:** A bar graph showing females living with HIV/AIDS by race/ethnicity and by transmission category.

- **Figure 6:** Two bar graphs illustrating persons 13 years of age and older living with HIV/AIDS by gender, transmission category and age group.

- **Figure 7:** Two bar graphs showing the current age and race/ethnicity of persons living with maternally transmitted HIV/AIDS.

The following should be noted in interpreting the data provided on the following pages:

- The data for recent years are incomplete due to the lag in case reporting.
- Unless individuals are known to be deceased from NYS or NYC Vital Records or the National Death Index, they are presumed to be living.
- HIV/AIDS case data from BHAE are all CDC-confirmed cases for which race/ethnicity must be included, and all cases where surveillance has been completed and for which race/ethnicity are unknown.
- Data on risk should be interpreted with caution. Due to the large increase in reported cases, backlogs have developed in case investigations that involve medical chart reviews. Since a medical chart review is usually required to obtain information on the mode of transmission (risk), this backlog has resulted in a large proportion of cases being presented with unknown risk. The BHAE will be investigating all cases reported without risk over the next two years, with priority given to all newly diagnosed HIV and AIDS cases. Due to the large volume of cases in NYC, the HIV Surveillance and Epidemiology Unit will be investigating all AIDS cases reported without risk and a sample of the prevalent HIV cases.

More specific data on race/ethnicity, risk, gender and age for living HIV and AIDS cases, cumulative AIDS cases and newly diagnosed HIV and AIDS cases are available in routine HIV/AIDS surveillance and epidemiology reports published by the New York State and New York City Health Departments. These reports can be accessed at their respective websites:

NYS Department of Health: www.health.state.ny.us

NYC Department of Health and Mental Hygiene: www.nyc.gov/html/doh

Epidemiologic Profile of New York State [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases*

Region of Residence at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Albany Region	1,538	1,907	3,951
Binghamton Region	150	179	356
Bronx	7,120	11,885	28,102
Brooklyn	7,203	14,398	35,767
Buffalo Region	1,259	1,527	3,173
Lower Hudson Region	1,283	2,759	6,082
Manhattan	10,084	17,668	47,357
Mid-Hudson Region	1,139	1,962	4,389
Nassau/Suffolk Region	1,473	3,058	7,584
Queens	3,643	8,210	18,712
Rochester Region	1,035	1,379	2,891
Staten Island	579	1,026	2,744
Syracuse Region	1,251	1,647	3,205
Total	**37,757**	**67,605**	**164,313**

*Only regions outside of NYC include cases identified as prisoners since the majority of prisoners are diagnosed in state correctional facilities which are located outside NYC.

Childbearing Women:

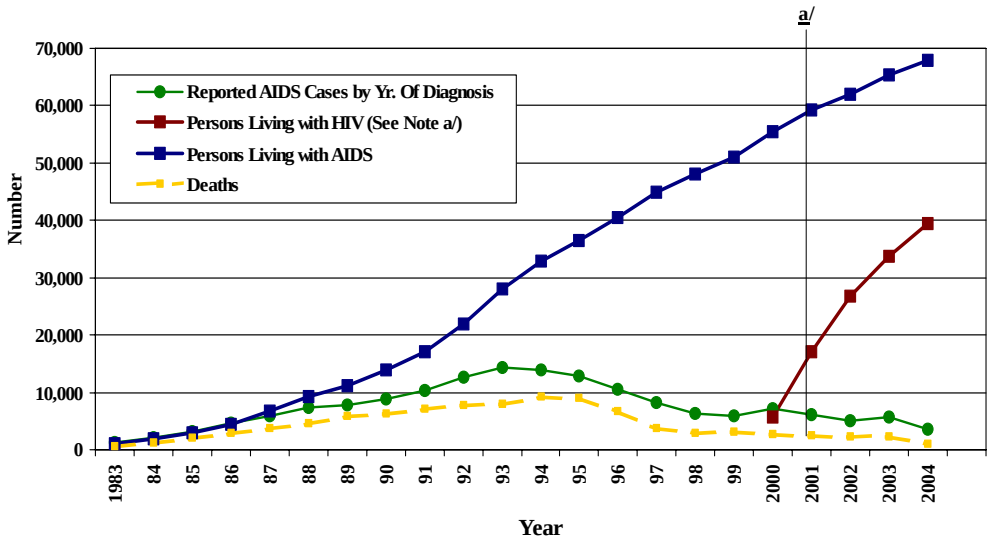
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in New York State had a prevalence of 0.30% (n=727), or approximately 1 in 333 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York State [1/]

Figure 2

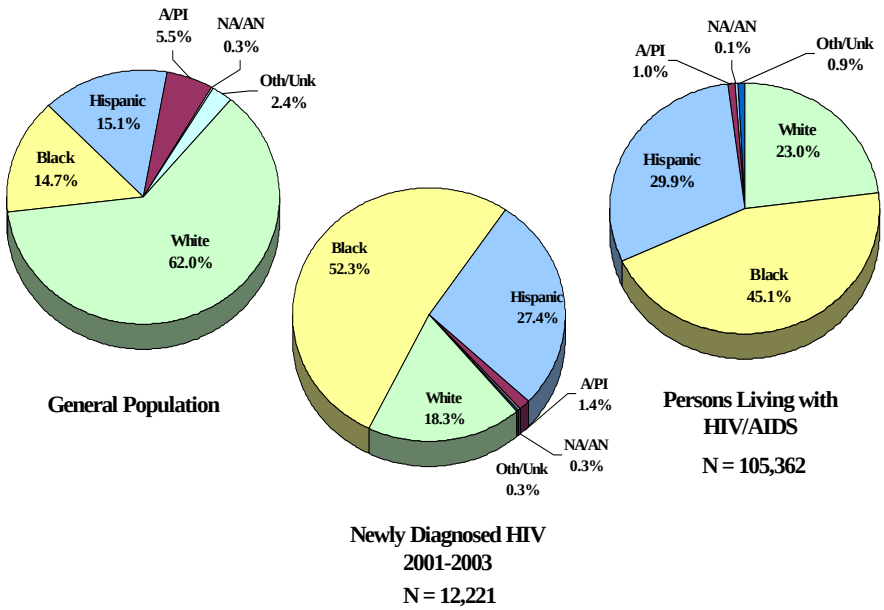
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] in New York State - 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Includes prisoners for regions outside of NYC.
1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York State [1/]

Figure 4

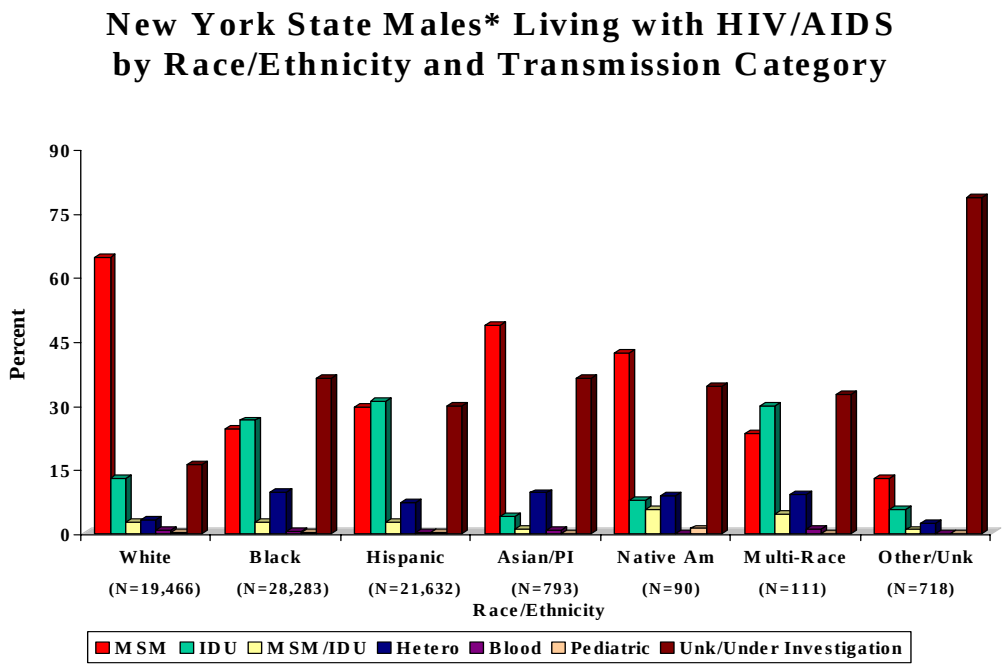
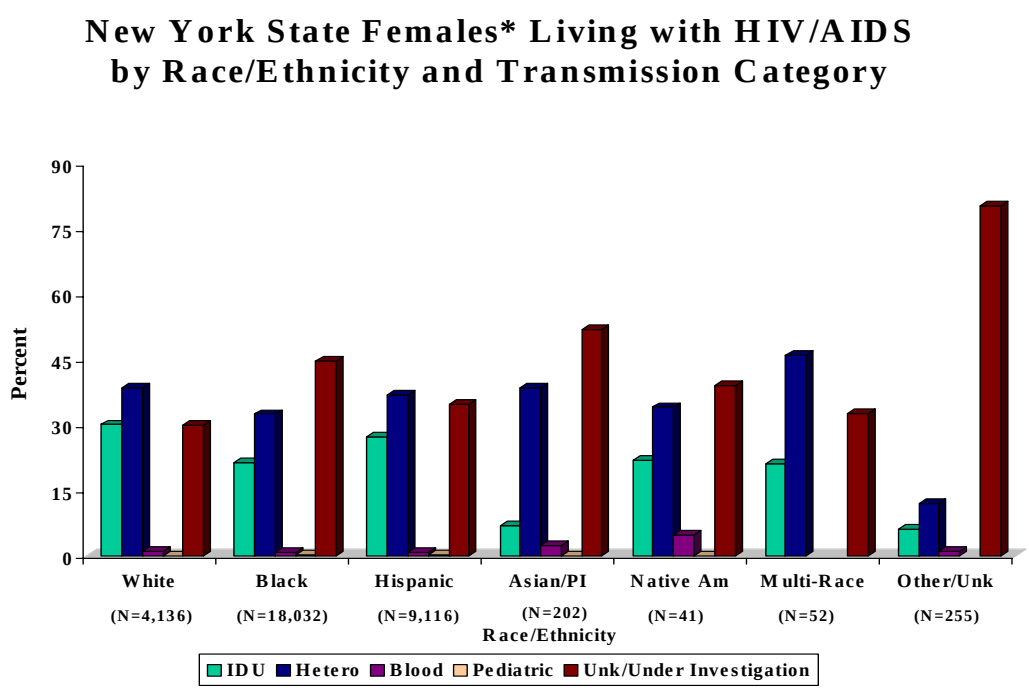


Figure 5

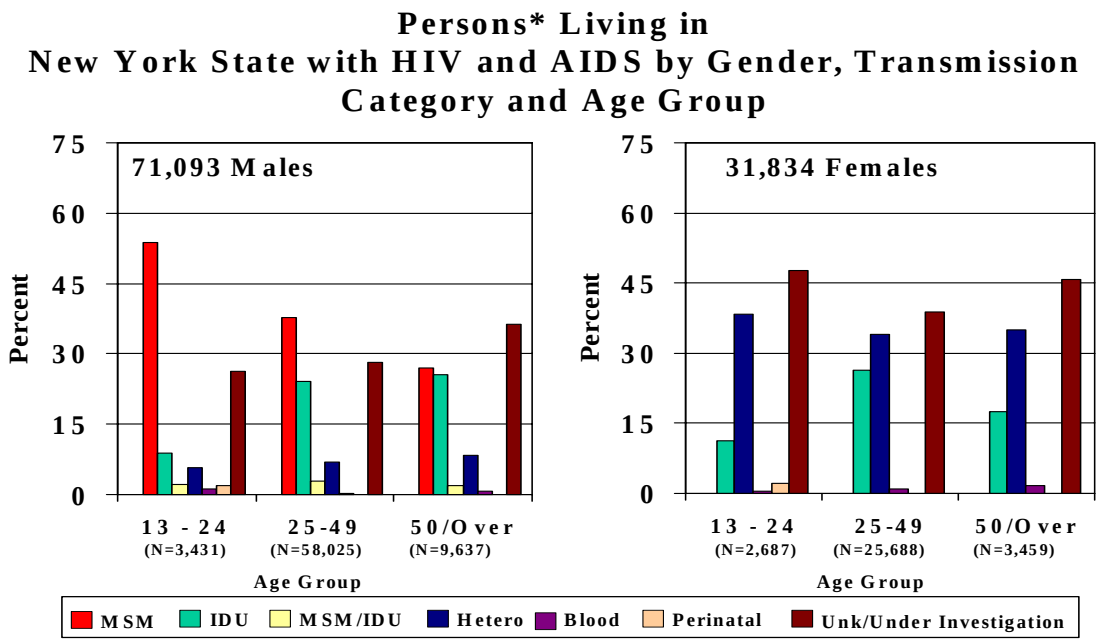


* Includes prisoners for regions outside of NYC.

1/ Cases reported through December 2004 regardless of diagnosis date.

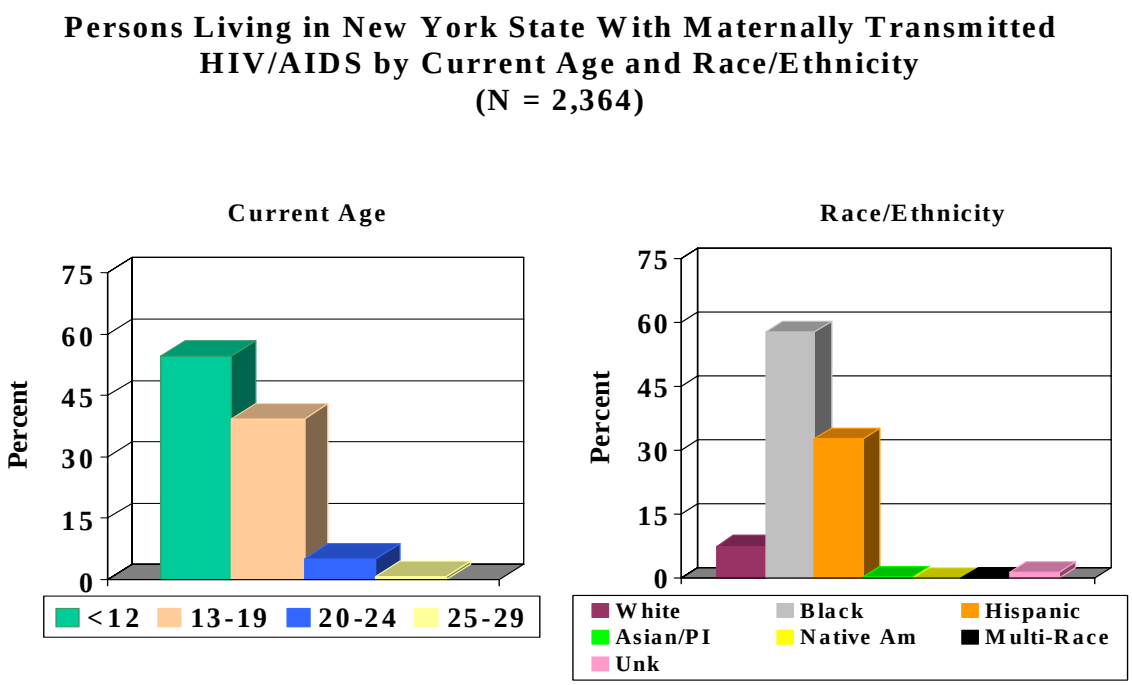
Epidemiologic Profile of New York State [1/]

Figure 6



* Includes prisoners for regions outside NYC; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York City [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases*

County of Residence At Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Bronx	7,120	11,885	28,102
Brooklyn	7,203	14,398	35,767
Manhattan	10,084	17,668	47,357
Queens	3,643	8,210	18,712
Staten Island	579	1,026	2,744
TOTAL	28,629	53,187	132,682

*Excludes prisoners.

Childbearing Women:

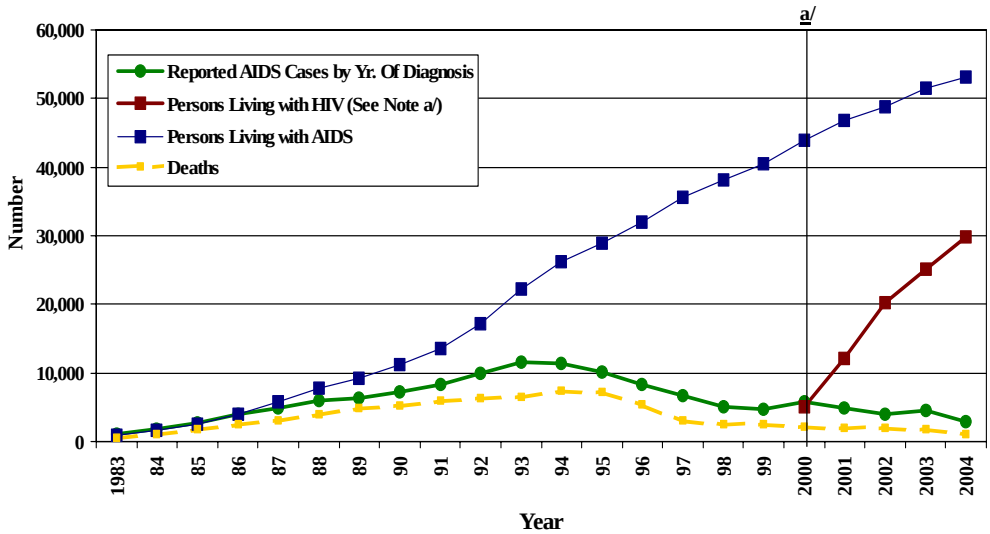
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in New York City had a prevalence of 0.51% (n=578), or approximately 1 in 196 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York City [1/]

Figure 2

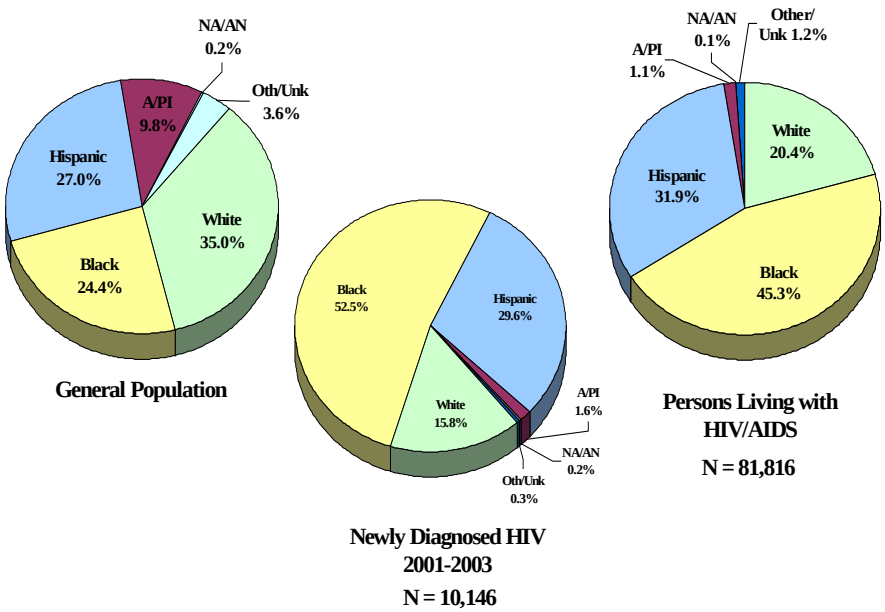
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York City [1/]

Figure 4

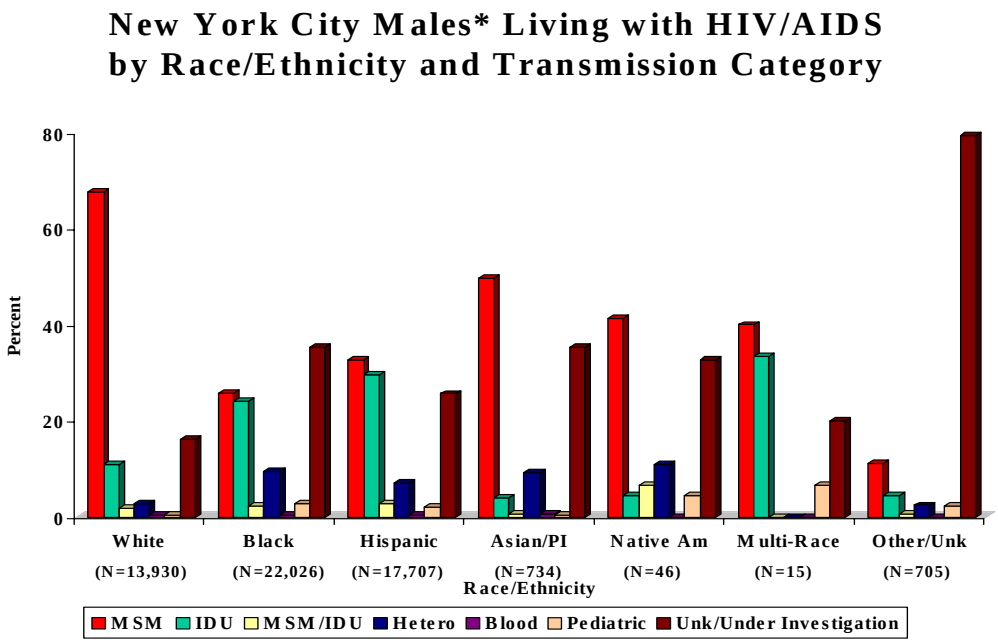
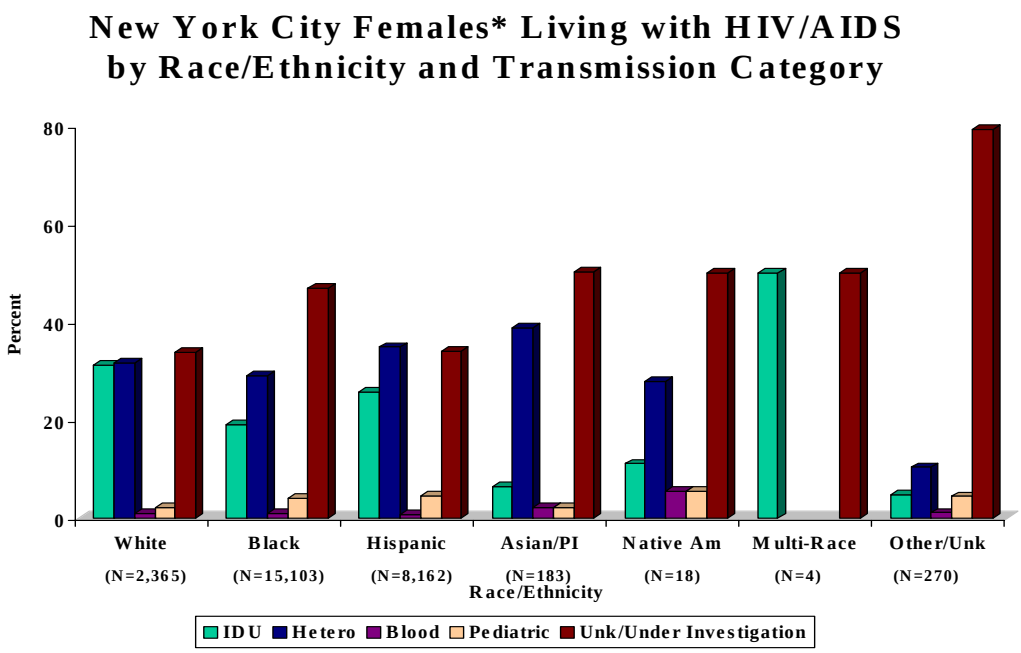


Figure 5

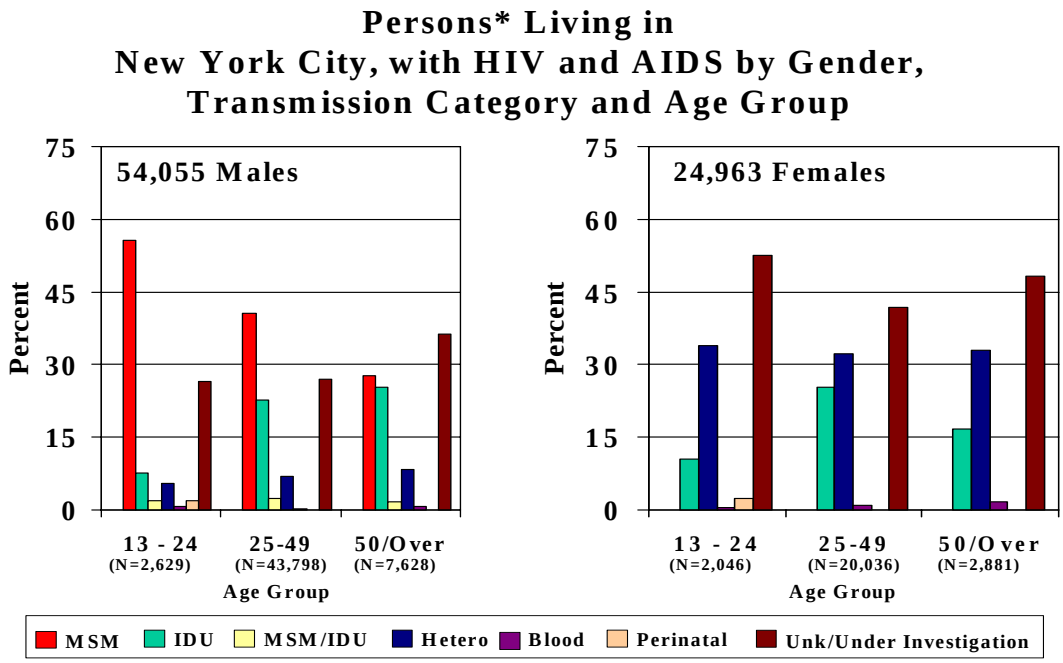


* Excludes Prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

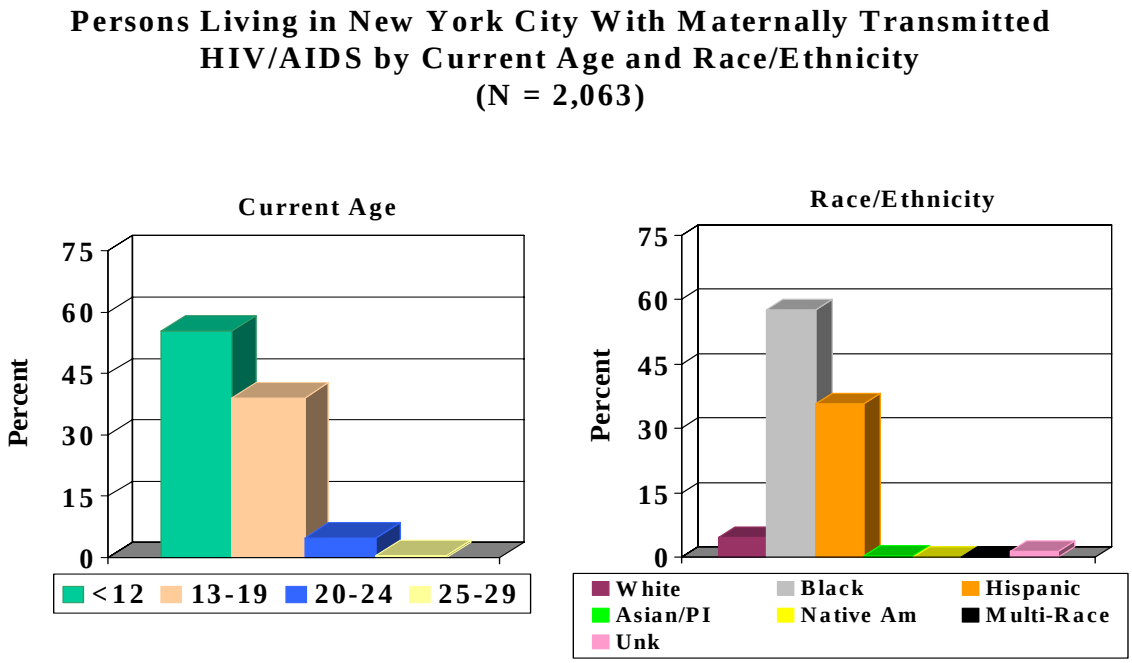
Epidemiologic Profile of New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Bronx, New York City [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases*

United Hospital Fund Neighborhood at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Kingsbridge-Riverdale	156	298	692
Northeast Bronx	519	823	1,818
Fordham-Bronx Park	1,251	2,090	4,706
Pelham-Throgs Neck	1,056	1,801	4,235
Crotona-Tremont	1,419	2,375	5,663
High Bridge-Morrisania	1,437	2,557	6,138
Hunts Point – Mott Haven	922	1,614	3,930
Unknown	360	327	920
TOTAL	**7,120**	**11,885**	**28,102**

*Excludes prisoners.

Childbearing Women:

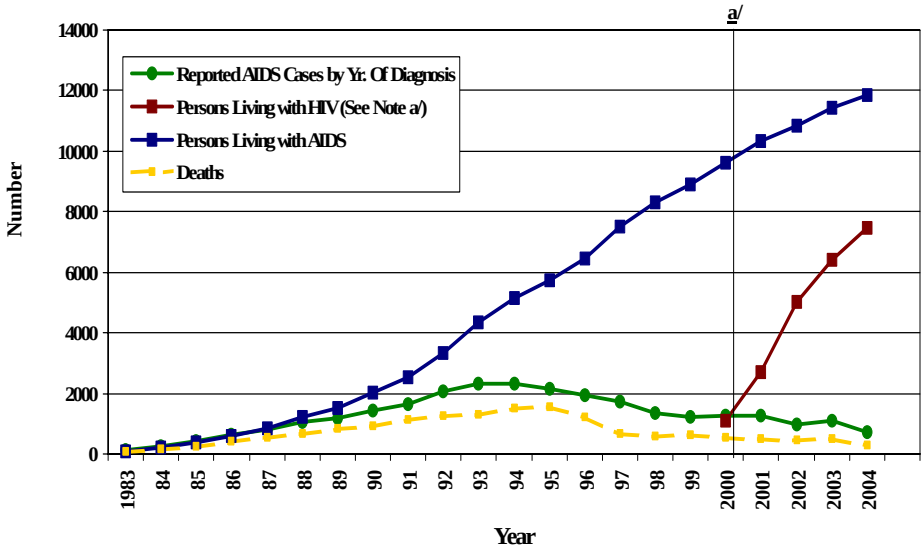
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Bronx had a prevalence of 0.95% (n=206), or approximately 1 in 105 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Bronx, New York City [1/]

Figure 2

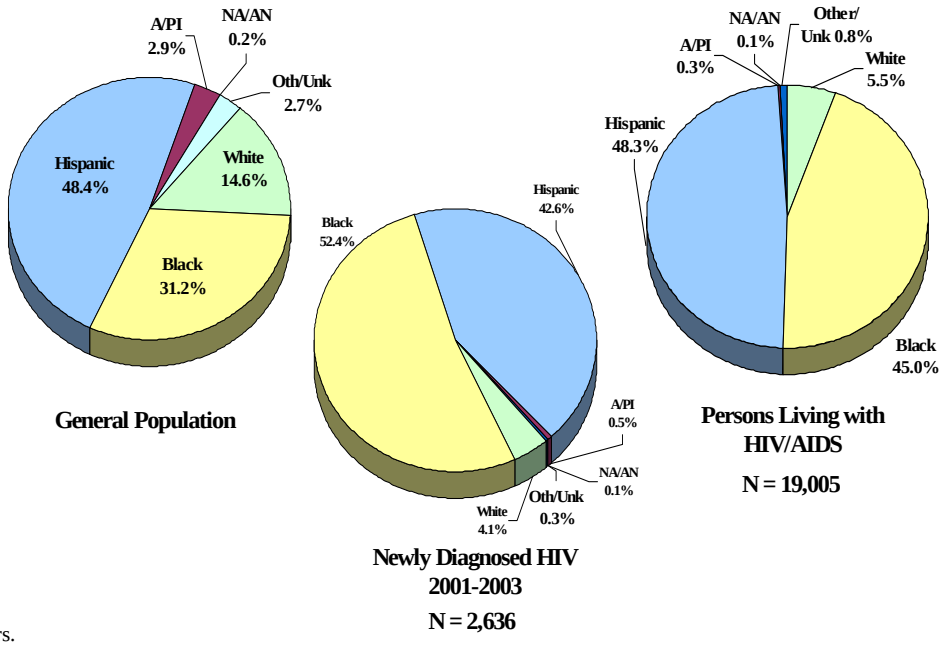
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Bronx, New York City [1/]

Figure 4

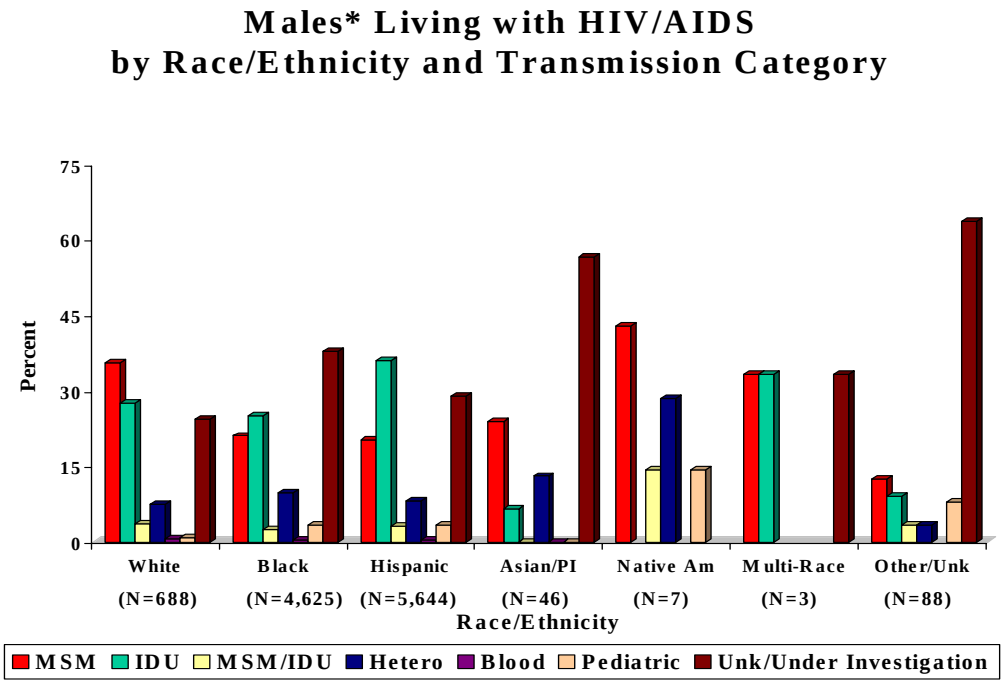
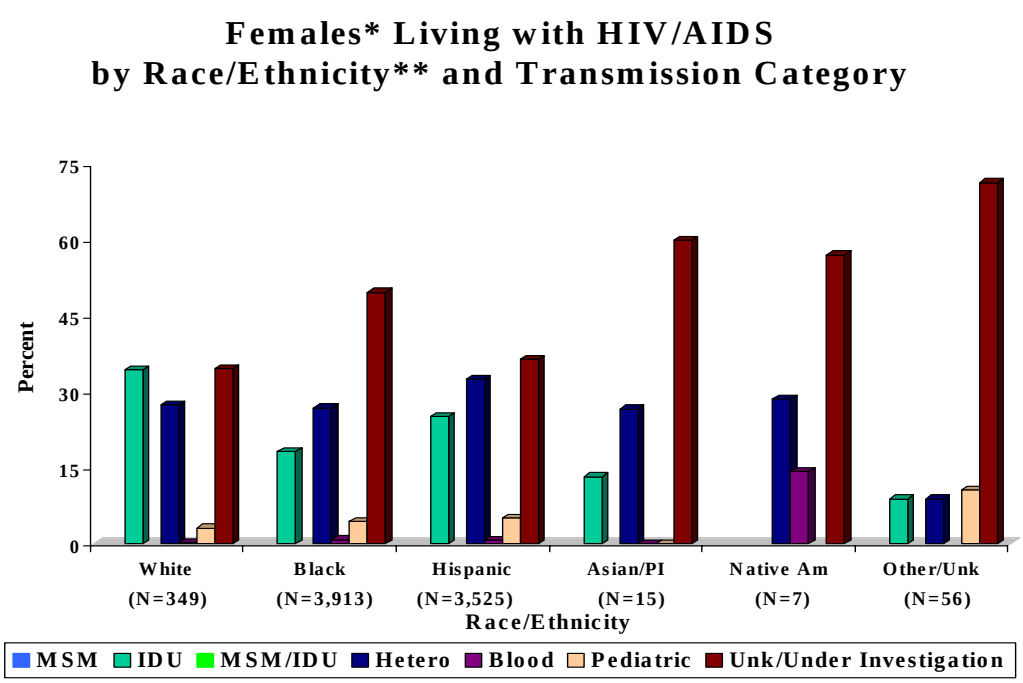


Figure 5



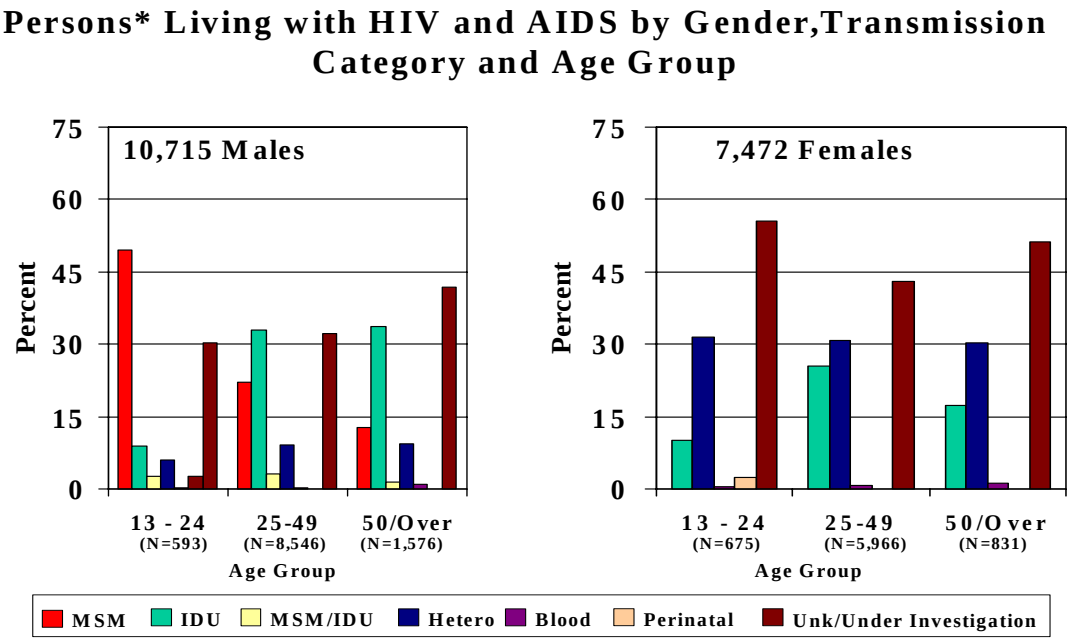
* Excludes Prisoners

** There were no Multi-Race cases.

1/ Cases reported through December 2004 regardless of diagnosis date.

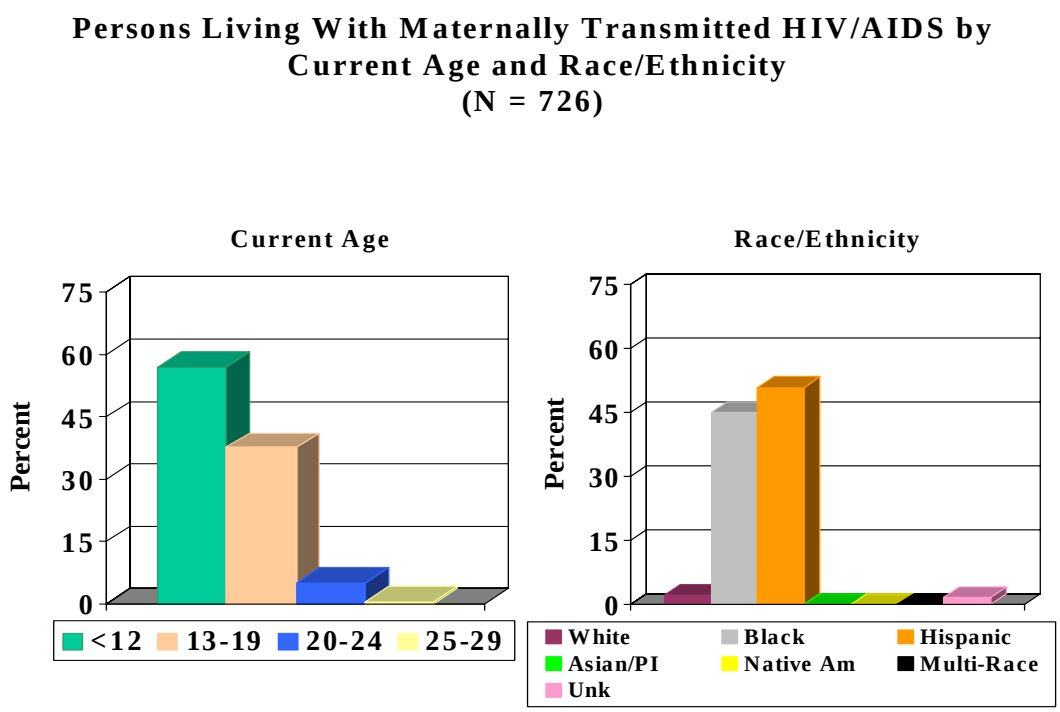
Epidemiologic Profile of Bronx, New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Brooklyn, New York City [1/]

Figure 1 **Persons Living with HIV and AIDS and Cumulative AIDS Cases***

United Hospital Fund Neighborhood at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Greenpoint	243	556	1,461
Downtown-Heights-Slope	814	1,697	4,755
Bedford Styvesant-Crown Heights	1,704	3,472	8,624
East New York	728	1,402	3,218
Sunset Park	178	448	1,123
Borough Park	243	548	1,461
East Flatbush-Flatbush	1,027	2,315	4,993
Canarsie-Flatlands	353	561	1,161
Bensonhurst-Bay Ridge	144	288	856
Coney Island-Sheepshead Bay	267	661	1,703
Williamsburg-Bushwick	874	1,956	4,970
Unknown	628	494	1,442
Totals	7,203	14,398	35,767

*Excludes prisoners.

Childbearing Women:

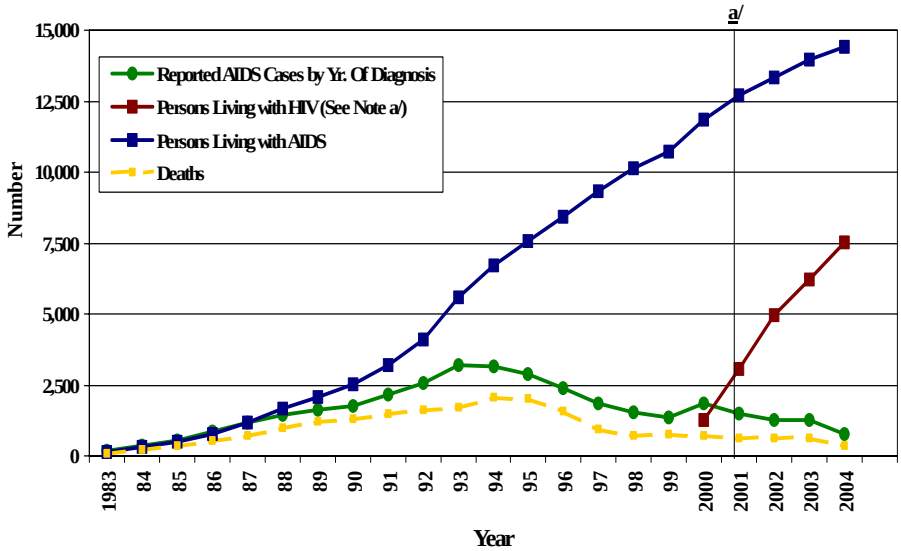
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in Brooklyn had a prevalence of 0.54% (n=205), or approximately 1 in 185 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Brooklyn, New York City [1/]

Figure 2

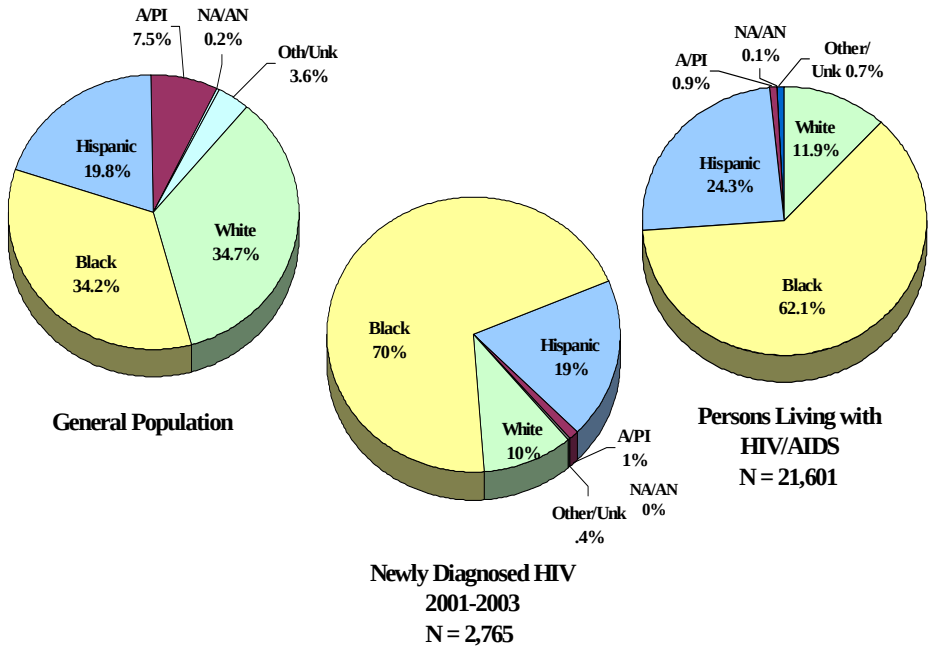
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*

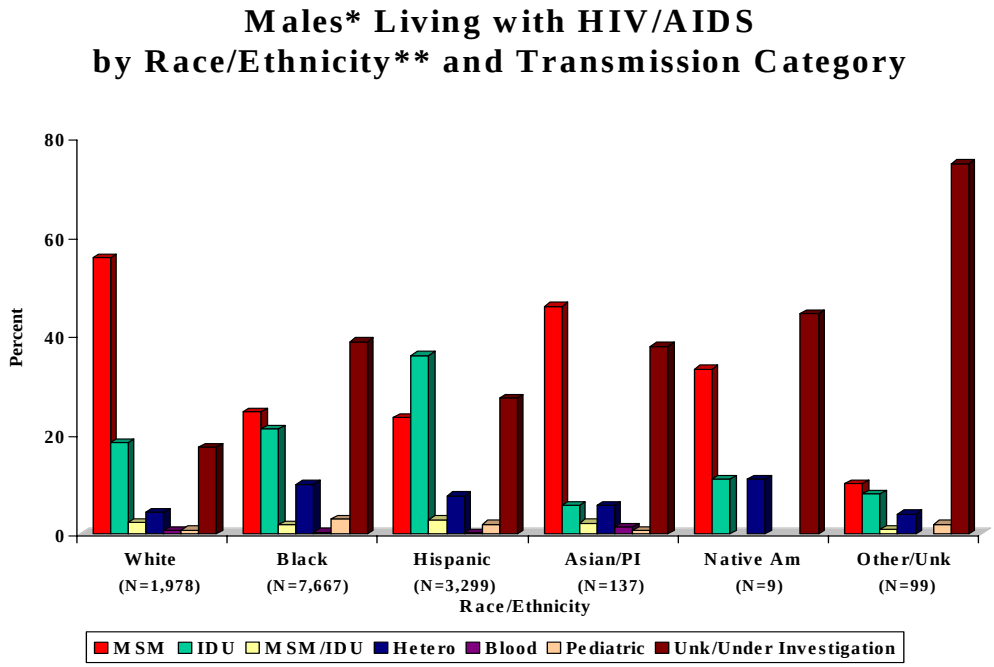


* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

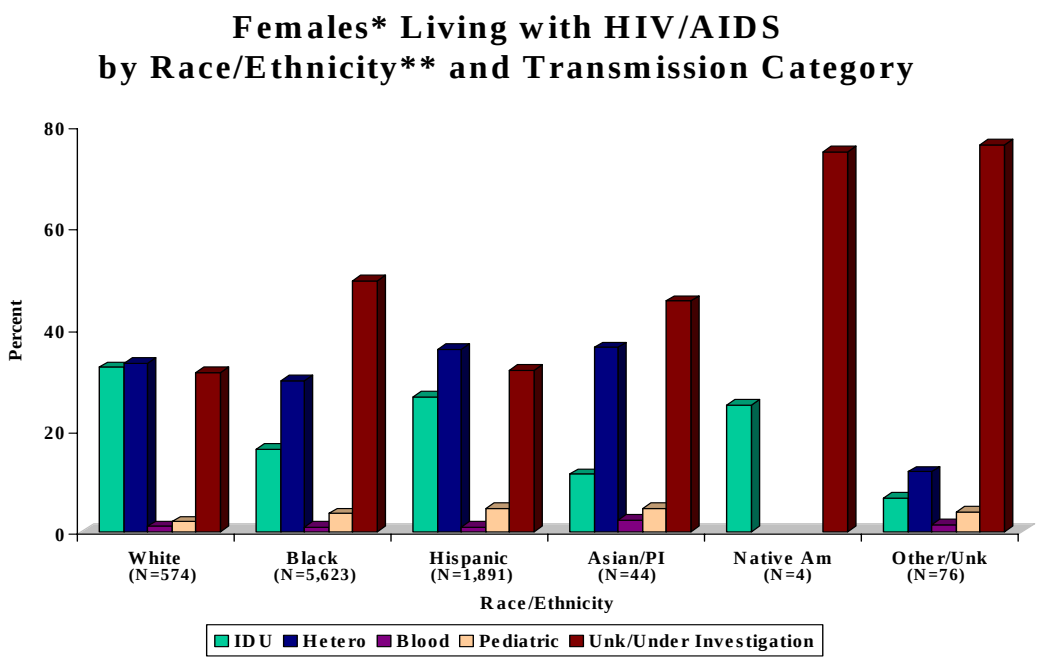
Epidemiologic Profile of Brooklyn, New York City [1/]

Figure 4



**Multi-Race data not included due to small cell size.

Figure 5



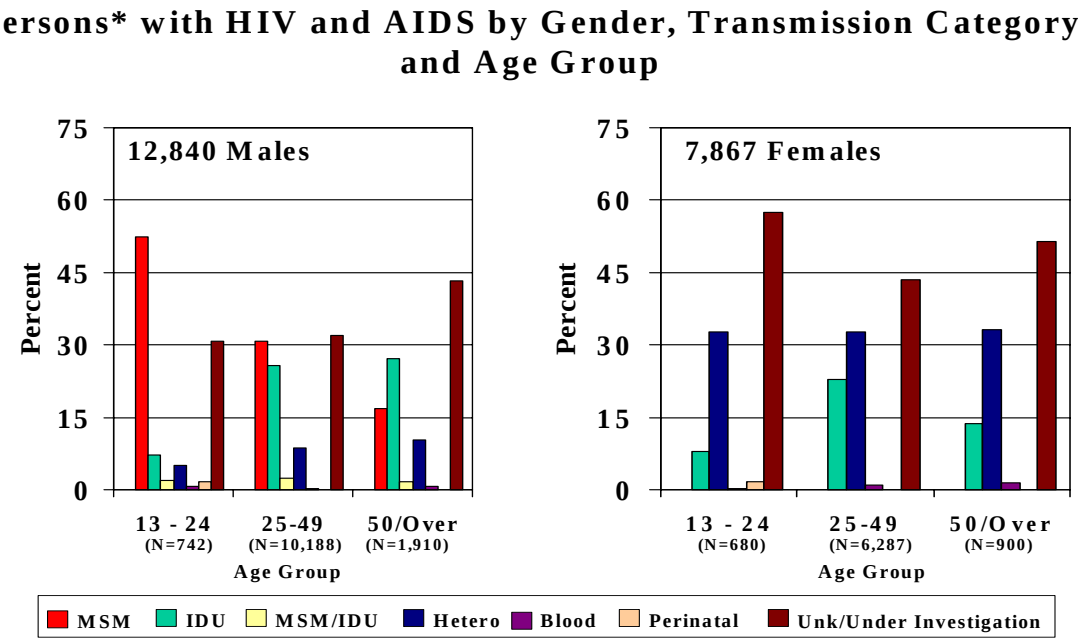
* Excludes Prisoners

** There were no Multi-Race cases.

1/ Cases reported through December 2004 regardless of diagnosis date.

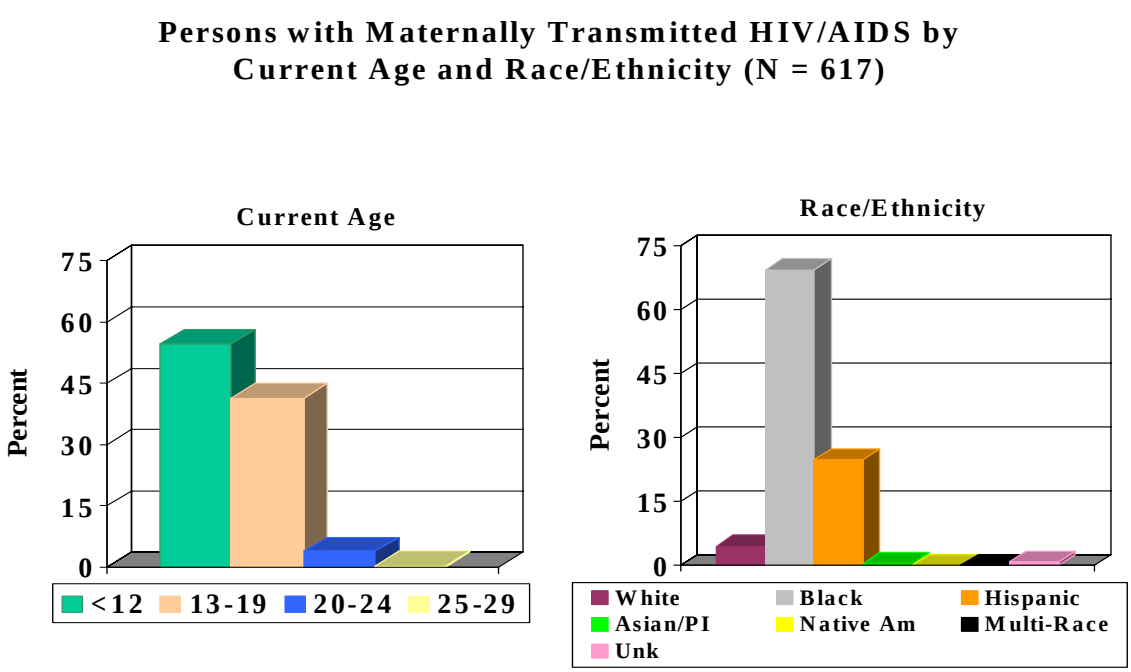
Epidemiologic Profile of Brooklyn, New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Manhattan, New York City [1/]

Figure 1 **Persons Living with HIV and AIDS and Cumulative AIDS Cases***

United Hospital Fund Neighborhood at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Washington Heights – Inwood	1,069	1,970	4,469
Central Harlem-Morningside Heights	1,276	2,286	6,064
East Harlem	880	1,631	4,436
Upper West Side	917	1,989	6,221
Upper East Side	400	822	2,209
Chelsea-Clinton	1,885	2,939	7,472
Gramercy Park-Murray Hill	604	1,250	3,383
Greenwich Village-Soho	608	1,181	3,477
Union Square-Lower East Side	951	1,907	5,547
Lower Manhattan	131	209	513
Unknown	1,363	1,484	3,566
TOTAL	10,084	17,668	47,357

*Excludes prisoners.

Childbearing Women:

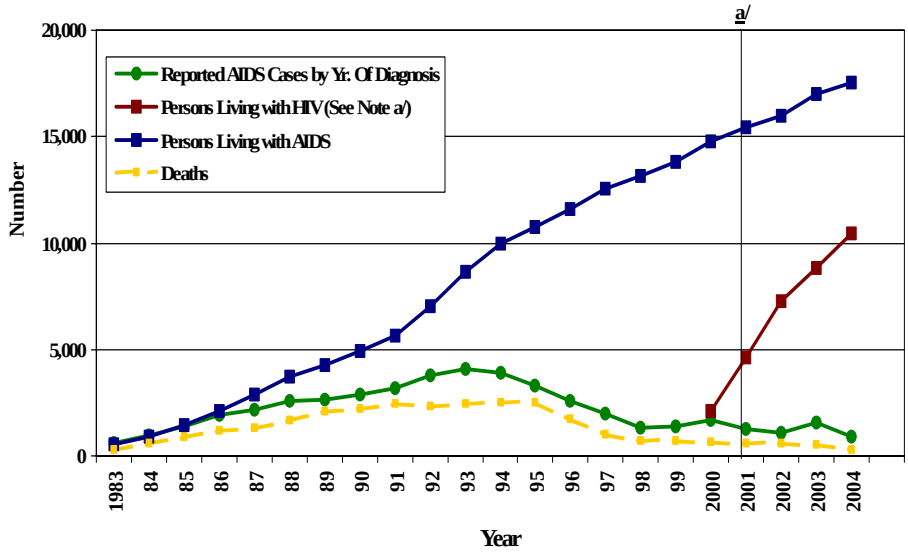
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in Manhattan had a prevalence of 0.47% (n=91), or approximately 1 in 213 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Manhattan, New York City [1/]

Figure 2

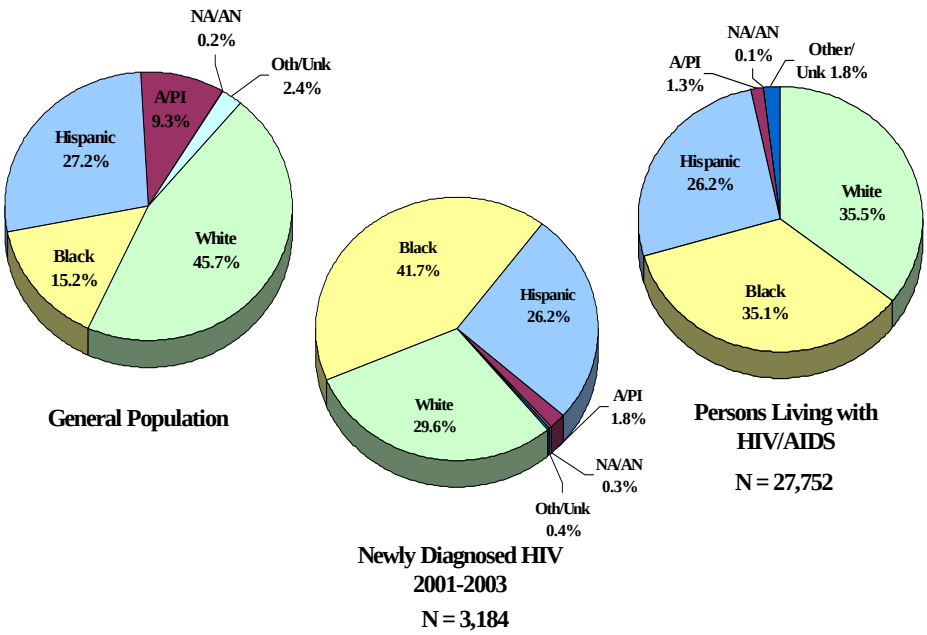
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*

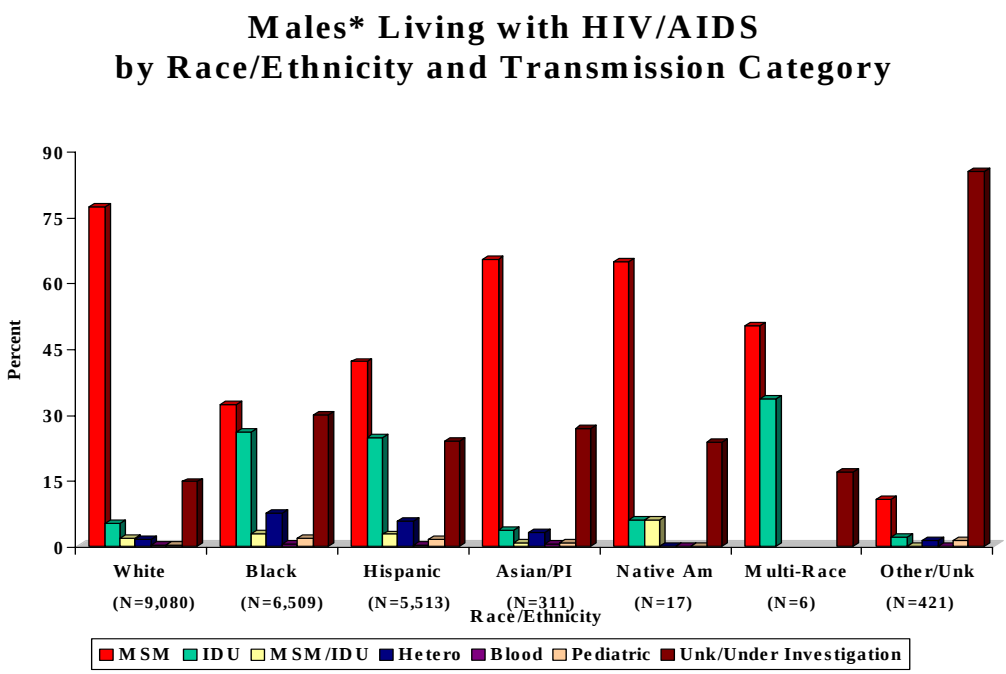


* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Manhattan, New York City [1/]

Figure 4



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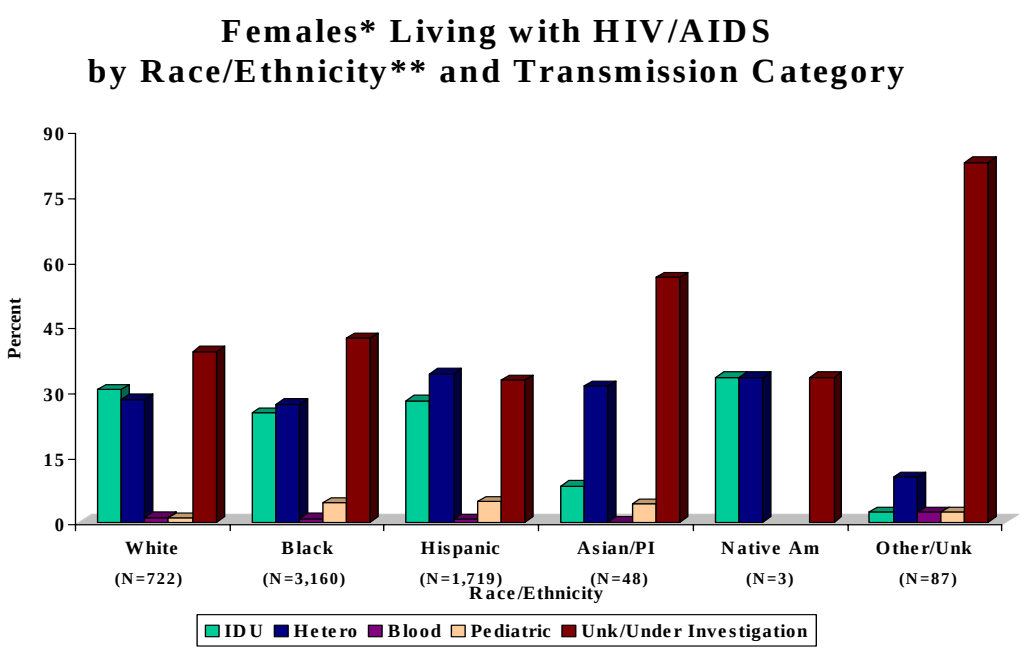


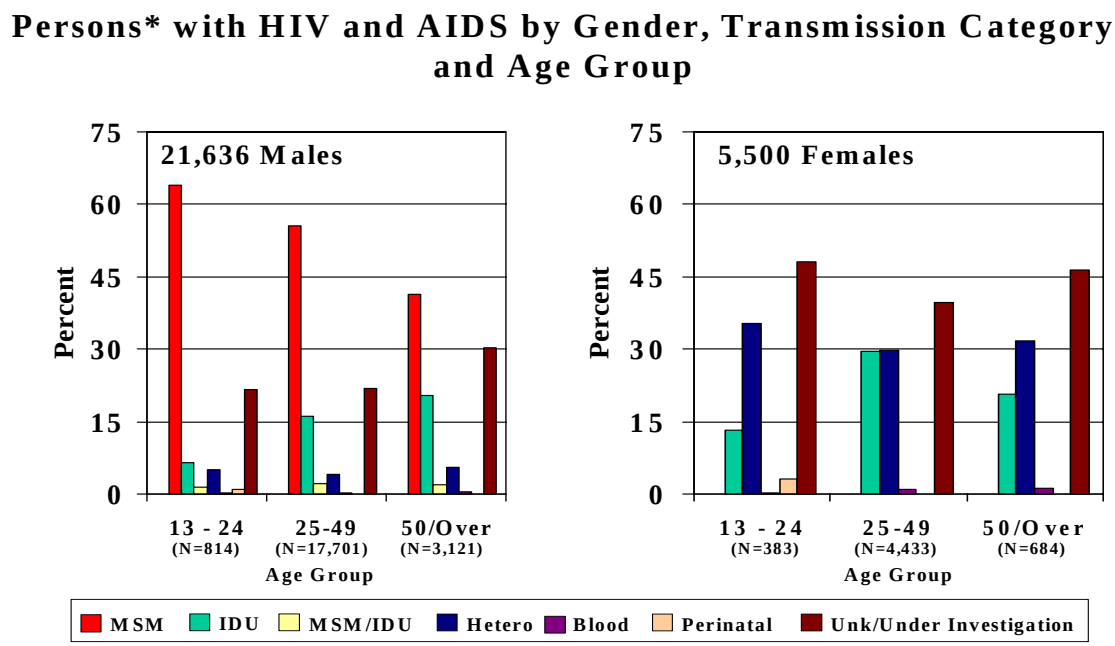
* Excludes Prisoners

** Multi-Race data not included due to small cell size.

1/ Cases reported through December 2004 regardless of diagnosis date.

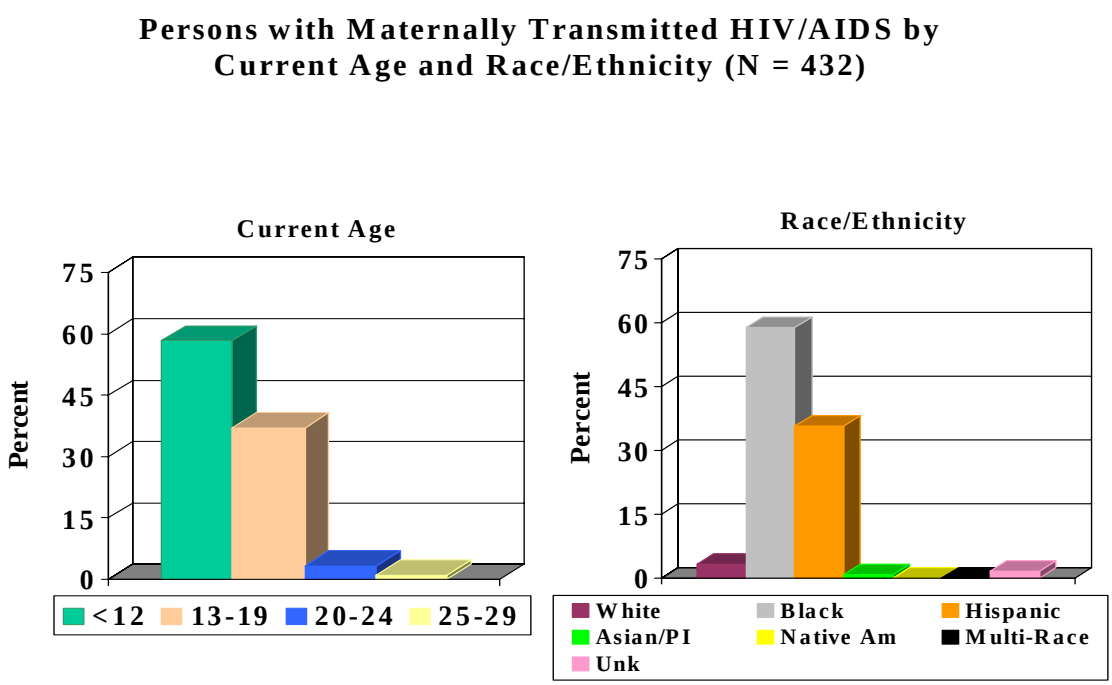
Epidemiologic Profile of Manhattan, New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Queens, New York City [1/]

Figure 1 **Persons Living with HIV and AIDS and Cumulative AIDS Cases***

United Hospital Fund Neighborhood at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Long Island City-Astoria	499	876	1,940
West Queens	798	2,400	4,977
Flushing-Clearview	171	413	948
Bayside – Little Neck	35	88	225
Ridgewood-Forest Hills	283	529	1,248
Fresh Meadows	72	128	326
Southwest Queens	357	719	1,760
Jamaica	710	1,535	3,741
Southeast Queens	280	617	1,333
Rockaway	244	442	1,085
Unknown	194	463	1,129
TOTAL	3,643	8,210	18,712

*Excludes prisoners.

Childbearing Women:

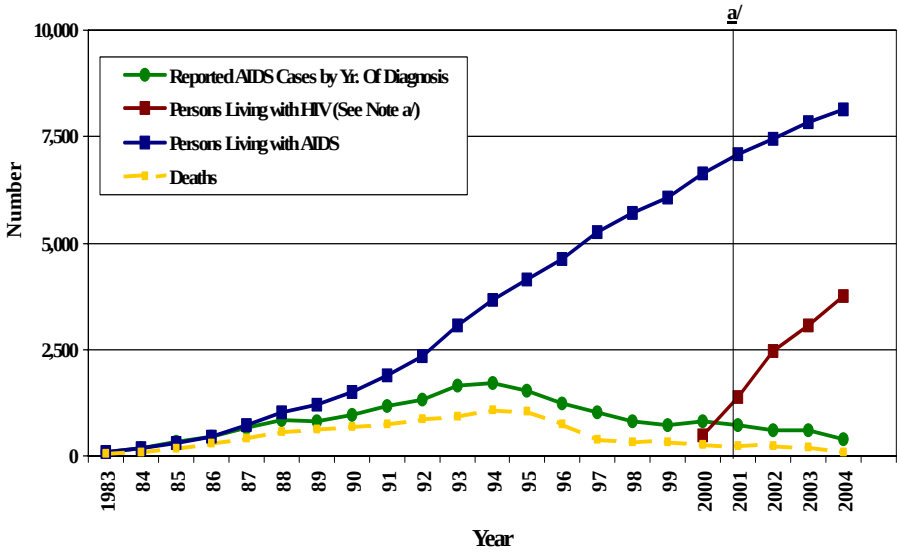
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in Queens had a prevalence of 0.21% (n=63), or approximately 1 in 476 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Queens, New York City [1/]

Figure 2

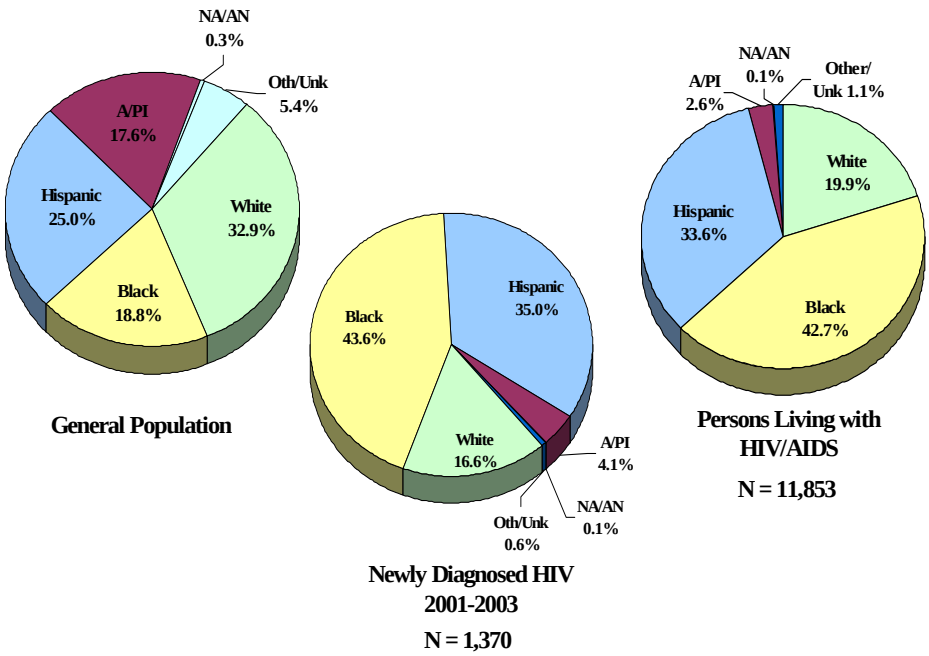
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*

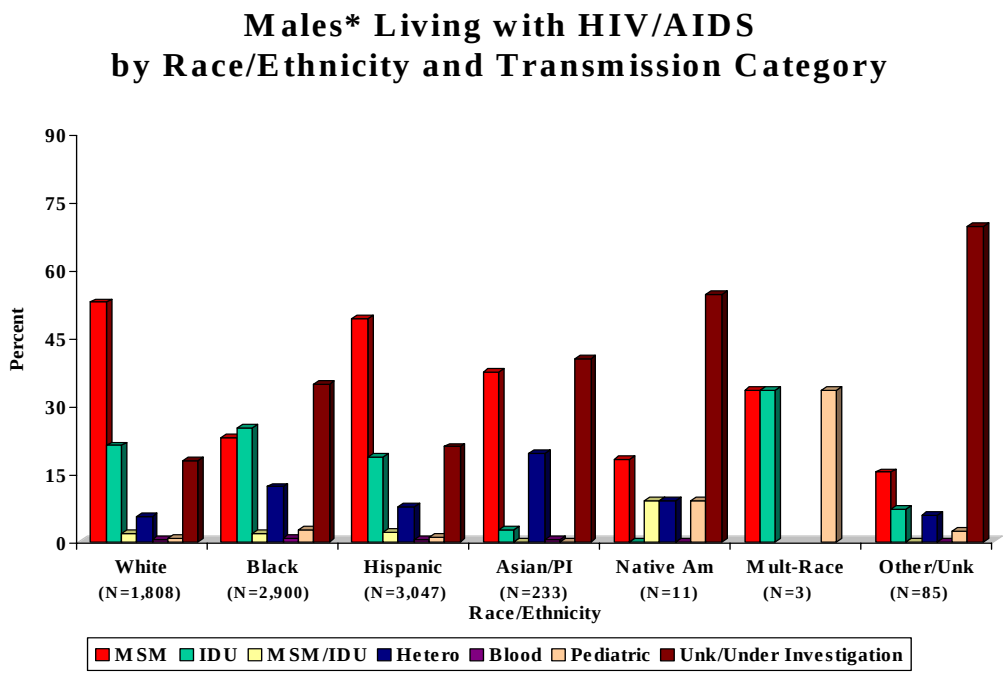


* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Queens, New York City [1/]

Figure 4



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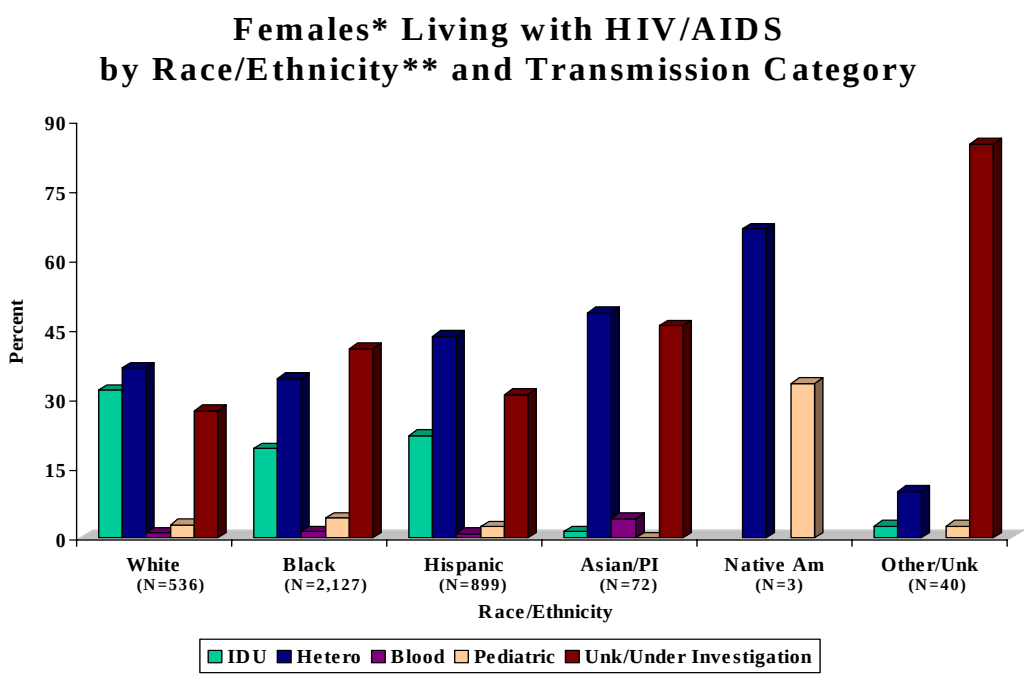

* Excludes Prisoners

** Multi-Race data not included due to small cell size.

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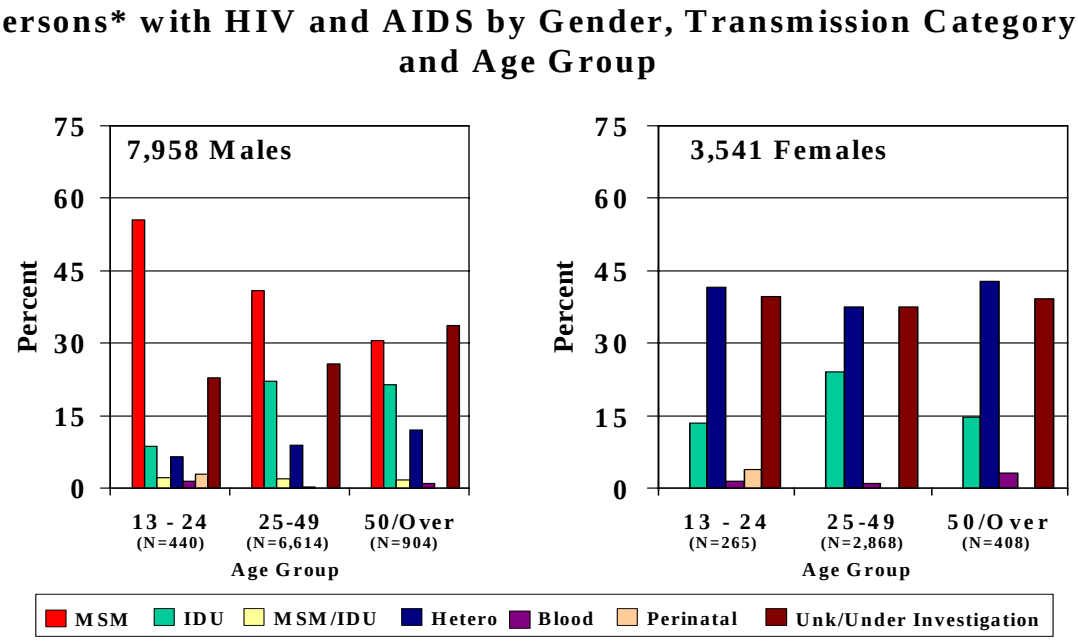
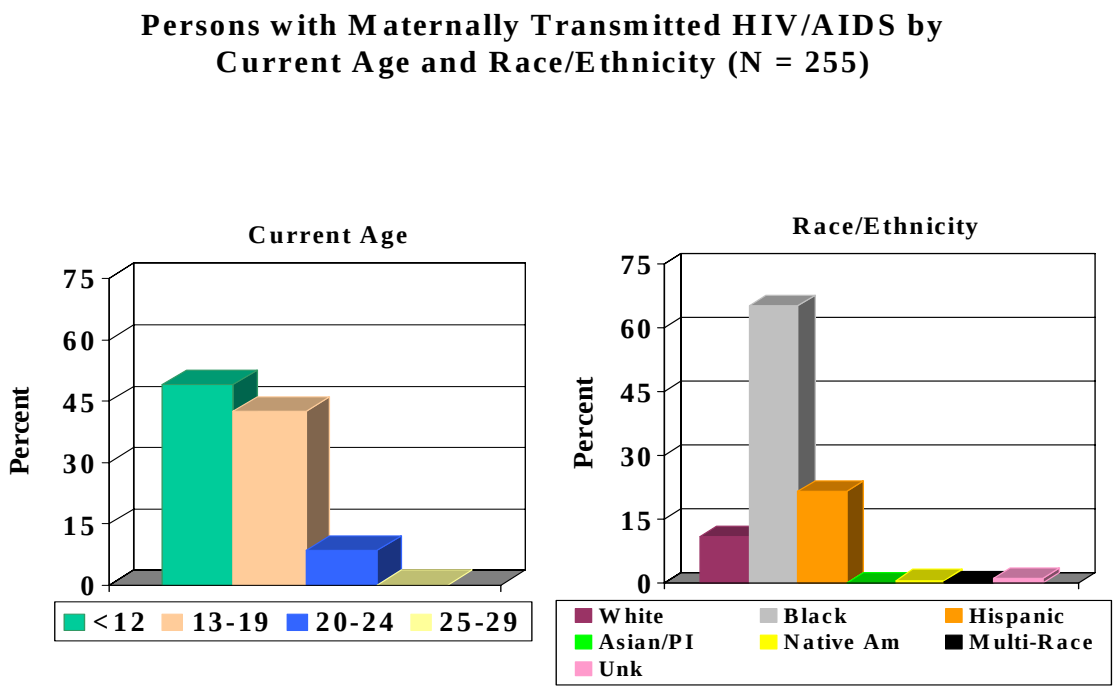
Epidemiologic Profile of Queens, New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Staten Island, New York City [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases*

United Hospital Fund Neighborhood at Time of Diagnosis	Living with HIV Infection	Living with AIDS	Cumulative AIDS Cases
Port Richmond	111	207	525
Stapleton-St. George	247	459	1,241
Willowbrook	42	73	240
South Beach-Tottenville	110	193	580
Unknown	69	94	158
TOTAL	579	1,026	2,744

*Excludes prisoners.

Childbearing Women:

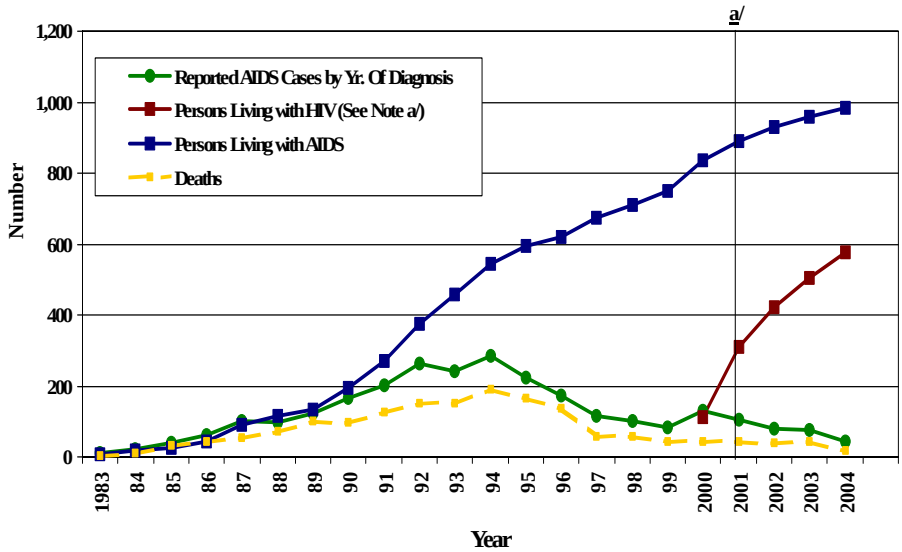
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in Staten Island had a prevalence of 0.24% (n=13), or approximately 1 in 417 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Staten Island, New York City [1/]

Figure 2

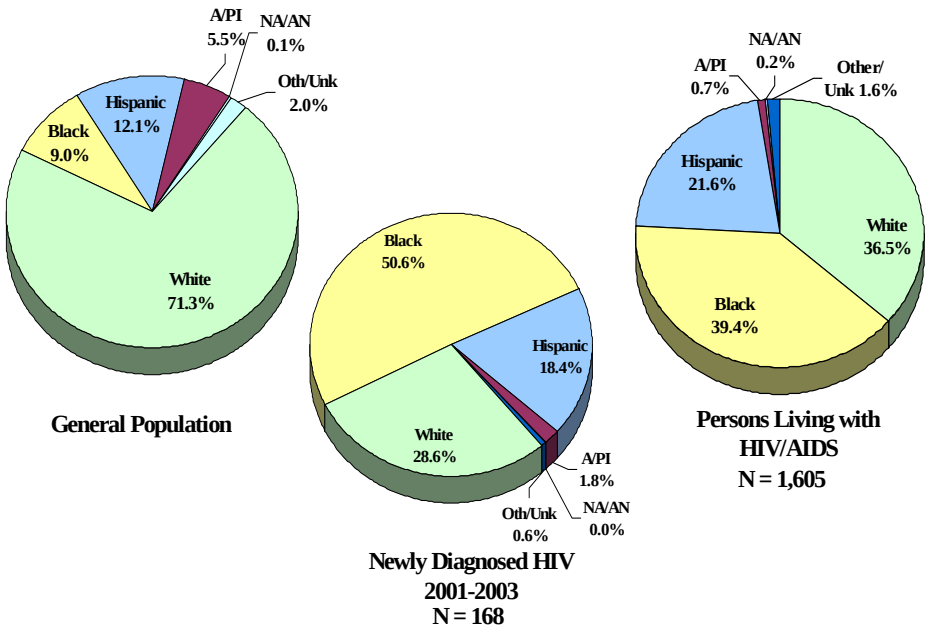
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

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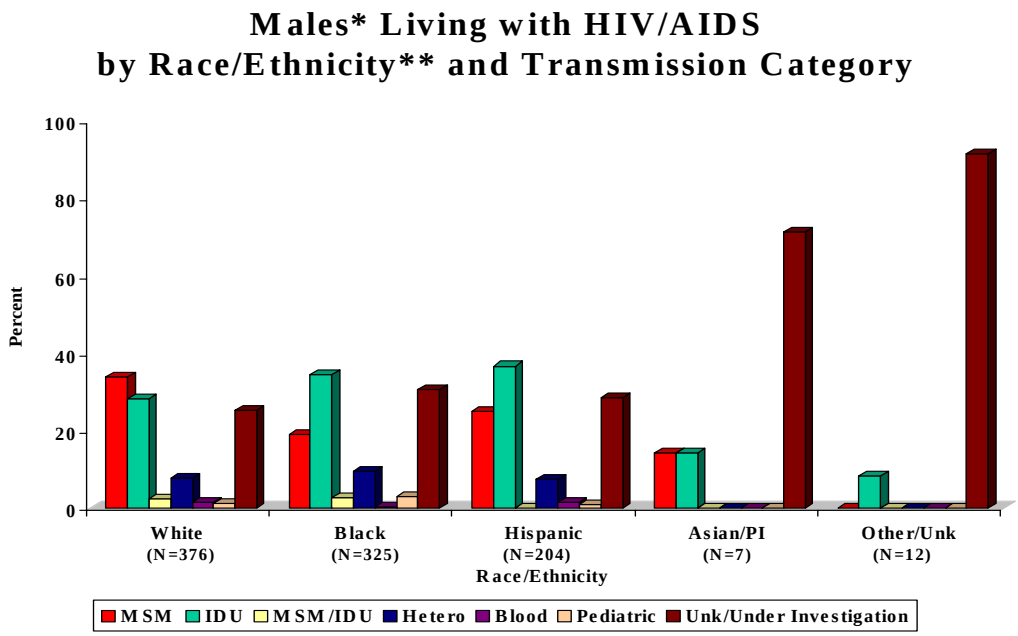
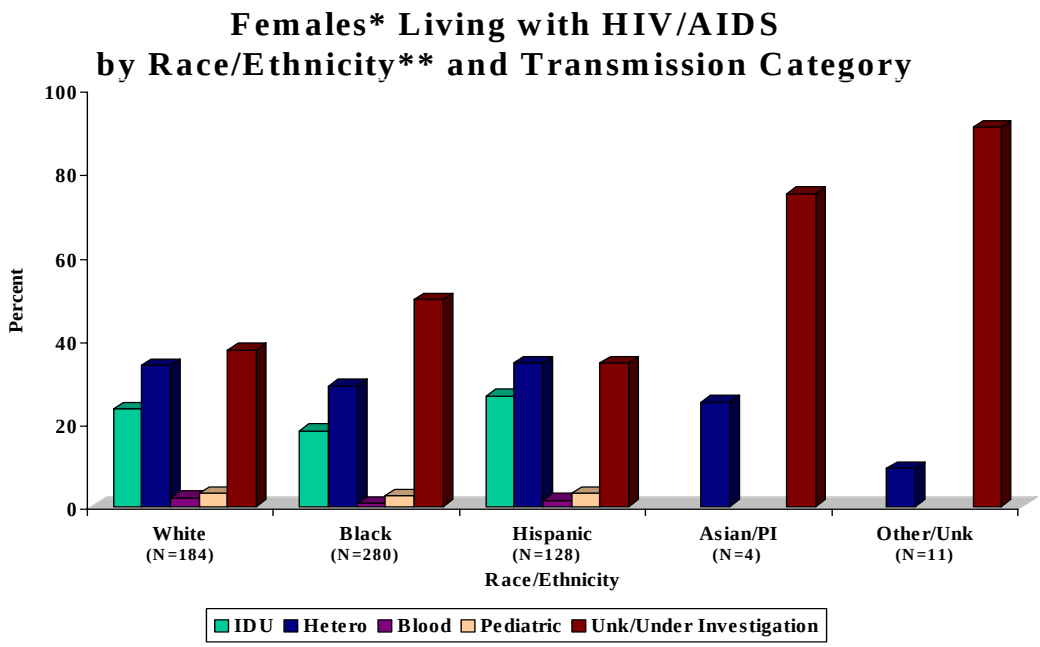
Epidemiologic Profile of Staten Island, New York City [1/]

Figure 4



**Native American and Multi-Race data not included due to small cell sizes

Figure 5



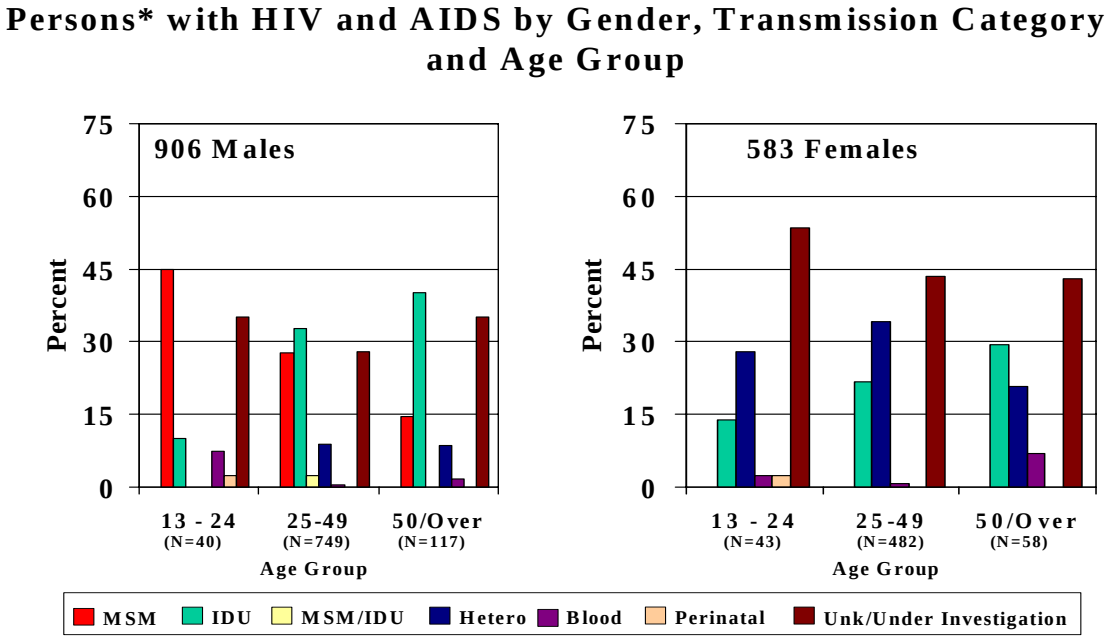
* Excludes Prisoners

** Native American data not included due to small cell sizes. There were no Multi-Race cases.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Staten Island, New York City [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

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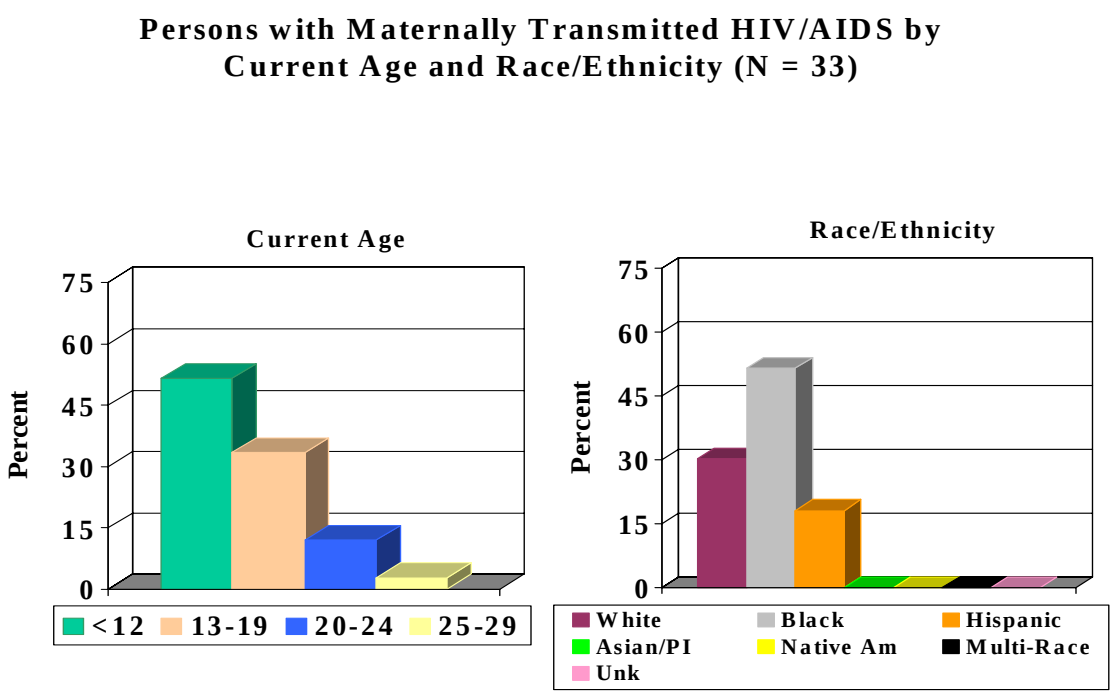


1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York State, Excluding New York City [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

Region of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Albany	861	1,538	1,161	1,907	2,497	3,951
Binghamton	142	150	166	179	337	356
Buffalo	714	1,259	1,021	1,527	2,310	3,173
Lower Hudson	1,009	1,283	2,419	2,759	5,529	6,082
Mid-Hudson	685	1,139	1,298	1,962	3,064	4,389
Nassau/Suffolk	1,431	1,473	3,005	3,058	7,477	7,584
Rochester	747	1,035	1,162	1,379	2,512	2,891
Syracuse	562	1,251	915	1,647	1,936	3,205
Totals	6,151	9,128	11,147	14,418	25,662	31,631

Childbearing Women:

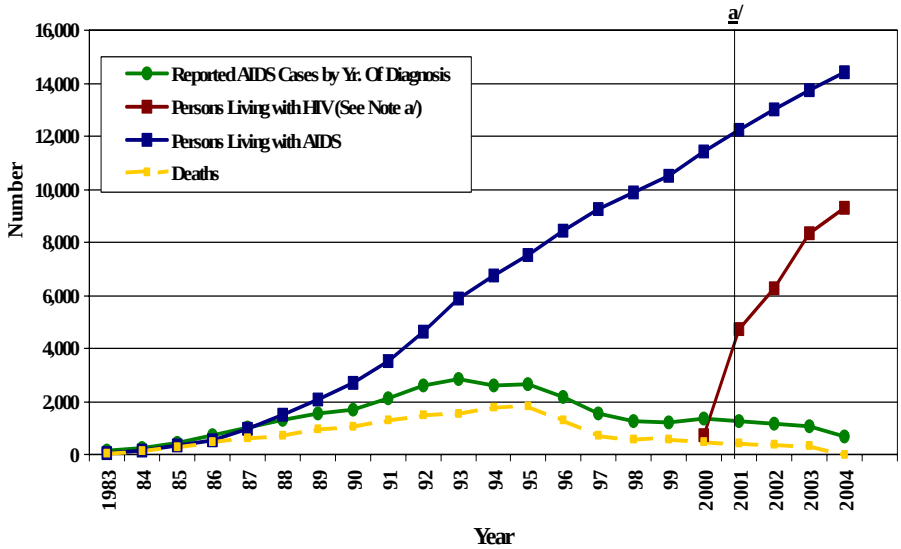
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in New York State, excluding NYC, had a prevalence of 0.12% (n=144), or approximately 1 in 833 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York State, Excluding New York City [1/]

Figure 2

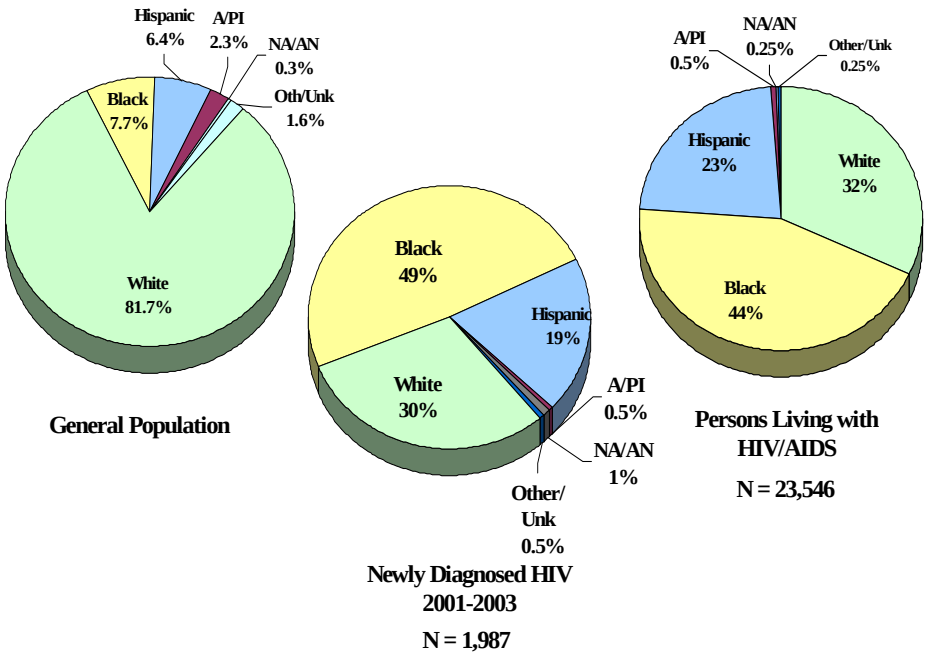
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Includes prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of New York State, Excluding New York City [1/]

Figure 4

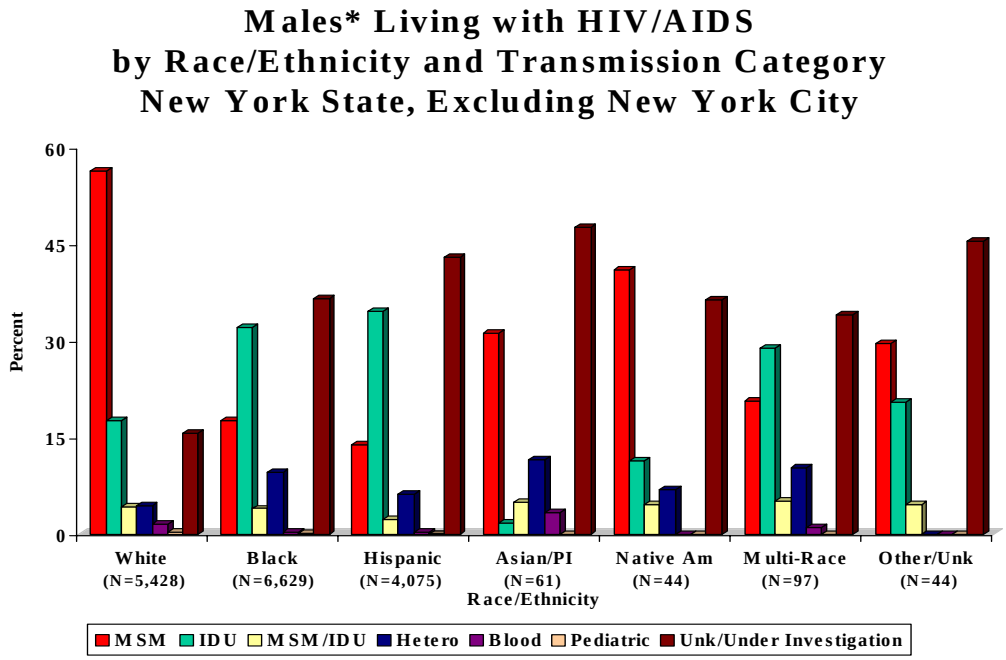
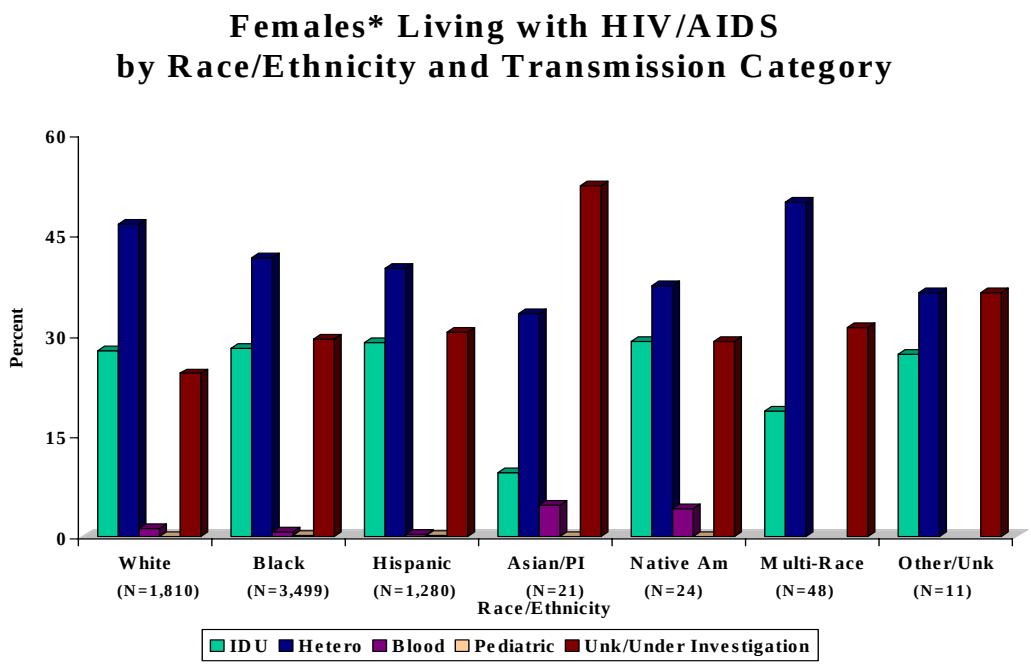


Figure 5

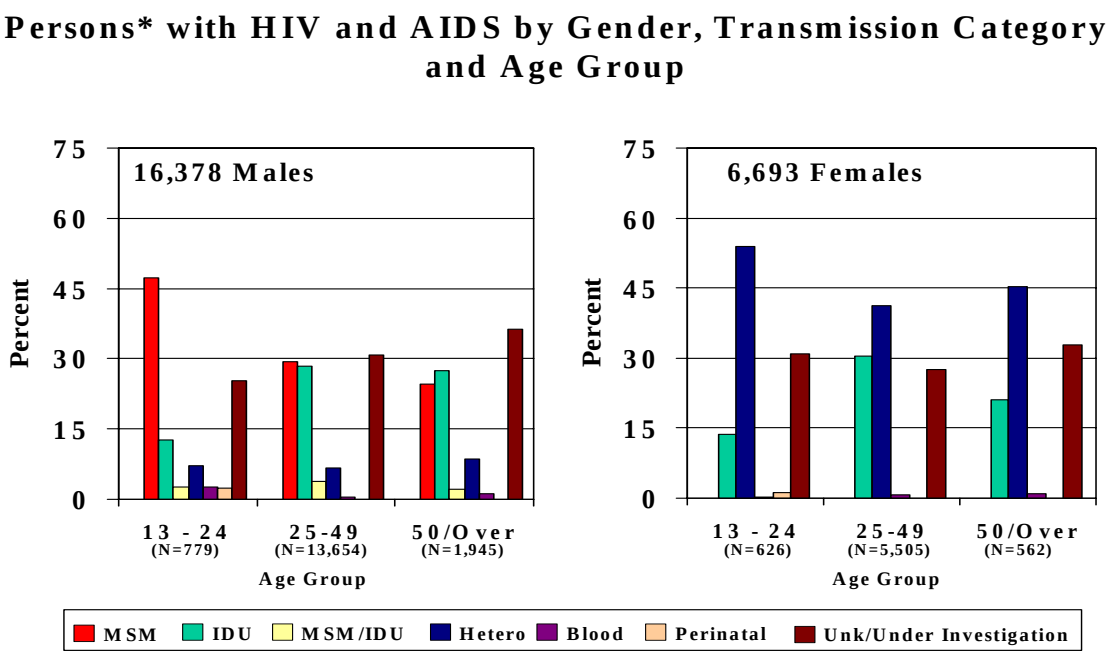


* Includes Prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

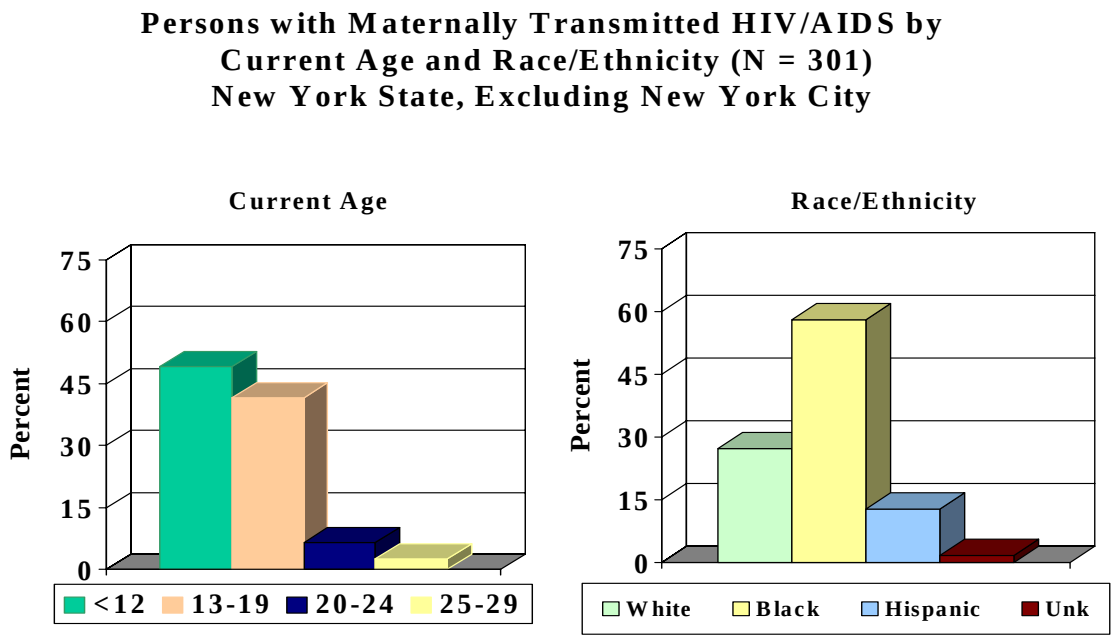
Epidemiologic Profile of New York State, Excluding New York City [1/]

Figure 6



* Includes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Albany (Northeast) Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Albany	348	383	496	516	1,040	1,070
Clinton	19	133	27	210	58	445
Columbia	30	73	30	57	79	130
Delaware	21	21	21	22	41	42
Essex	11	56	16	82	48	180
Franklin	13	235	20	223	36	366
Fulton	18	21	20	21	40	42
Greene	22	76	39	116	69	209
Hamilton	1	1	1	1	2	2
Montgomery	27	29	29	29	71	71
Otsego	21	21	31	32	66	67
Rensselear	87	91	124	128	253	257
Saratoga	42	87	77	132	175	291
Schenectady	156	163	172	184	380	393
Schoharie	13	20	8	12	33	37
Warren	21	21	30	30	60	60
Washington	11	107	20	112	46	289
Totals	861	1,538	1,161	1,907	2,497	3,951

Childbearing Women:

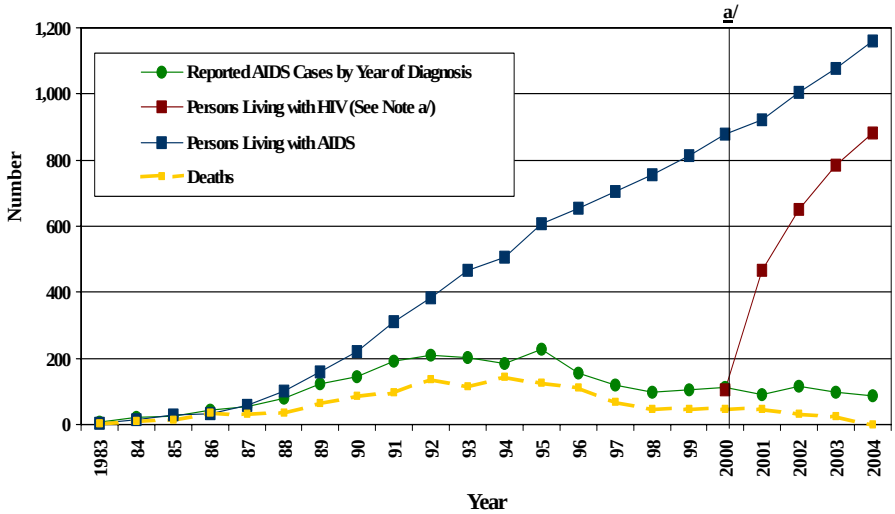
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Albany Region had a prevalence of 0.12% (n=17), or approximately 1 in 833 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Albany (Northeastern) Ryan White Region [1/]

Figure 2

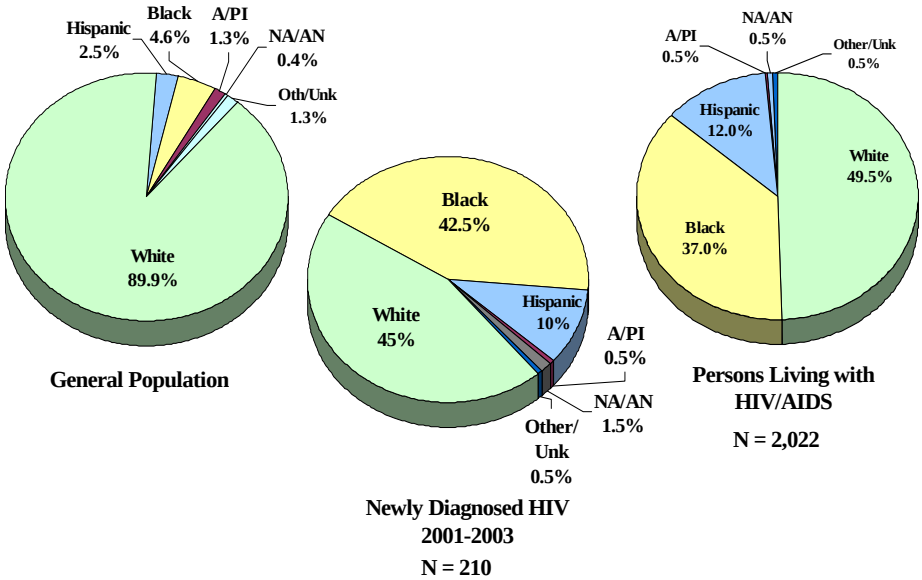
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths [b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes Prisoners
1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Albany (Northeastern) Ryan White Region [1/]

Figure 4

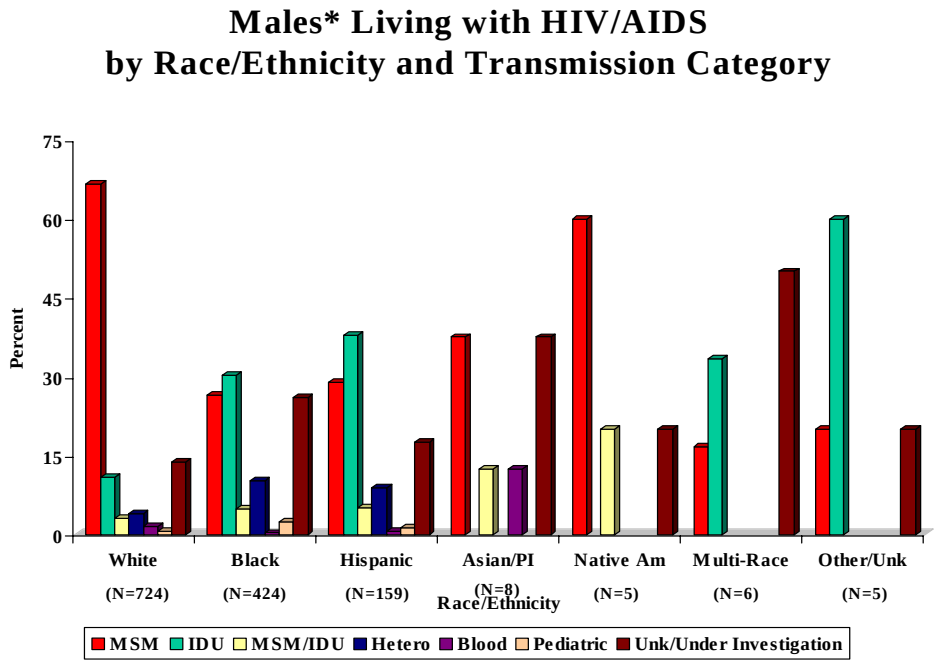
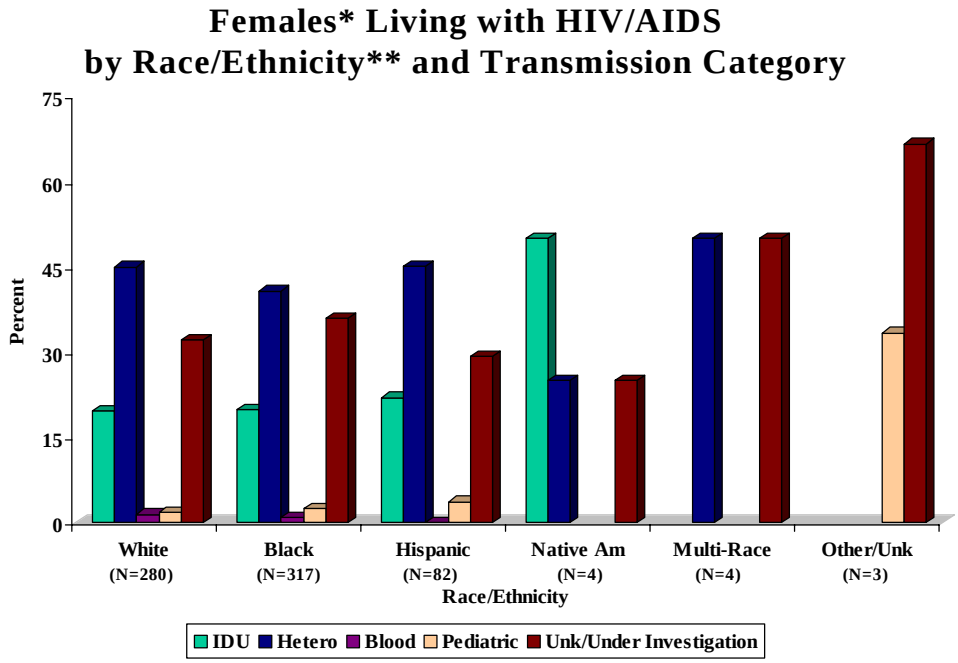


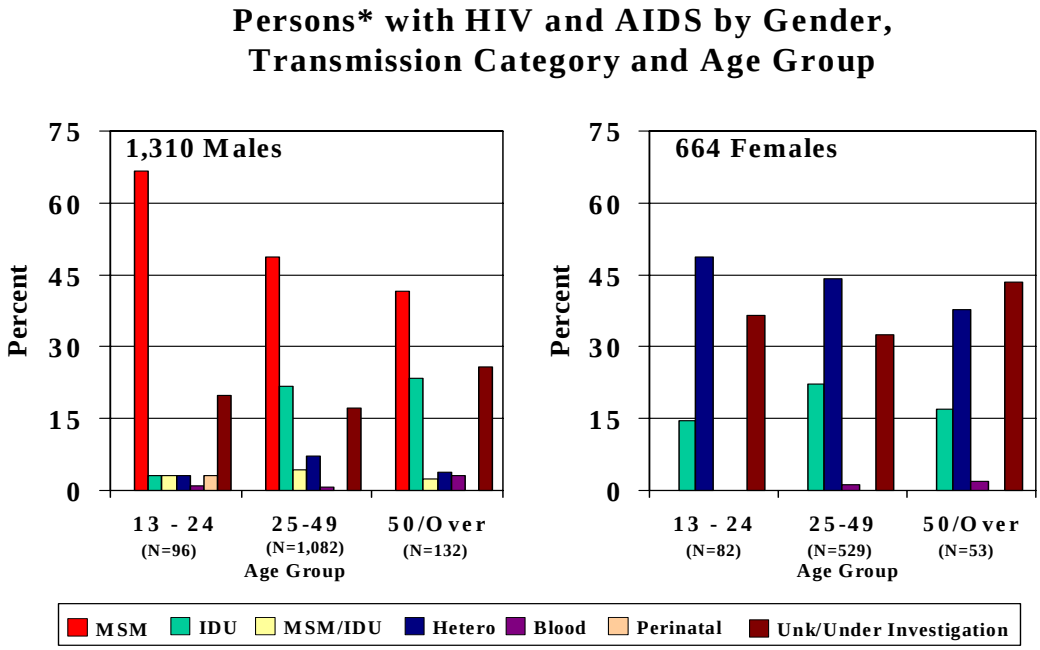
Figure 5



* Excludes Prisoners
**Asian/Pacific Islander data not included due to small cell sizes
1/ Cases reported through December 2004 regardless of diagnosis date.

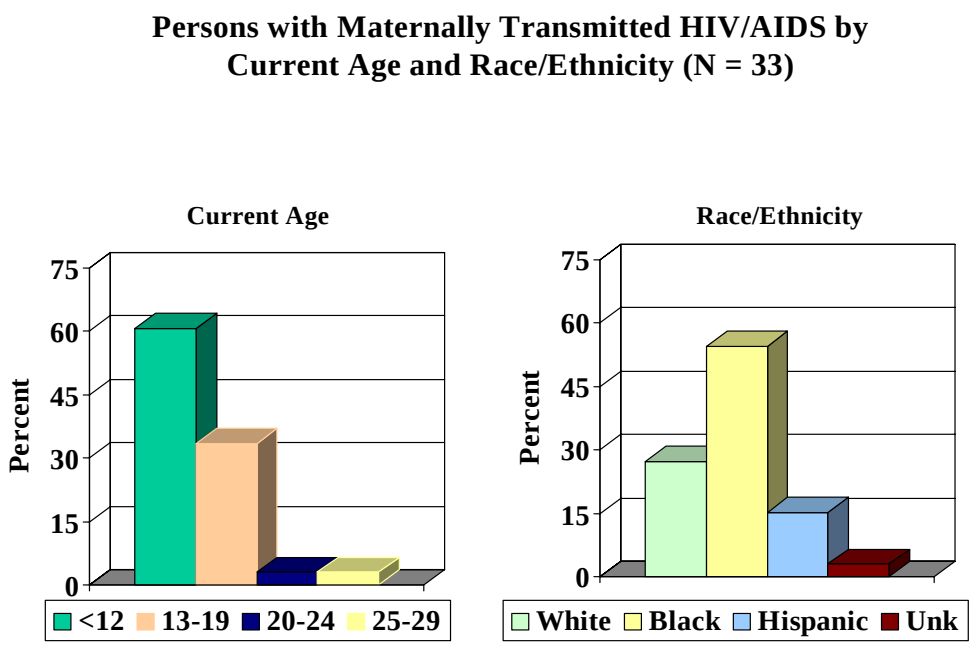
Epidemiologic Profile of Albany (Northeastern) Ryan White Region [1/]

Figure 6



*Excludes prisoners; reported cases ages ≥ 13 years with known gender

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Binghamton Tri-County Ryan White Region [1/]

Figure 1 **Persons Living with HIV and AIDS and Cumulative AIDS Cases**

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Broome	117	120	132	136	271	275
Chenango	14	19	23	32	38	53
Tioga	11	11	11	11	28	28
Totals	142	150	166	179	337	356

Childbearing Women:

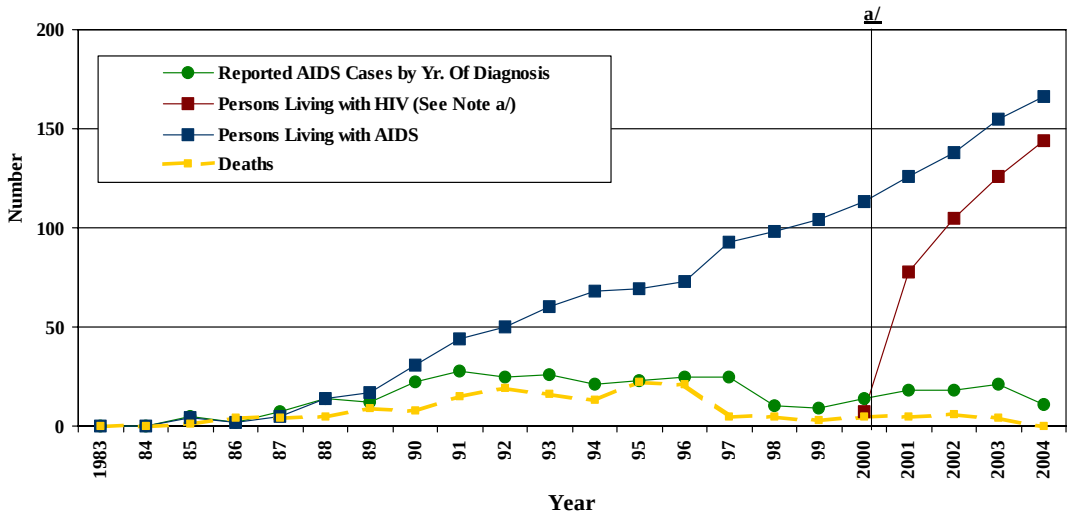
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Binghamton Tri-County Region had a prevalence of 0.14% (n=4), or approximately 1 in 714 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Binghamton Tri-County Ryan White Region [1/]

Figure 2

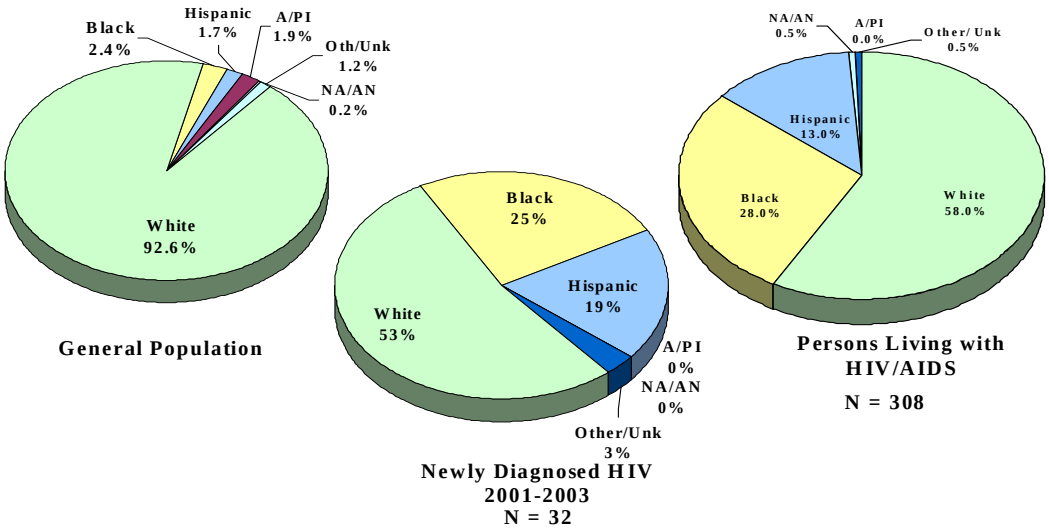
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes Prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Binghamton Tri-County Ryan White Region [1/]

Figure 4

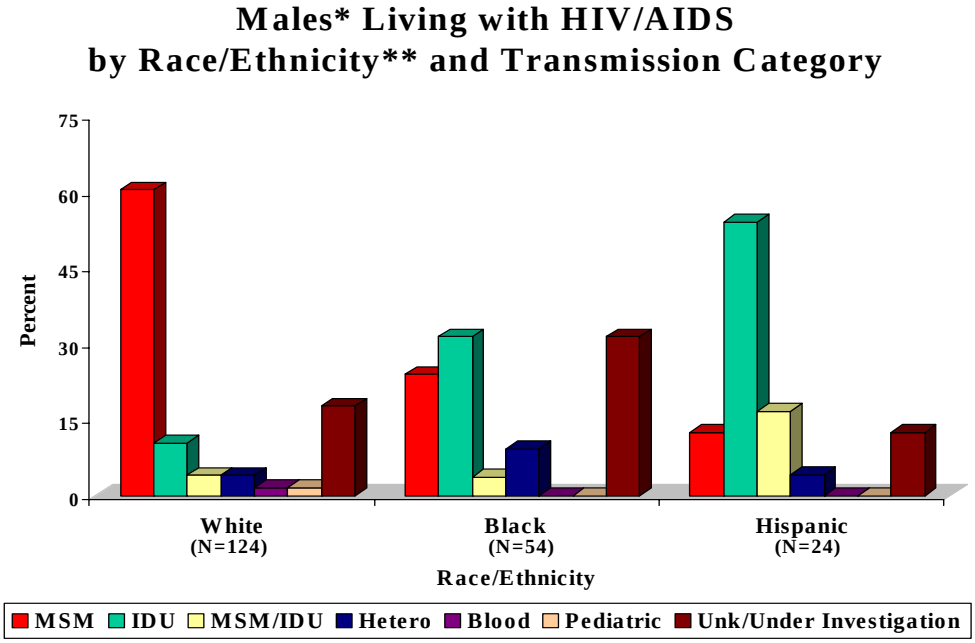
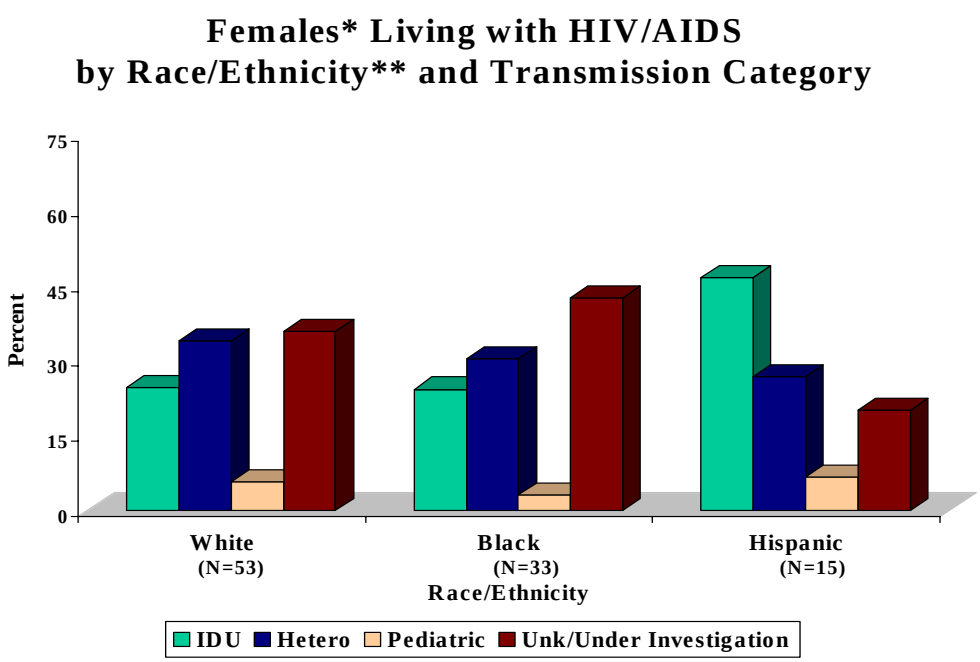


Figure 5



* Excludes Prisoners

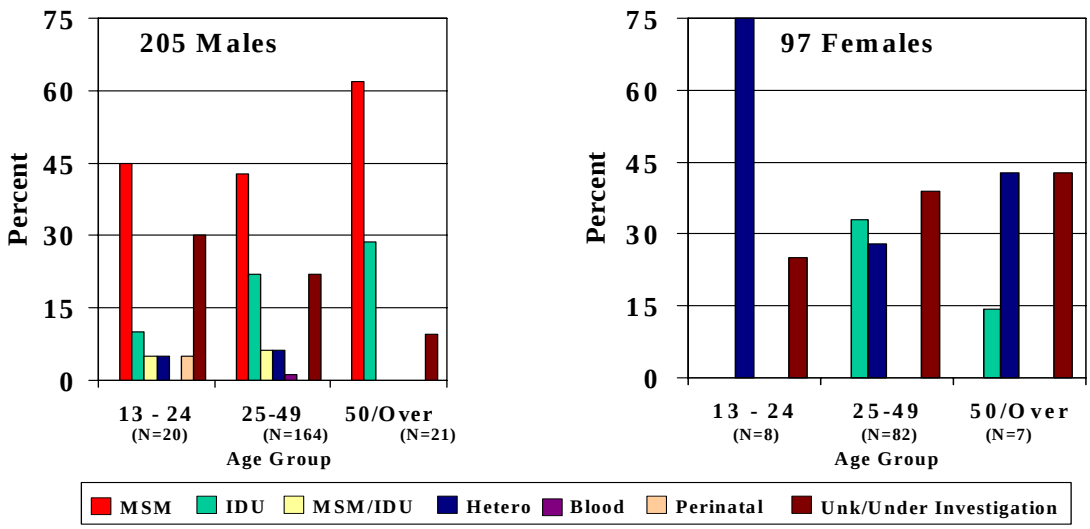
**Asian/Pacific Islander, Native American, Multi-Race and Other/Unknown data not included due to small cell sizes

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Binghamton Tri-County Ryan White Region [1/]

Figure 6

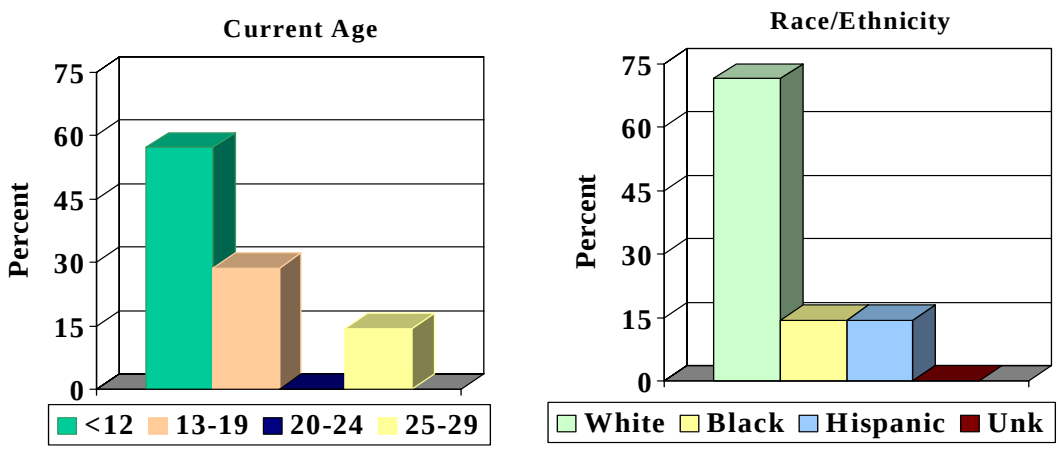
Persons* with HIV and AIDS by Gender, Transmission Category and Age Group



*Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7

Persons with Maternally Transmitted HIV/AIDS by Current Age and Race/Ethnicity (N = 7)



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Buffalo (Western) Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Allegany	4	4	8	9	20	21
Cattaraugus	19	59	20	45	44	74
Chautauqua	56	112	63	80	113	135
Erie	553	646	799	901	1,821	2,017
Genesee	15	15	21	23	43	45
Niagara	50	53	77	81	211	215
Orleans	11	251	24	236	41	357
Wyoming	6	119	9	152	17	309
Totals	714	1,259	1,021	1,527	2,310	3,173

Childbearing Women:

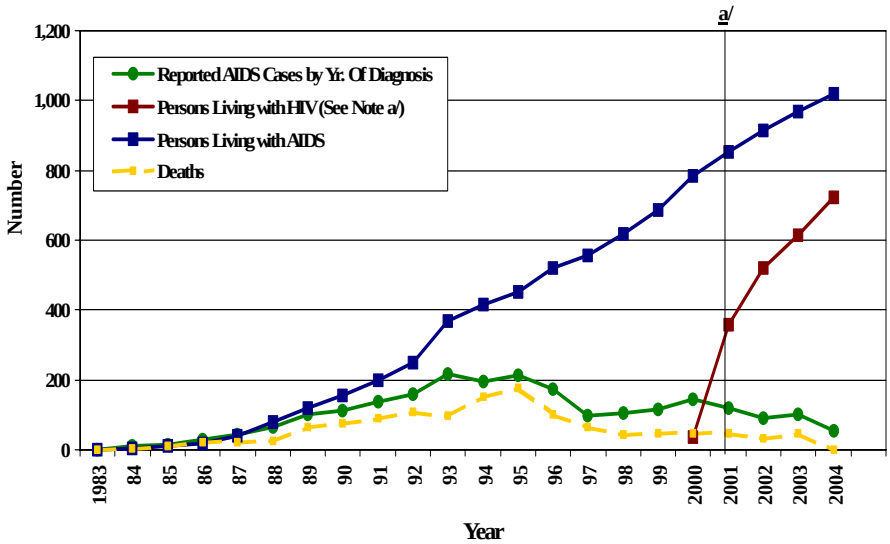
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Buffalo Region had a prevalence of 0.14% (n=24), or approximately 1 in 714 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Buffalo (Western) Ryan White Region [1/]

Figure 2

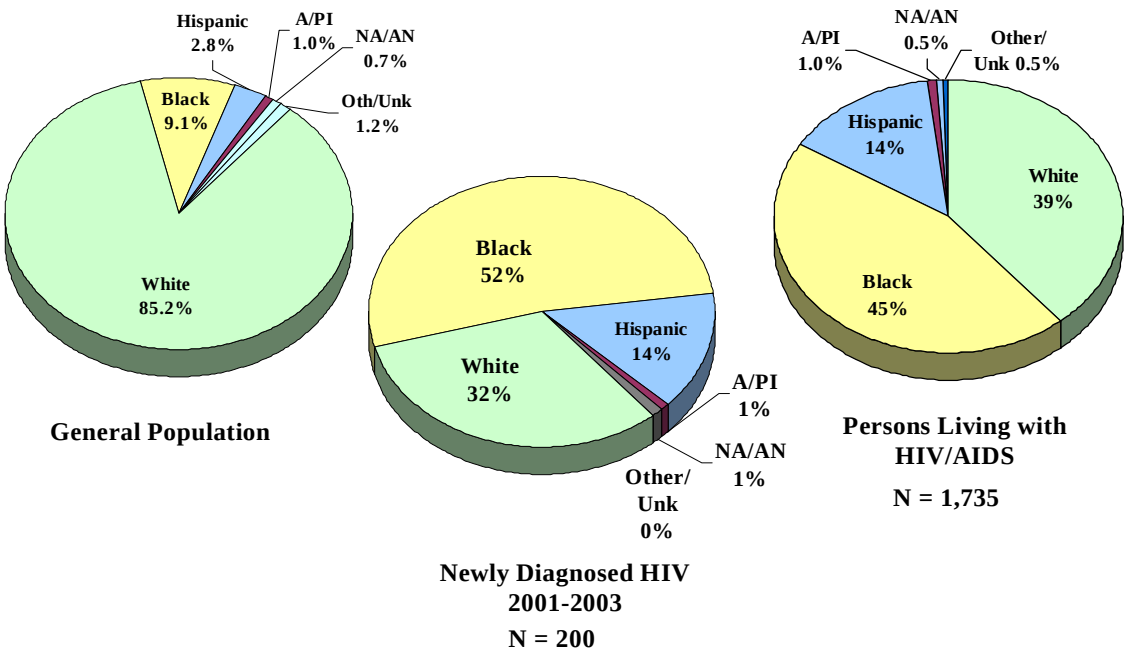
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Buffalo (Western) Ryan White Region [1/]

Figure

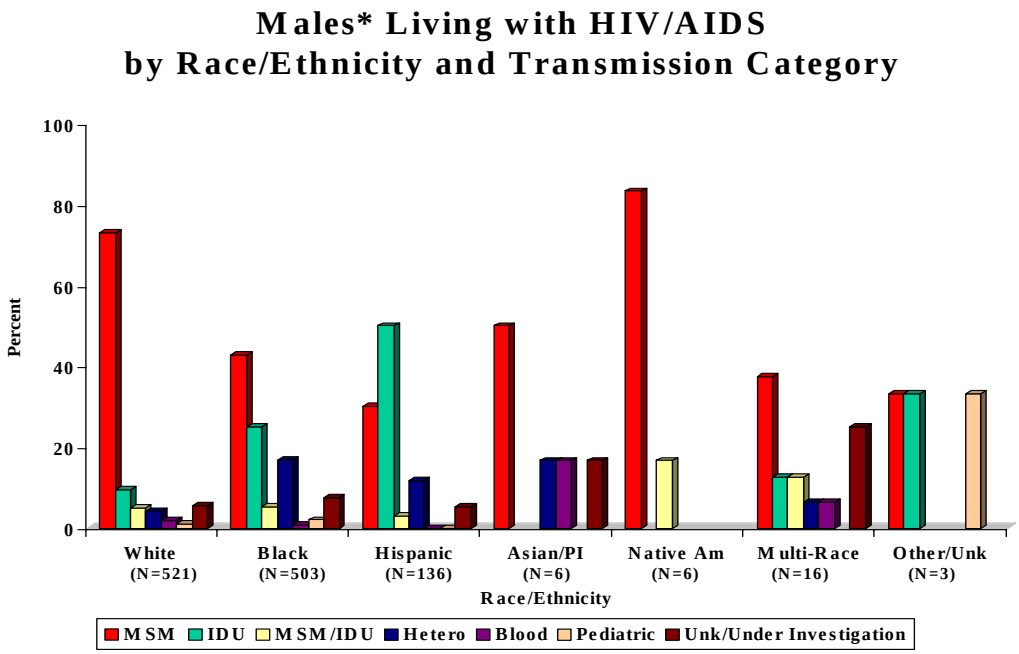
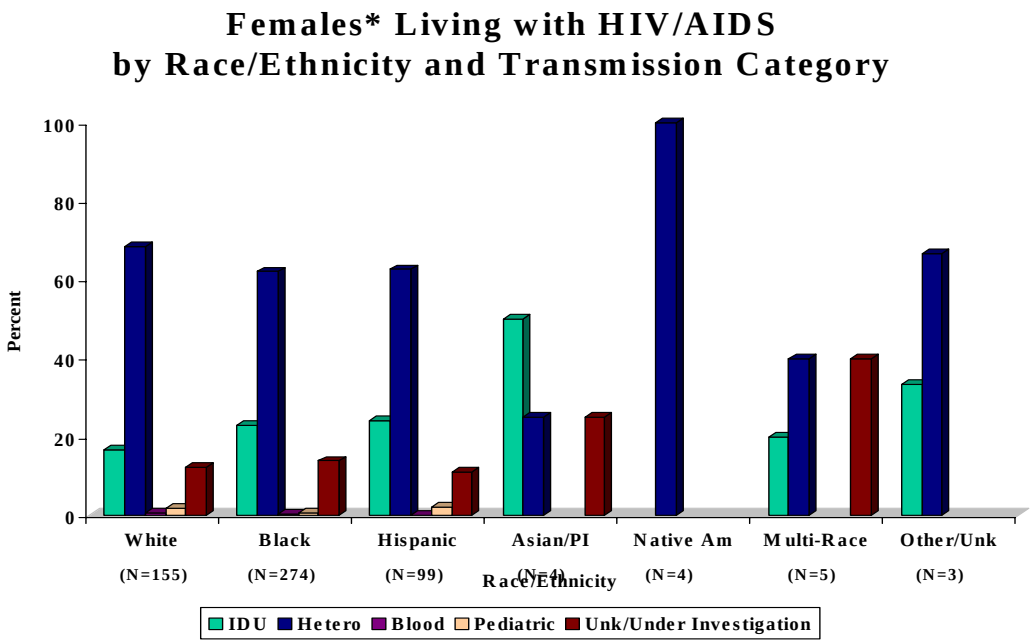


Figure 5

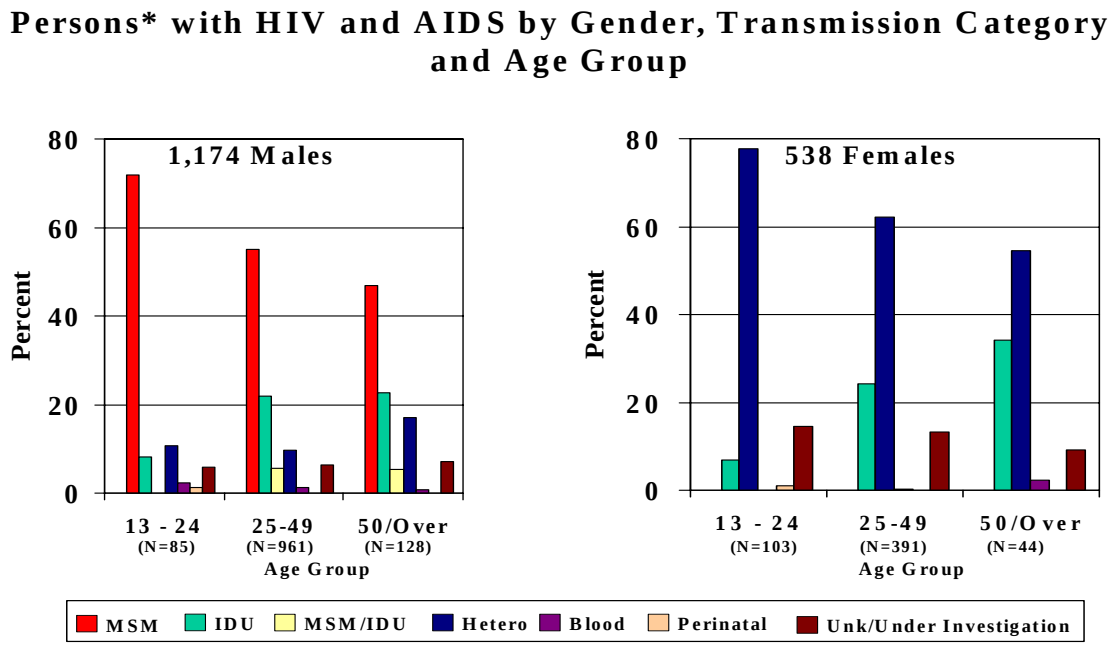


* Excludes Prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

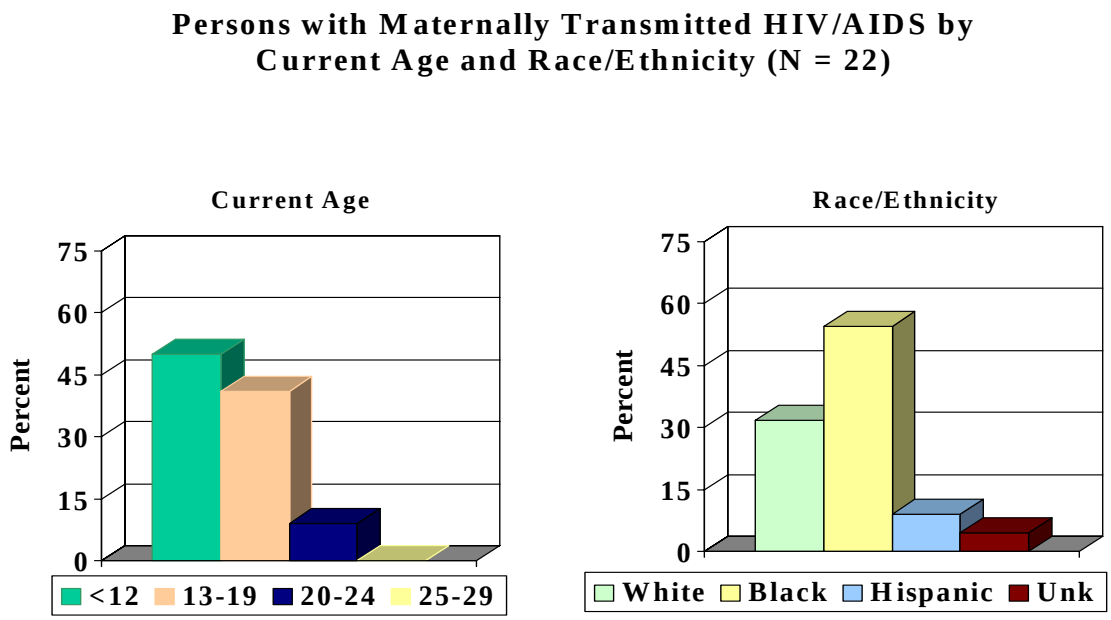
Epidemiologic Profile of Buffalo (Western) Ryan White Region [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Lower Hudson Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Putnam	26	27	73	74	167	168
Rockland	156	159	399	464	864	931
Westchester	827	1,097	1,947	2,221	4,498	4,983
Totals	1,009	1,283	2,419	2,759	5,529	6,082

Childbearing Women:

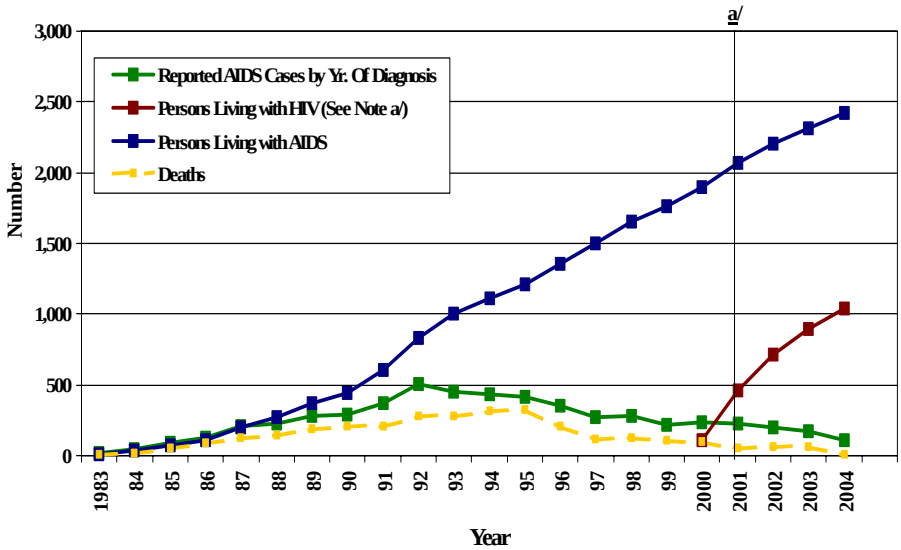
2004 data from the NYS Comprehensive Newborn Screening Program notes that women giving birth in the Lower Hudson Region had a prevalence of 0.15% (n=25), or approximately 1 in 666 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Lower Hudson Ryan White Region [1/]

Figure 2

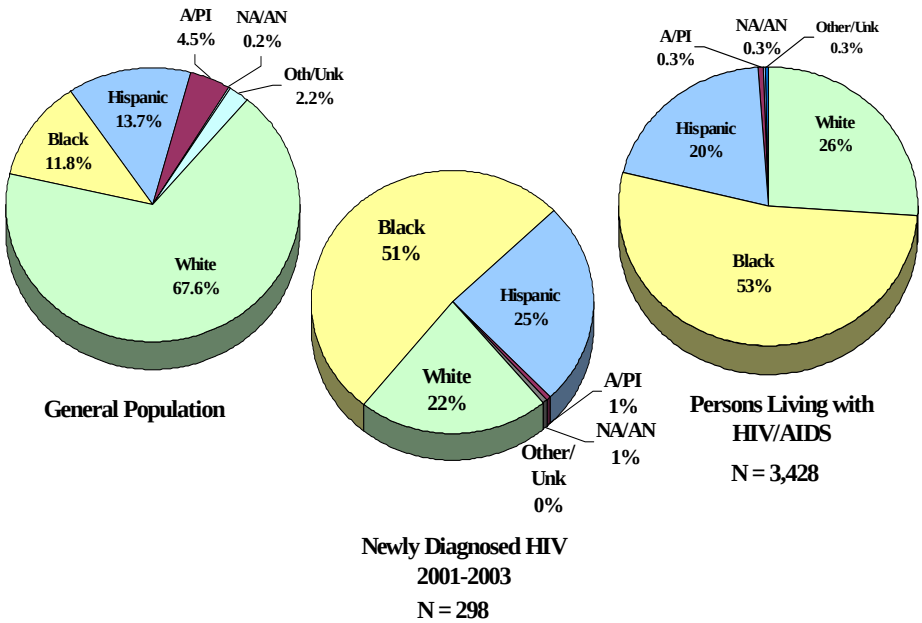
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*

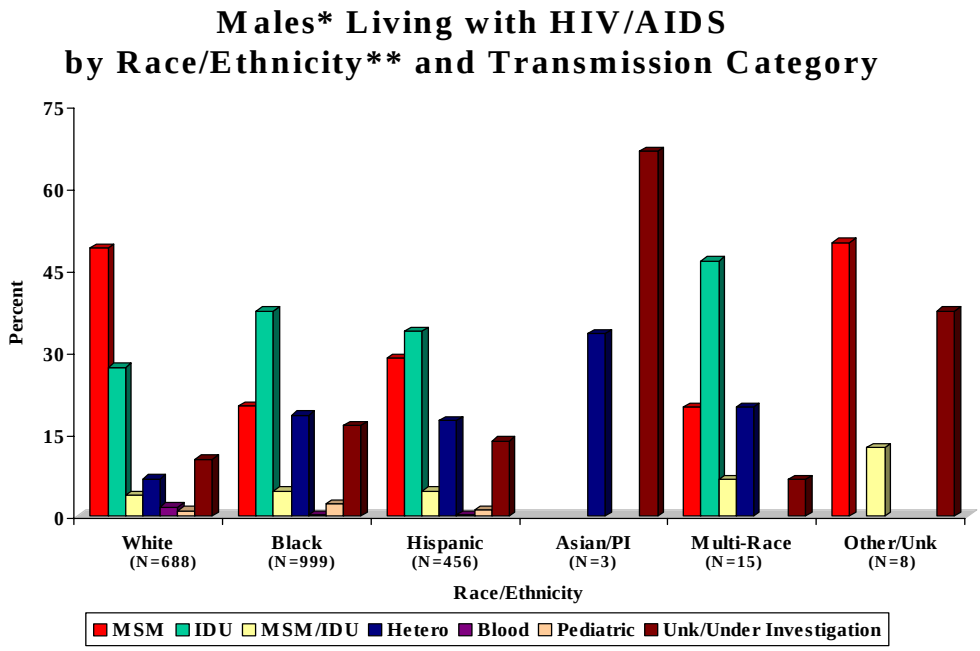


* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

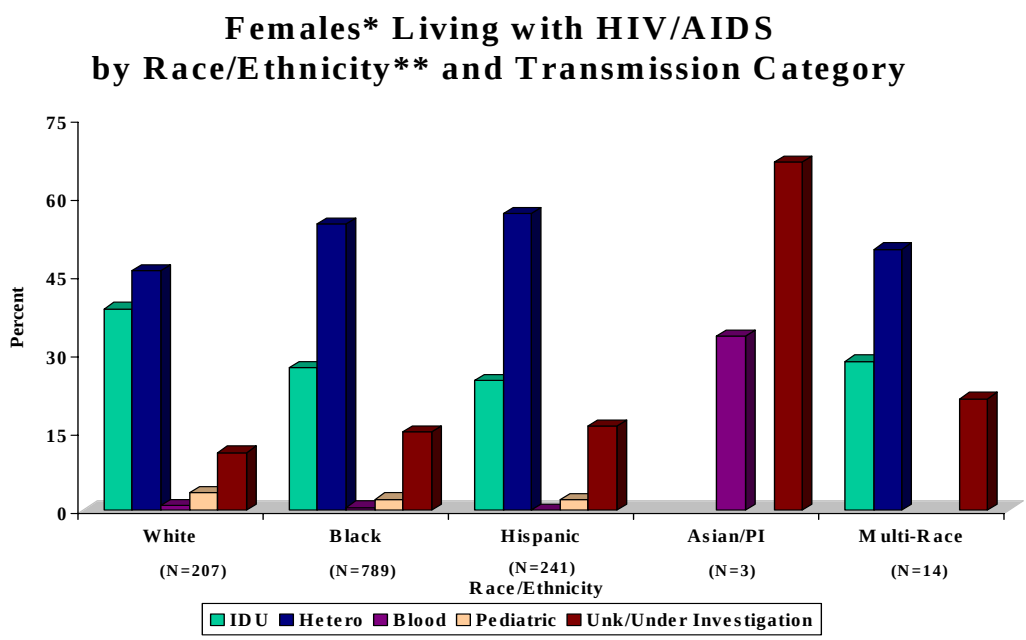
Epidemiologic Profile of Lower Hudson Ryan White Region [1/]

Figure 4



**Native American data not included due to small cell sizes

Figure 5



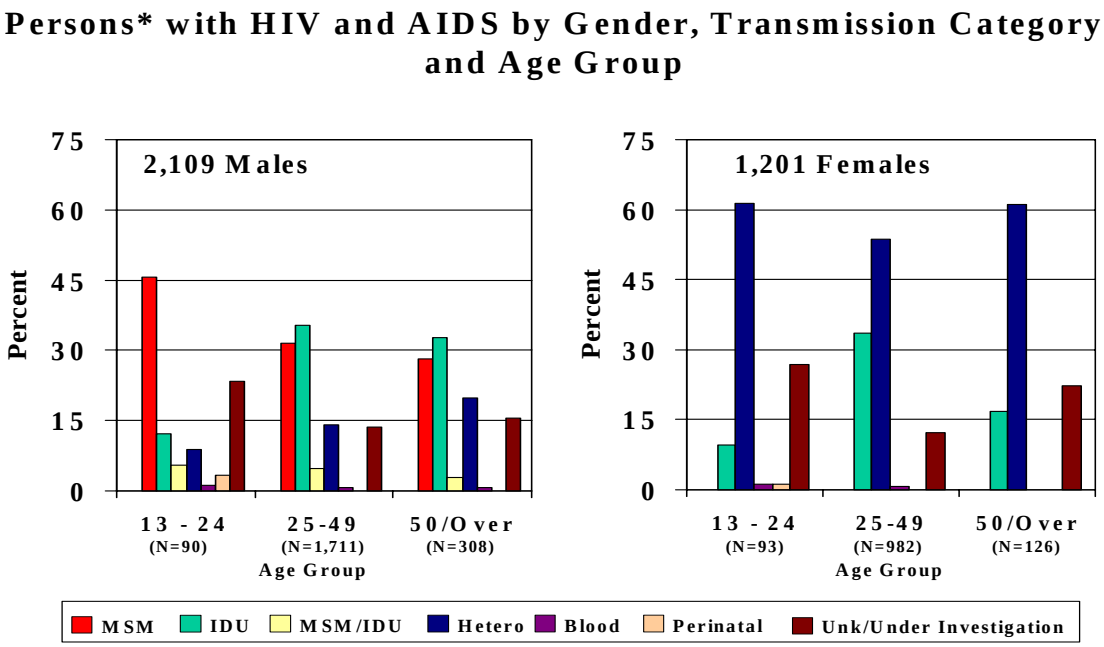
* Excludes Prisoners.

** Native American data not included due to small cell sizes. There are no Other/Unknown cases.

1/ Cases reported through December 2004 regardless of diagnosis date.

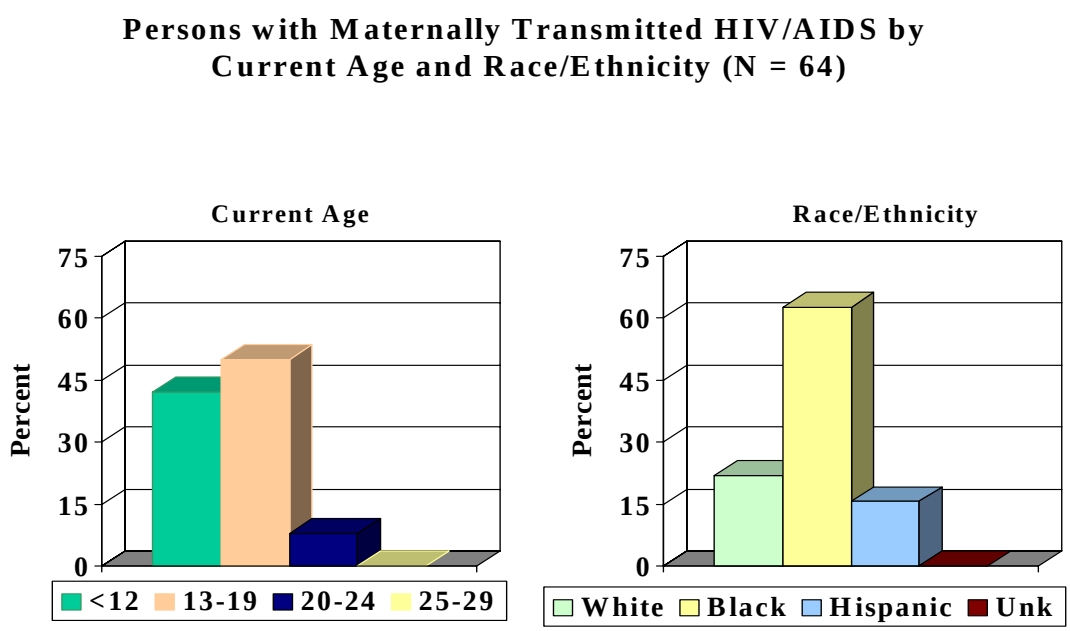
Epidemiologic Profile of Lower Hudson Ryan White Region [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Mid-Hudson Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Dutchess	206	397	374	666	892	1,534
Orange	229	318	479	607	1,102	1,328
Sullivan	125	187	185	261	477	631
Ulster	125	237	260	428	593	896
Total	685	1,139	1,298	1,962	3,064	4,389

Childbearing Women:

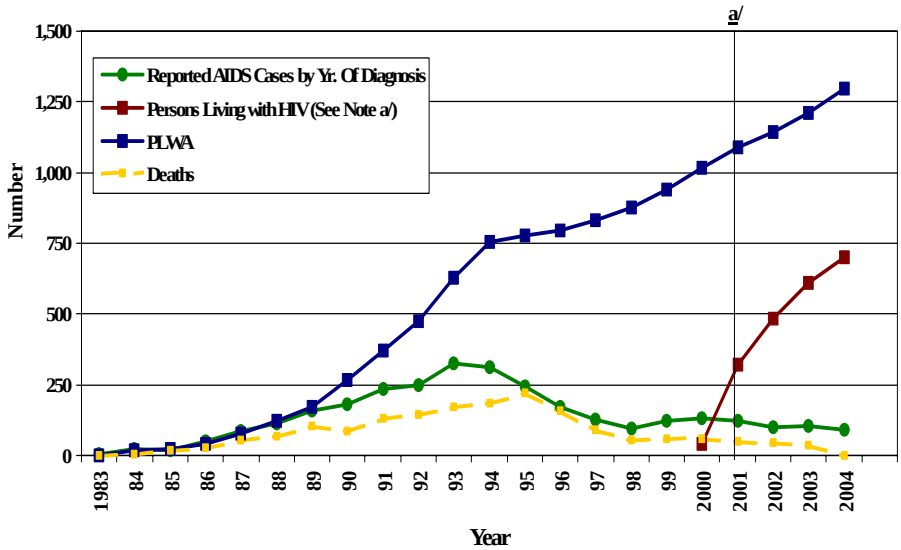
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Mid-Hudson Region had a prevalence of 0.17% (n=17), or approximately 1 in 588 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Mid-Hudson Ryan White Region [1/]

Figure 2

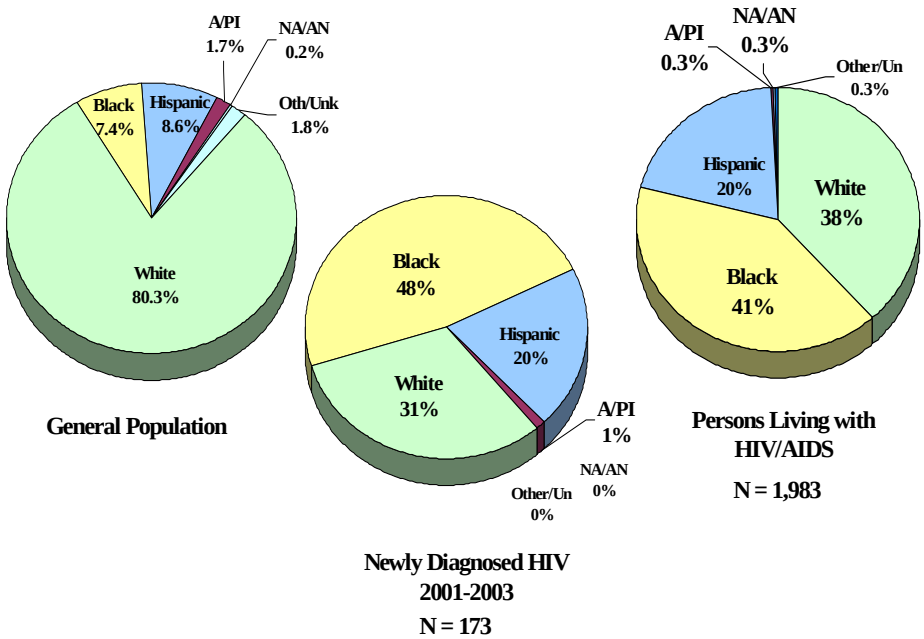
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*

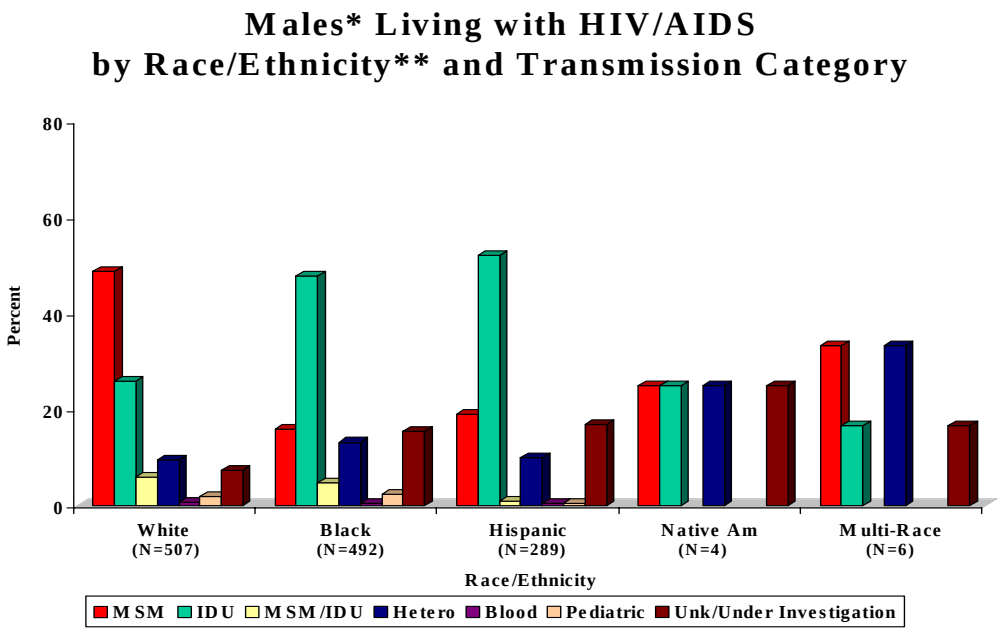


* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

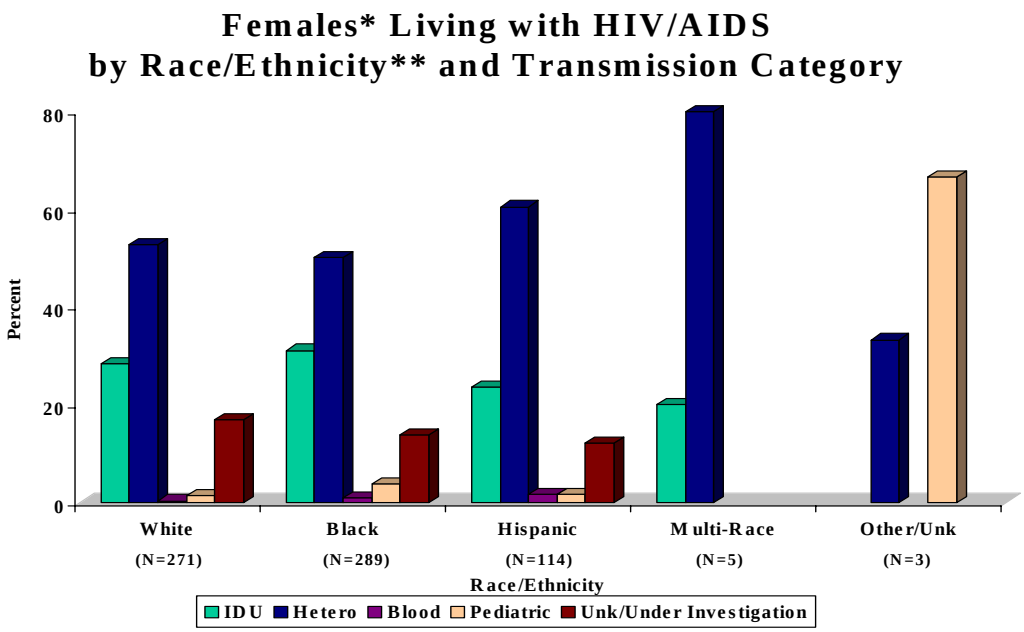
Epidemiologic Profile of Mid-Hudson Ryan White Region [1/]

Figure 4



**Asian/Pacific Islander data not included due to small cell sizes; there were no Other/Unknown cases.

Figure 5



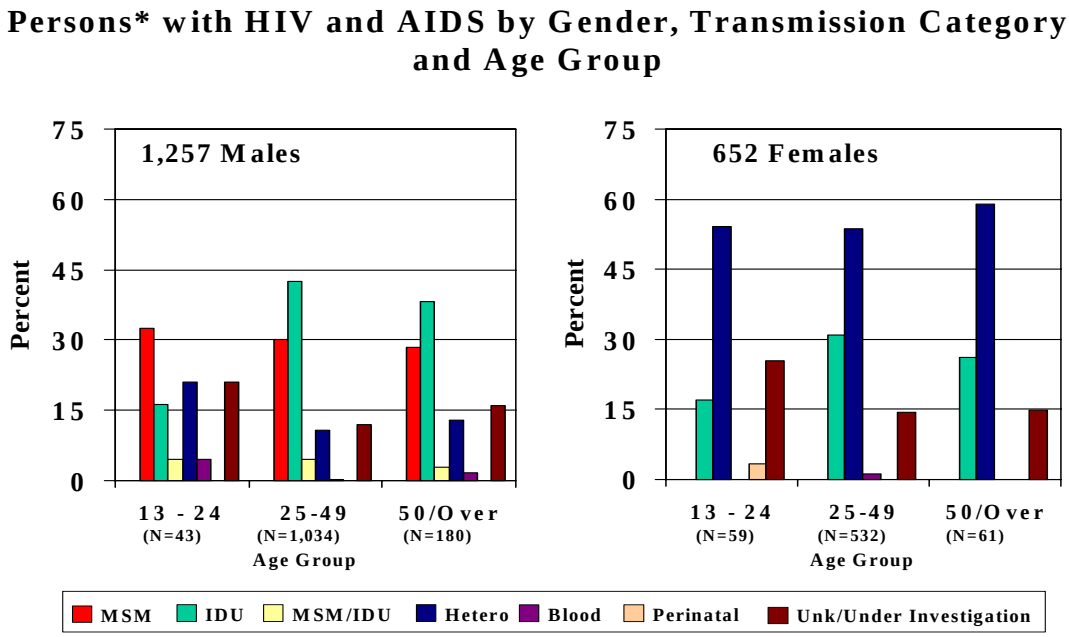
** Asian/Pacific Islander data not included due to small cell sizes; there were no Native American cases.

* Excludes Prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

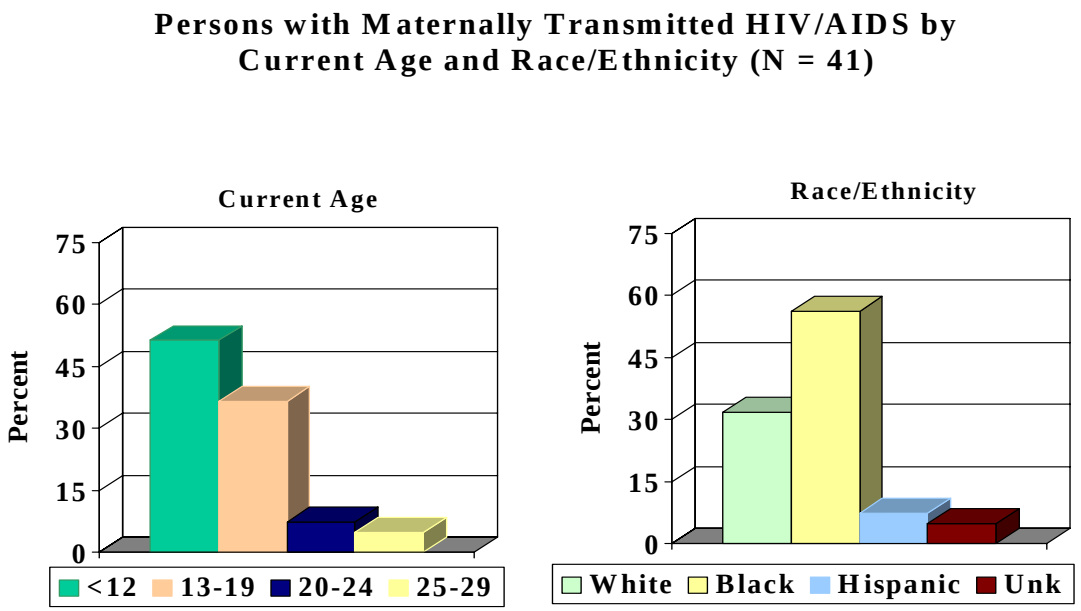
Epidemiologic Profile of Mid-Hudson Ryan White Region [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Nassau/Suffolk Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Nassau	686	709	1,507	1,533	3,765	3,812
Suffolk	745	764	1,498	1,525	3,712	3,772
Total	1,431	1,473	3,005	3,058	7,477	7,584

Childbearing Women:

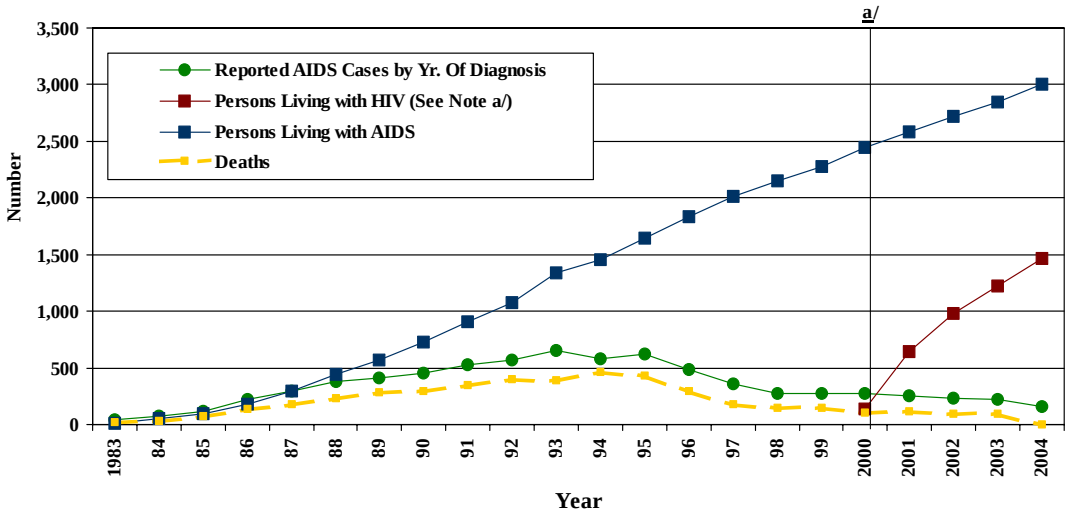
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Nassau/Suffolk Region had a prevalence of 0.09% (n=31), or approximately 1 in 1,111 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Nassau/Suffolk Ryan White Region [1/]

Figure 2

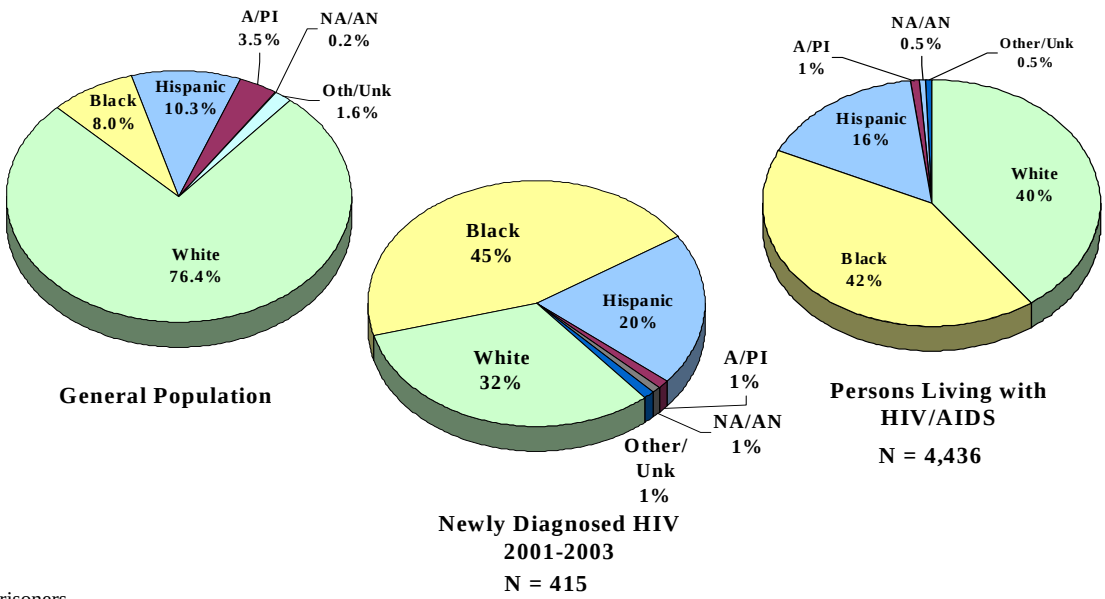
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes Prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Nassau/Suffolk Ryan White Region [1/]

Figure 4

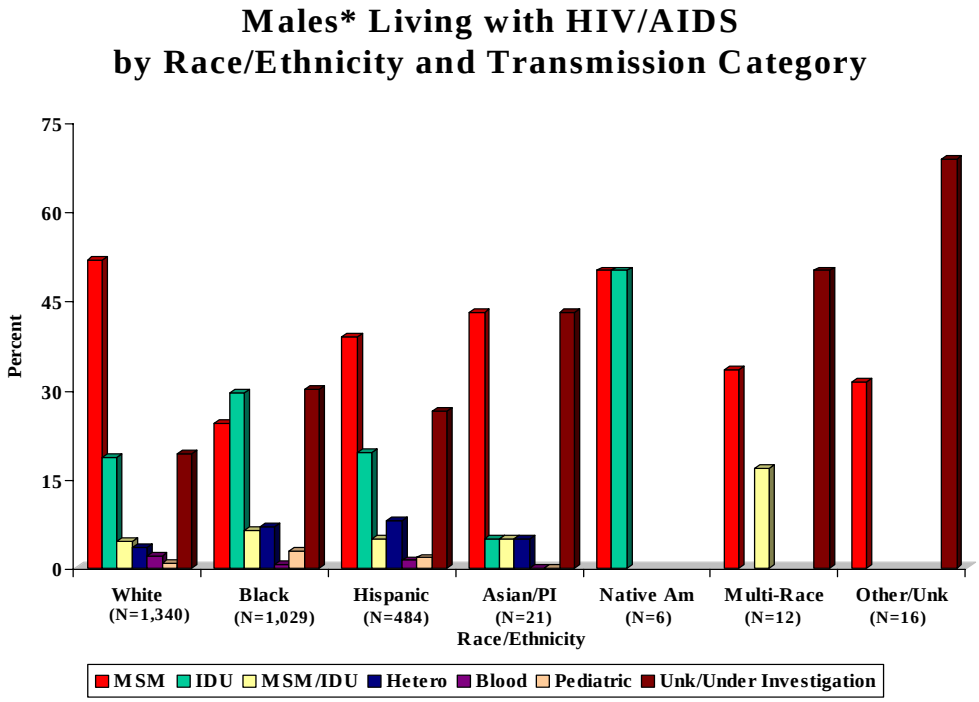
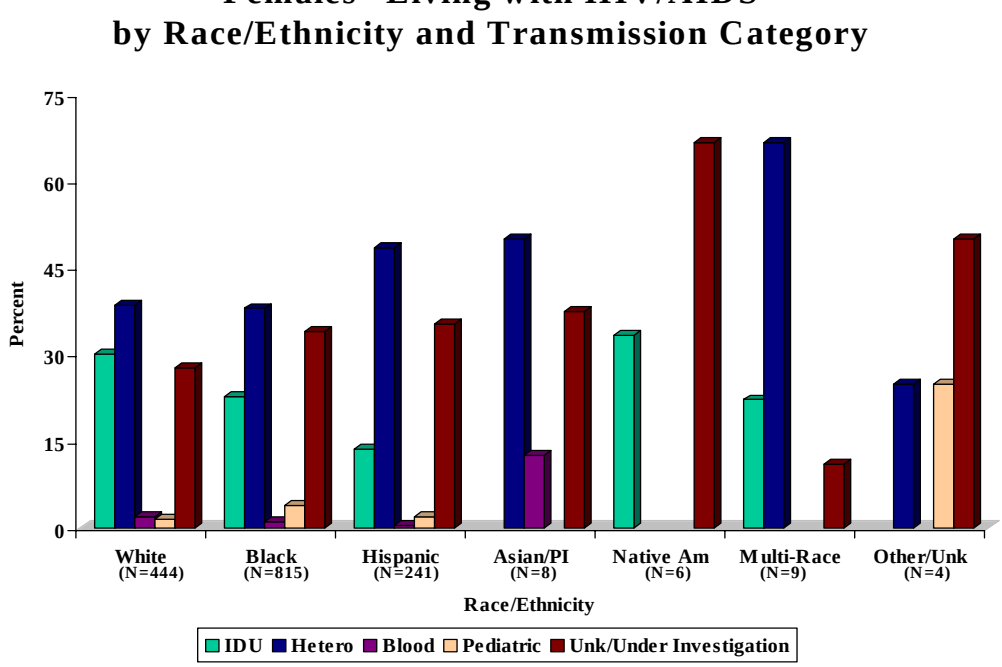


Figure 5



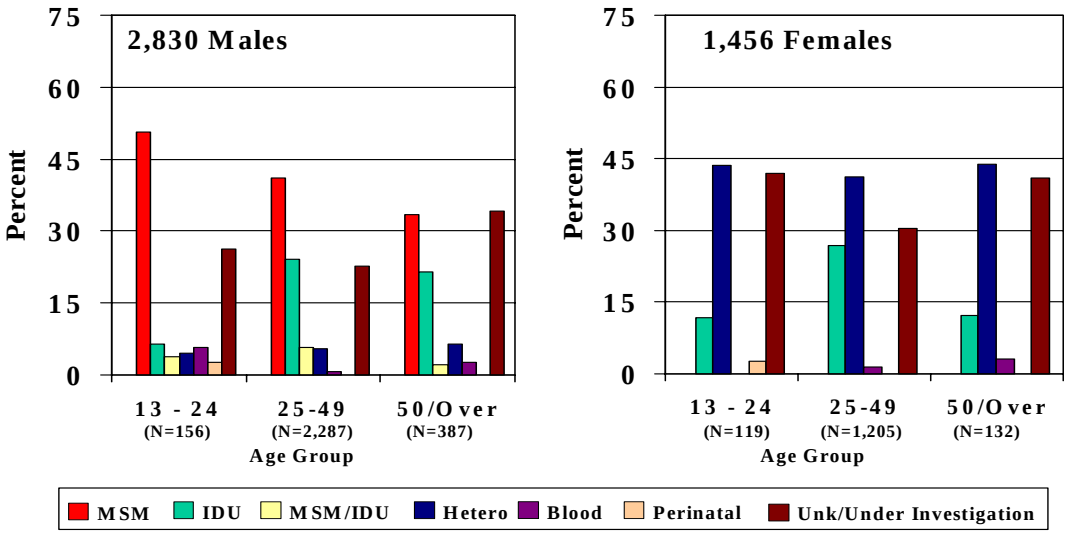
* Excludes Prisoners

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Nassau/Suffolk Ryan White Region [1/]

Figure 6

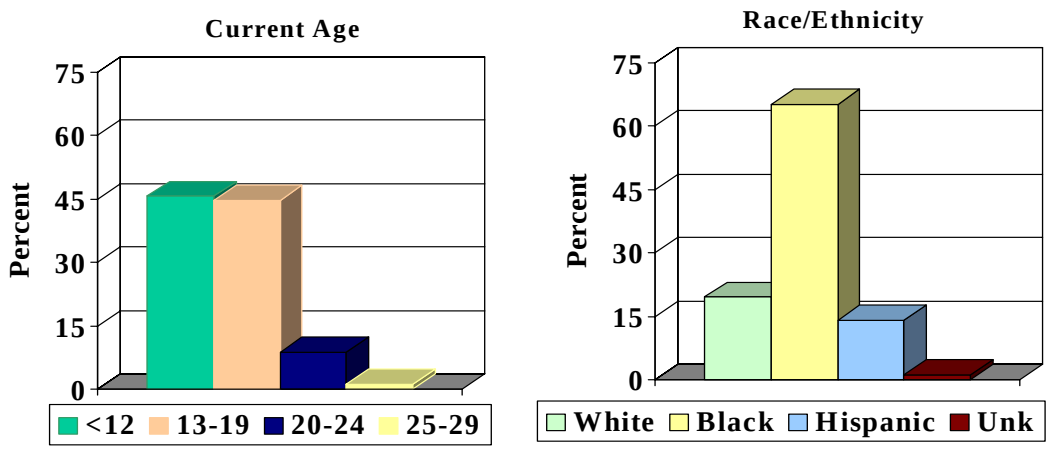
Persons* with HIV and AIDS by Gender, Transmission Category and Age Group



*Excludes prisoners; reported cases ages ≥ 13 years with known gender

Figure 7

Persons with Maternally Transmitted HIV/AIDS by Current Age and Race/Ethnicity (N=92)



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Rochester (Finger Lakes) Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Chemung	31	81	34	95	115	251
Livingston	15	101	31	103	67	201
Monroe	609	638	988	1,007	2,077	2,111
Ontario	20	21	35	36	57	58
Schuyler	2	7	2	4	12	14
Seneca	11	115	9	58	21	75
Steuben	17	19	26	26	72	72
Wayne	35	46	35	48	82	100
Yates	7	7	2	2	9	9
Totals	747	1,035	1,162	1,379	2,512	2,891

Childbearing Women:

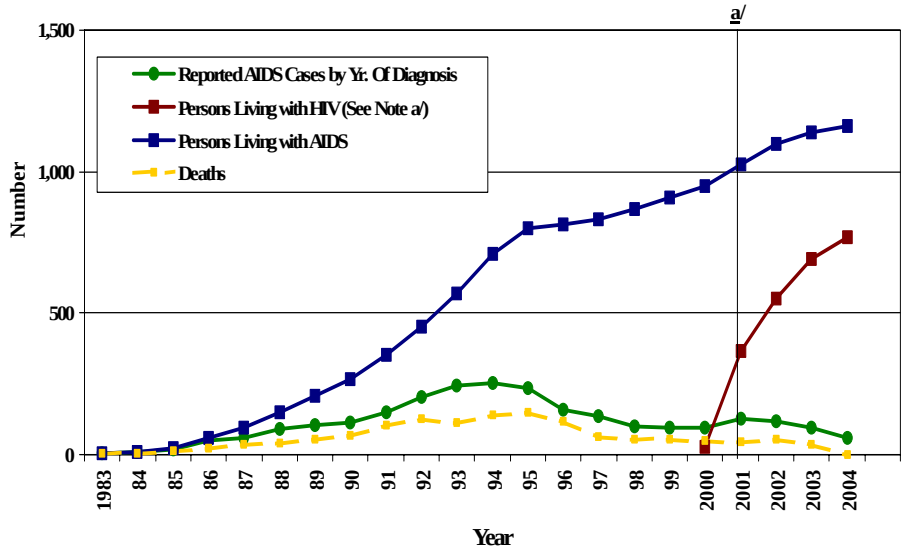
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Rochester Region had a prevalence of 0.11% (n=15), or approximately 1 in 909 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Rochester (Finger Lakes) Ryan White Region [1/]

Figure 2

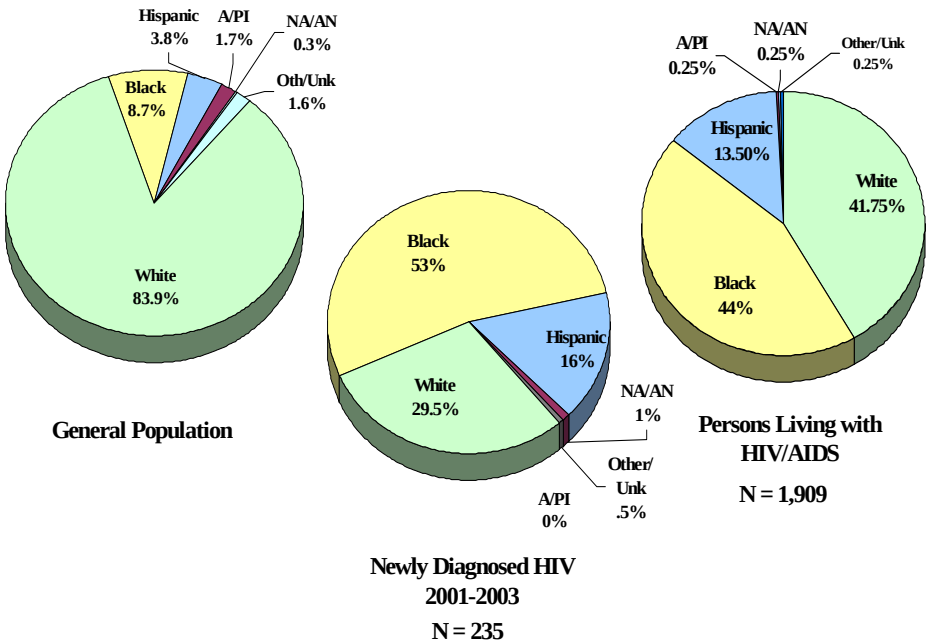
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Rochester (Finger Lakes) Ryan White Region [1/]

Figure 4

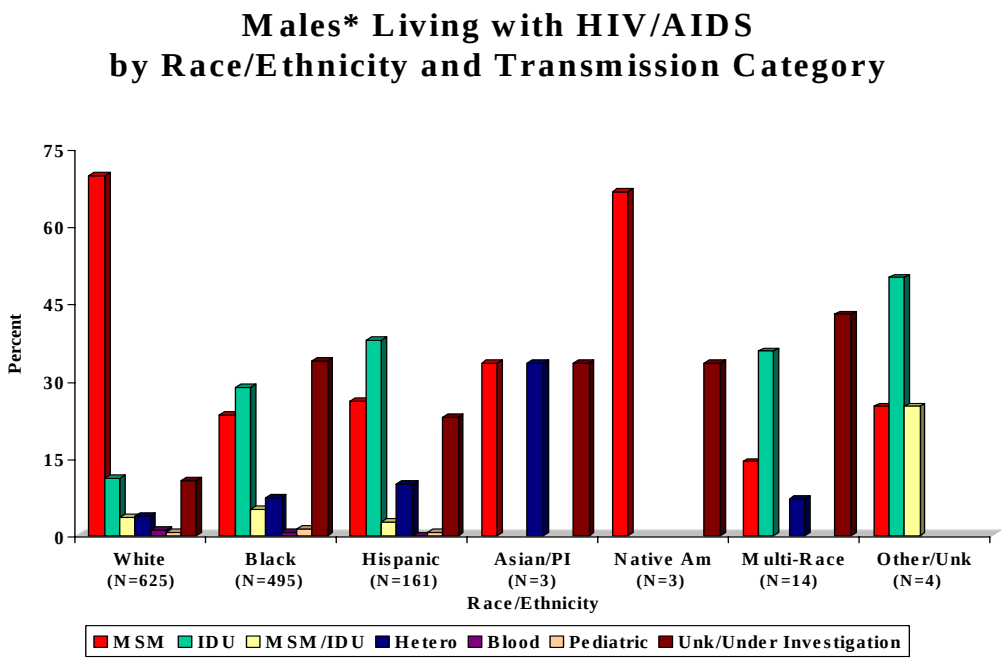
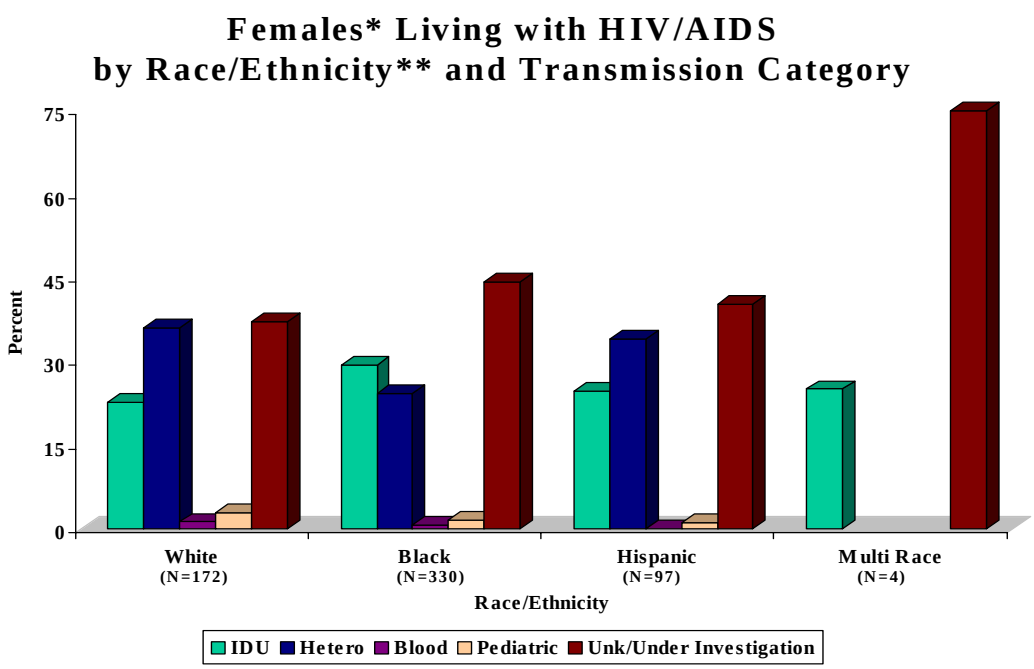


Figure 5



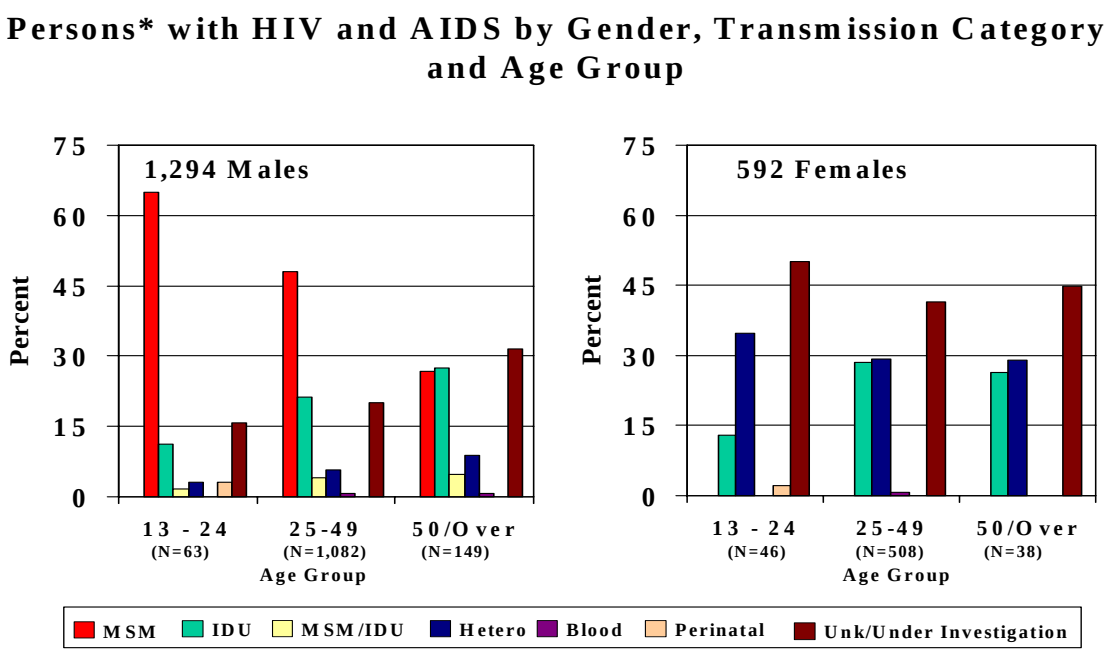
* Excludes Prisoners

** Asian/Pacific Islander, Native American and Other/Unknown data not included due to small cell sizes.

1/ Cases reported through December 2004 regardless of diagnosis date.

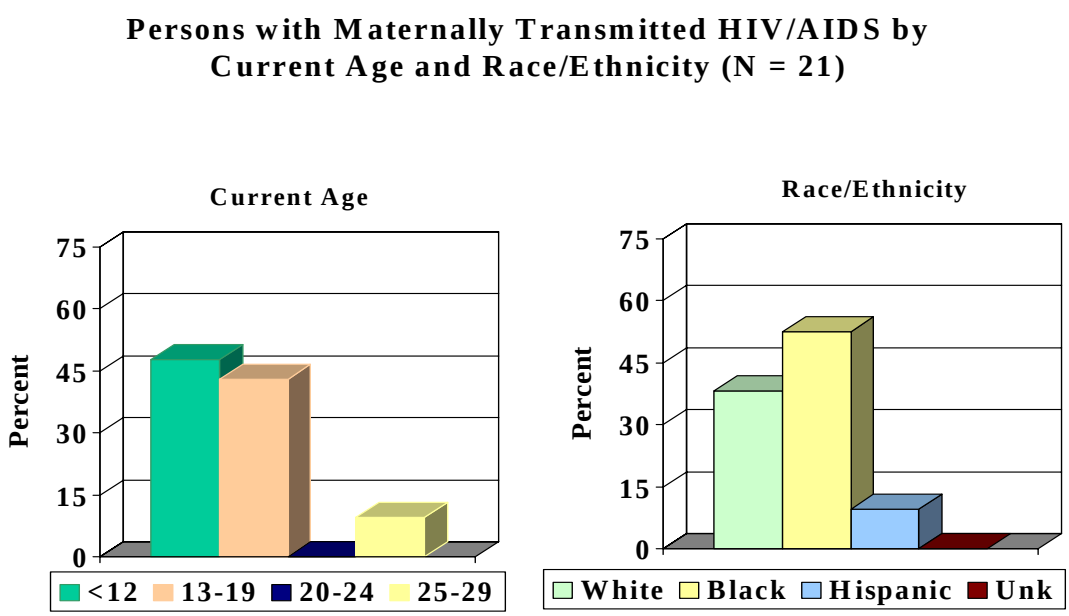
Epidemiologic Profile of Rochester (Finger Lakes) Ryan White Region [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Syracuse Ryan White Region [1/]

Figure 1

Persons Living with HIV and AIDS and Cumulative AIDS Cases

County of Residence at Time of Diagnosis	Living with HIV Infection		Living with AIDS		Cumulative AIDS Cases	
	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners	Excluding Prisoners	Including Prisoners
Cayuga	19	105	44	142	79	293
Cortland	6	6	9	9	21	21
Herkimer	14	14	14	14	32	32
Jefferson	26	197	37	171	73	282
Lewis	21	21	5	6	11	12
Madison	12	13	15	27	34	50
Oneida	108	367	163	480	350	923
Onondaga	285	293	479	490	1,061	1,077
Oswego	21	21	42	42	83	83
St. Lawrence	31	194	45	201	73	310
Tompkins	19	20	62	65	119	122
Totals	562	1,251	915	1,647	1,936	3,205

Childbearing Women:

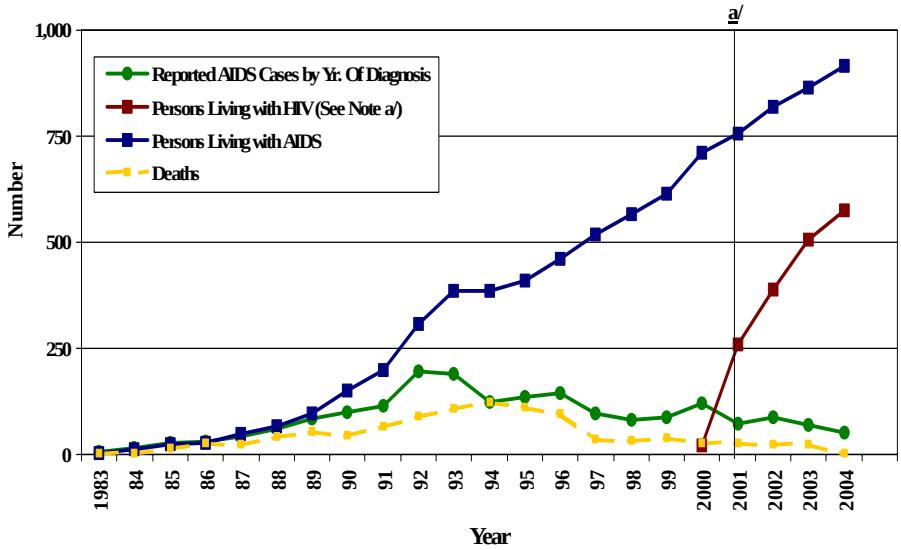
2002 data from the NYS Comprehensive Newborn Screening Program indicates that women giving birth in the Syracuse Region had a prevalence of 0.07% (n=11), or approximately 1 in 1,429 women giving birth had a positive HIV test result.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Syracuse Ryan White Region [1/]

Figure 2

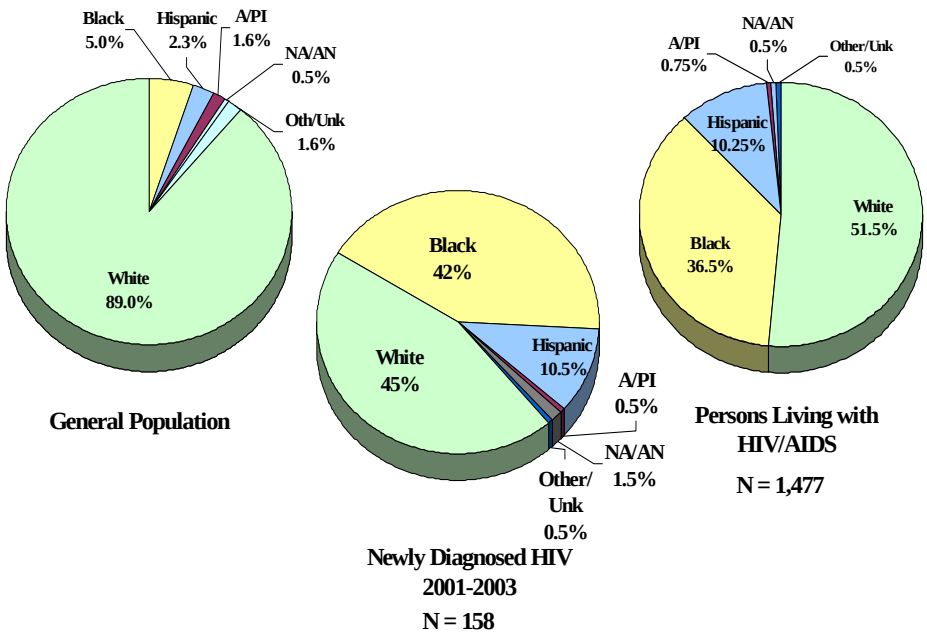
Reported AIDS Cases, Persons Living with HIV, Persons Living with AIDS, and Deaths[b/] 1983 through 2004*



a/ HIV named reporting in NYS started in 2000. This graph reflects the number of persons living with HIV who had been reported by the end of each year.
b/ Deaths from any cause for Persons with HIV/AIDS

Figure 3

Population Comparison: General Population, Newly Diagnosed HIV and Persons Living with HIV and AIDS*



* Excludes prisoners.

1/ Cases reported through December 2004 regardless of diagnosis date.

Epidemiologic Profile of Syracuse Ryan White Region [1/]

Figure 4

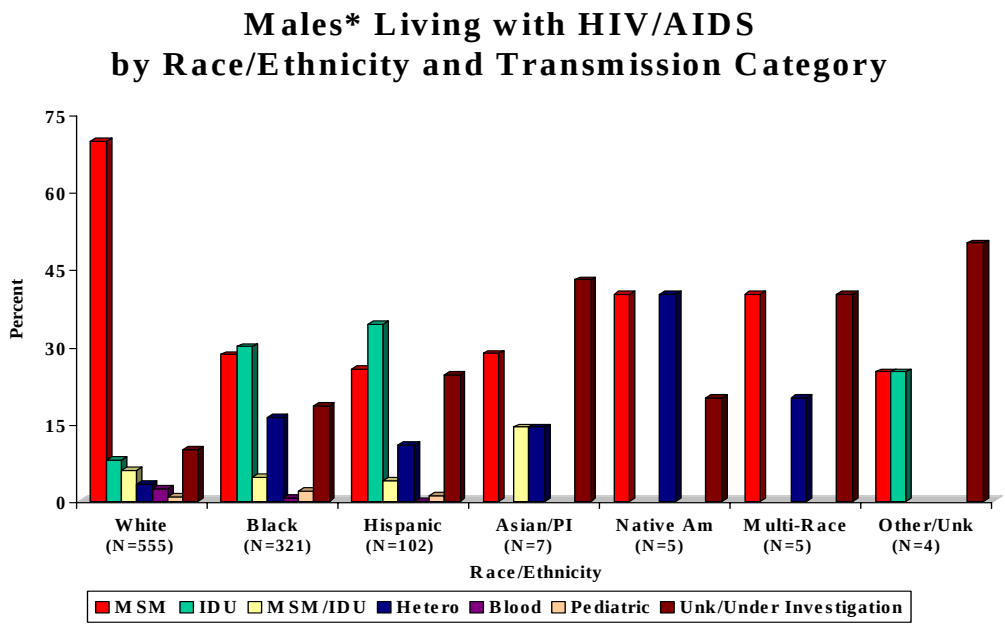
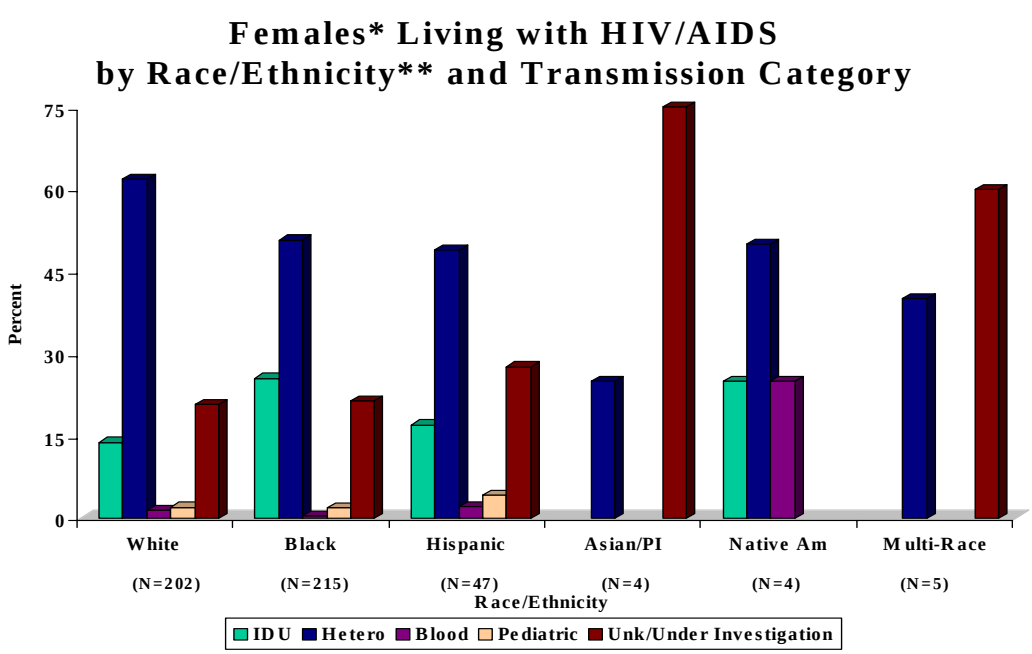


Figure 5



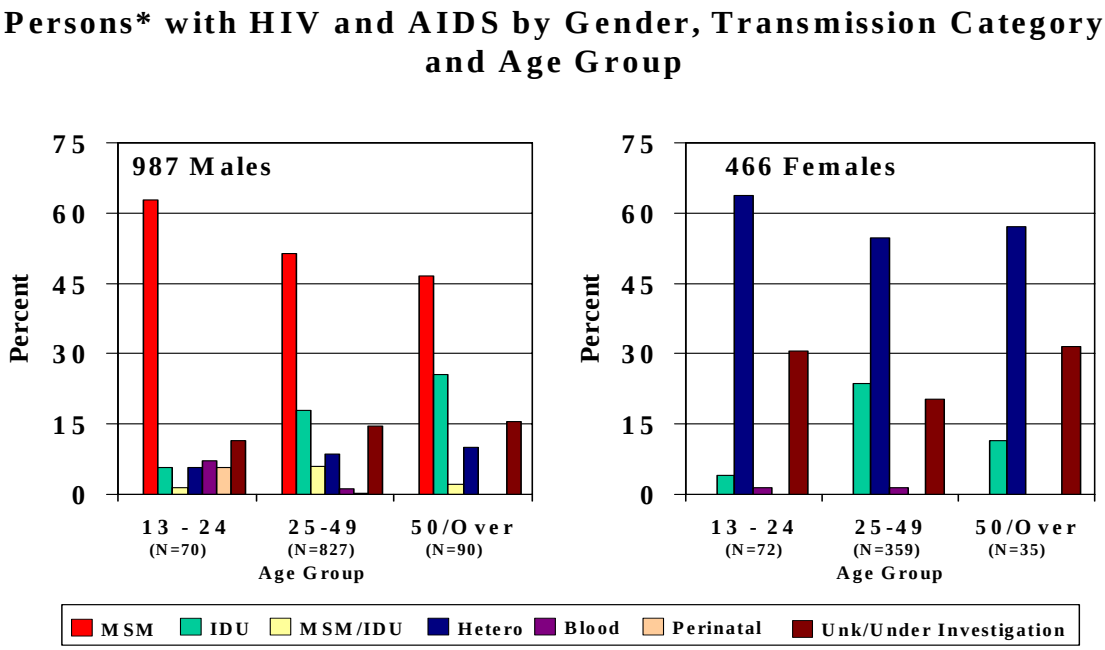
* Excludes Prisoners

** Other/Unknown data not included due to small cell size.

1/ Cases reported through December 2004 regardless of diagnosis date.

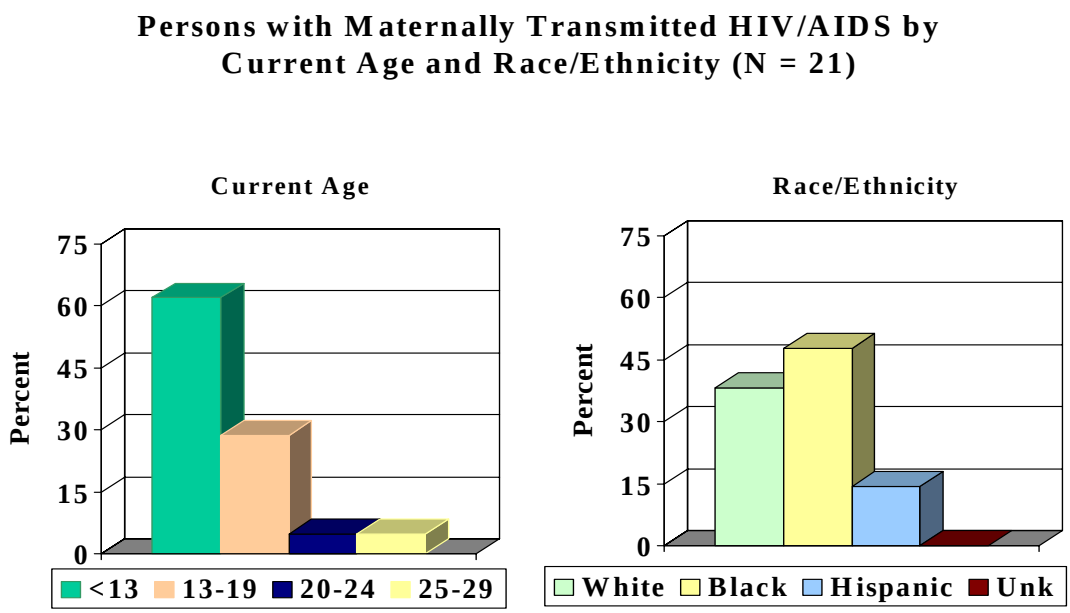
Epidemiologic Profile of Syracuse Ryan White Region [1/]

Figure 6



* Excludes prisoners; reported cases ages ≥ 13 years with known gender.

Figure 7



1/ Cases reported through December 2004 regardless of diagnosis date.

SECTION V:
ENVIRONMENTAL CONSIDERATIONS AND EMERGING TRENDS

This section briefly describes key environmental considerations and emerging trends that impact the HIV/AIDS epidemic in New York State. The issues identified, while broad and crosscutting, do not represent an exhaustive list. The HIV epidemic has dimensions that span the domains of public policy, medicine, socio-economics, social justice, and human relations. Each of these areas individually is subject to constant change, and their intersection has a dynamic influence on the course of the epidemic and responses to it. Planners, policymakers, clinicians, researchers and program directors, in both the public and private sectors, must be vigilant in assessing the environment and new trends, and in their willingness to join forces in combating HIV.

Growing Service Demands and New Mandates in an Era of Level and Decreasing Resources

The demand for HIV-related services is escalating due to infected individuals living longer and new infections continuing to occur. CDC and state initiatives in the last several years place great emphasis on identifying all HIV-positive individuals early in the course of infection and linking them to care and other services. For example, CDC launched a major new initiative in 2003, which includes making HIV testing a routine part of medical care and implementing new models for diagnosing HIV infection outside medical settings. CDC estimates that one in four New Yorkers living with HIV do not know they are infected. In 2005 the NYS Department of Health changed the regulations governing HIV testing and released a new *Guidance for HIV Counseling and Testing and Laboratory Reporting Requirements*. The intent is to significantly streamline the counseling and informed consent process in an effort to remove barriers to testing and care, as well as to provide more accurate information on the effectiveness of HIV treatment without compromising current statutory protections for confidentiality and informed consent. It is clear that such initiatives will result in more HIV-infected persons learning their status and seeking care and other services. Trends in New York State indicate that most new infections will occur among subpopulations with underlying health disparities, the uninsured and underinsured, and those without a medical care home.

While the demand is growing for publicly funded health care and support services, federal resources are not increasing. CARE Act funding levels have not matched the pace of escalating service needs and the increasing costs of providing these services. Contentious Federal Fiscal Year 2006 budget negotiations could result in a one or two percent across-the-board cut to health and human service programs, including the CARE Act, which would mean millions lost for support of CARE Act-funded services. Even before this reduction is felt, individuals in more than a quarter of the states have had limited access to life-saving combination therapy as their ADAPs are in crisis (e.g., closed to new enrollments, with waiting lists and limited formularies), and other states have had to eliminate or curtail service programs. New York State avoided the need for drastic cuts to its ADAP by implementing a series of cost containment measures and with an increased State appropriation in 2003 to supplement federal ADAP funds.

States and localities are also facing shrinking health care budgets, the continued rise in health care costs, and restrictions and cutbacks in State Medicaid programs. As a result of these budgetary restrictions, many State and local health departments, including those in New York, have had to critically review programs and staffing levels, and streamline operations to achieve maximum effectiveness with available funding.

Community-based organizations that provide case management and other essential "enabling" services that help growing numbers of HIV-infected clients meet immediate survival needs, access care, and stay in care have traditionally struggled to cover infrastructure costs that support service delivery. Diminishing resources and level budgets over the years are taking a toll on these community agencies; many are unable to retain trained staff and some have had to cease operations because of inadequate funding. Others are forced to consider programmatic and agency consolidations to reduce administrative and overhead costs in an era of flat funding.

Limited resources also negatively impact the ability of states and providers to comply with mandates for data collection and reporting, outcome evaluation and program accountability. Secure client level reporting systems, while ideal, require substantial investments in software development and maintenance, hardware, staff training, and technical assistance. Public funding for these efforts is inadequate to comply with the mandates for data and evaluation. New York State has developed a comprehensive quality management program that includes collection and analysis of data, performance measurement based on clinical care and support service standards and indicators, and quality improvement techniques. It is, however, increasingly difficult to maintain this effort without adequate dedicated resources.

Medicaid Reform

The Kaiser Commission on Medicaid and the Uninsured in its January 2005 paper on *Medicaid: Issues in Restructuring Federal Financing* (Document #129) notes that over the last 40 years, Medicaid has evolved to meet the health and long term care needs for one in ten Americans including people with low incomes, the working poor and their children, and the disabled. Compared to those covered by private insurance, individuals on Medicaid tend to be poorer and sicker**.** In New York State, Medicaid is the primary source of health care coverage for persons diagnosed with HIV or AIDS – approximately 65,000 are enrolled in Medicaid.

The growing federal budget deficit has led to attempts to limit federal Medicaid spending by decreasing matching payments, placing caps on spending or imposing mandatory percentage reductions to the program. The Administration has proposed modernization of Medicaid and a reduction of $45 billion in Medicaid spending over ten years. Details regarding modernization are not yet clear, but they may include proposals for a block grant or capped allotment. Advocates have voiced strong concerns that reductions in federal support for Medicaid could limit states' capacity to provide health coverage to low income families, respond to unpredictable situations, and support providers at levels that promote accessible and affordable health care. In March 2005, an amendment passed in the U.S. Senate that removed deep cuts to Medicaid from the Senate Budget Resolution and replaced it with a bipartisan commission to study Medicaid and make recommendations for reform. However,

as of late November 2005, harsh cuts to federal domestic health care and social service programs are still on the table; it is expected that negotiations on the final federal budget will begin in earnest in late November and early December. Advocates are working to ensure Congressional representatives understand the impact of such cuts on safety net programs such as Medicaid, Medicare, food stamps and housing aid.

There are pressures to reduce Medicaid spending at the State level as well in response to escalating costs and demands from counties to ease their financial burden relating to the local share of Medicaid costs. The final 2005-06 State budget includes some cuts to Medicaid that will take effect over the next year. New or increased co-pays were also approved for some services, as well as assessments on health care facilities. Other major items, such as the conversion of non-profit insurance companies and how the conversion funds will be directed, are still being negotiated.

Continuing Disproportionate Impact of the Epidemic on Communities of Color, Particularly Among Blacks and Hispanics

In 1981, the number of reported AIDS cases in New York State among persons of color was higher than among whites, and this has been true every year since. NYS AIDS case data from 1999 through 2004 indicate that 81.3 percent of all AIDS cases are among persons of color: 50.4 percent among African Americans, 29.2 percent among Hispanics, one percent among Asian/Pacific Islanders, and less than one percent among Native Americans. Persons of color are estimated to make up more than 77 percent of persons living with AIDS in New York State.

The continuing disproportionate impact on Blacks and Hispanics in New York State is clearly evident when analyzing recent HIV case reports and mortality data.

Although Blacks constitute about 14 percent of the New York State population, 50 percent of newly diagnosed HIV cases reported and confirmed through December 2004 were among Blacks, more than any other racial or ethnic group. About 64 percent of newly diagnosed HIV cases in women, and 43 percent of newly diagnosed HIV cases in men were Black. The overall HIV case rate for Blacks was about 11 times that for Whites and 2 times that for Hispanics. AIDS is the leading cause of death for Black men and women ages 25 to 44.

Hispanics constitute about 15 percent of the New York State population, but accounted for 28 percent of newly diagnosed HIV cases reported and confirmed through December 2004. About 25 percent of newly diagnosed HIV cases in women, and 29 percent of newly diagnosed HIV cases in men were Hispanic. The overall HIV case rate among Hispanics was about 7 times that for Whites. AIDS is the leading cause of death for Hispanic men and women ages 25 to 44.

Of newly diagnosed HIV cases reported through December 2004, Asians and Pacific Islanders represent about two percent and Native Americans less than one percent. Many believe that cases among these populations are undercounted due to lack of access to testing and care, misidentification of Native Americans by providers, as well as HIV-related stigma, language and cultural beliefs that present barriers to testing and care. The unique needs of Asians/Pacific Islanders and Native Americans are summarized in the Statewide Needs and Barriers section of this document.

It is important to understand how diverse these communities of color are. The New York State AIDS Advisory Council Report *Communities at Risk: HIV/AIDS in Communities of Color (2000/01)* (Document #42) indicates that every population consists of many subpopulations and every community of many culturally diverse individuals. Black New Yorkers have varied geographic origins from across the globe - from Africa to the Caribbean. Hispanic New Yorkers emanate primarily from Puerto Rico, the Dominican Republic, Cuba, Central and South America and Mexico. Subpopulations of Asians and Pacific Islanders come from many different countries and speak over 100 different languages. There are eight different Native American nations located within New York State, each with its own government and membership. Additionally, Native Americans in New York State are extremely diverse, representing more than 75 different nations from across the country.

This profile of New York's communities of color and the disproportionate impact of the epidemic on Blacks and Hispanics underscores how essential it is to tailor messages and strategies not only to racial and ethnic communities in general but also to those particular subgroups within communities thought to be at highest risk for HIV infection and those most difficult to reach with service interventions. The need for cultural and linguistic competence in HIV prevention, care and service provision was noted across New York State. The needs summarized in this document reflect local and regional assessments that are based on epidemiological profiles, key informant input, provider and consumer advisory groups, and surveys.

The State AIDS Advisory Council Report concludes: "Given the burden of HIV/AIDS in communities of color, resources and creative thought must be directed to the development and implementation of strategies that will most effectively counter this crisis. With more HIV-infected people living healthier, sexually active lives, there is an even greater need for improved HIV prevention and treatment services."

HIV Case Reporting

HIV became a reportable disease on June 1, 2000. The addition of HIV case reporting significantly increased the number of cases that would have been reported under the previous AIDS reporting system. New York State leads the nation in the number of HIV (not AIDS) cases reported to the Centers for Disease Control and Prevention with nearly 37,500 HIV case reports between June 1, 2000 and December 31, 2004. During the same time period, NYS reported nearly 30,200 AIDS cases.

The New York State HIV/AIDS Surveillance Report for 2003 indicates that among newly diagnosed HIV cases, there are a greater proportion of younger persons than among AIDS cases. Surveillance data indicates that statewide through 2003, 81 percent of persons newly diagnosed with HIV are persons of color.

Emerging High Risk, Underserved Subpopulations and Changing Service Needs

As the HIV epidemic in New York State continues to evolve and new trends become evident through HIV case reporting and special studies, it is clear that the health and human service delivery systems need to adapt to be responsive. These changes include both the subpopulations that must be targeted for prevention and services, as well as new services and/or innovative methods of delivery to meet needs. The following are examples of the challenges faced in confronting the HIV epidemic in this first decade of the new century.

- ***Late Diagnosis and/or Entry into Care*:**
  Preliminary data from the HIV surveillance system published by the New York City Department of Health and Mental Hygiene (NYCDOHMH) indicates that in New York City approximately one in four new HIV diagnoses are concurrent with an AIDS diagnosis. NYCDOHMH data indicates further that more than a third of newly diagnosed HIV cases have either a CD4 count of less than 350 at the time of HIV diagnosis or an AIDS diagnosis within one year of the HIV diagnosis. This data is particularly disturbing given the comprehensive continuum of HIV care and services in place in New York State. More research is needed to determine the demographic characteristics of these patients, their testing history, and why they did not access care earlier. This information is critical to conducting targeted outreach and making testing, care and services more accessible to individuals who are being diagnosed and/or entering care very late in the course of their infection. This data may underscore the need to focus on service delivery models that do not require the patient to cross the threshold of a hospital or clinic, (e.g., testing in community settings already serving high risk subpopulations), and care provided in storefront settings or on mobile medical vans.

- ***Care for Chronic HIV and Co-Morbidities*:**
  As HIV has become a chronic disease and infected persons live longer due to combination therapy, they are experiencing other medical problems relating to the aging process, long-term side effects of medications, and other co-morbidities such as hepatitis, tuberculosis, sexually transmitted diseases, cancer, heart disease, diabetes and mental illness. As a result, care providers must be vigilant in treating "the whole patient." Appropriate referrals to specialty care and close coordination with other disciplines are essential to ensure good communication and holistic care. HIV as a chronic disease underscores the need for proactive care coordination across clinical settings, case management to address the full range of patients' needs and foster communication among disciplines, and the "enabling" supportive services that help patients access and remain in care. HIV Program Directors also face the dilemma of stretching limited HIV resources to cover treatments for other diseases that HIV-

infected persons often confront, most notably hepatitis, TB and mental illness, since there are inadequate funding streams to cover this care for the uninsured.

- ***Integrating Prevention into Care and Other Services for HIV Positive Persons:***
  As a result of earlier identification of HIV and improved medical treatment, many more people are living with HIV and AIDS, a trend that began in the mid 1990s. In New York State there are over 105,500 persons living with HIV/AIDS based on reports received through December 2004. As a result, new strategies are being piloted to help persons with HIV practice behaviors that will stop further transmission of the virus. In 2003, CDC issued guidance on *Incorporating HIV Prevention into the Medical Care of Persons Living with HIV* (Document #132). This guidance notes that "medical care providers can substantially affect HIV transmission by screening their HIV-infected patients for risk behaviors, communicating prevention messages, discussing sexual and drug-use behavior, positively reinforcing changes to safer behavior, referring patients for services such as substance abuse treatment, facilitating partner notification, counseling and testing, and identifying and treating other sexually transmitted diseases (STDs)." Specific recommendations are detailed in the CDC guidance document. The AIDS Institute also encourages non-clinical providers to review their services and identify appropriate opportunities to promote HIV prevention with their HIV positive clients in a manner that is sensitive, effective and tailored to the unique needs of each person, and to provide assistance in notifying partners either directly or by referral to department of health notification assistance programs (CNAP and PNAP).

- ***Reaching Immigrant Populations:***
  There are special challenges in reaching and serving the many immigrant populations that reside in New York State. Immigrants from over 150 countries reside in New York City and other parts of the State. Recent immigrants have limited access to care as they most often face language and literacy barriers, and they may be suspicious of treatments that differ from their own cultural beliefs and practices. These individuals also confront financial barriers to care since they are uninsured and lack information about assistance programs for which they are eligible. In fact, immigrants who are not documented may avoid any contact with the health care system out of fear of arrest or deportation.

- ***Rise in STDs/HIV among Gay Men and MSM*:**
  There is a resurgence of Sexually Transmitted Diseases (STDs) and HIV among men who have sex with men (MSM), including men in the gay community and those who do not identify as gay, in New York State and across the nation. After steadily declining for ten years, the number of reported cases of primary and secondary (P&S) syphilis more than doubled in New York City from 117 in 2000 to 282 in 2001. In 2004, the rate of P&S syphilis cases continued to increase in New York City, though the rate of increase from 2003 (16 percent) was lower than that seen in recent years. As has been observed for the past six years, the majority of cases of P&S syphilis in 2003 occurred among men, most of whom report sex with other men. Approximately half of MSM P&S syphilis cases report HIV co-infection. In 2003, CDC issued a

report summarizing dramatic increases in syphilis rates in cities throughout the United States, particularly among gay and bisexual men. The high rate of HIV co-infection among these men was highlighted as a concern for HIV transmission. Complacency regarding HIV, some of it attributable to apathy or "prevention fatigue" and the misperception of HIV as a treatable chronic disease with few health or lifestyle consequences, has contributed to risky sexual behaviors -- and with these risky behaviors have come new HIV and STD infections.

- ***Alarming HIV Seroprevalence among Young MSM of Color*:**
  Particularly alarming are the results of the New York City arm of the national Young Men's Study conducted in the late 1990s (Document #157). Data from one phase of the study dealing with young MSM ages 15 to 22 indicate very high rates of HIV seroprevalence, especially considering the young age of the study participants: 18 percent among African Americans, 16 percent among MSM of mixed race, 9 percent among Hispanics, and 3 percent among Whites. Another phase of this study, dealing with young MSM ages 23-29, found the HIV seroprevalence rates to be 33 percent among African Americans, 25 percent among MSM of mixed race, 14 percent among Hispanics, and 2 percent among Whites. Data from the national study indicates that most of the young men testing positive were unaware they were infected and a majority believed they were at low risk even though half reported having unprotected sex with another man in the previous six months. The Young Men's Study led to a unique collaboration among community-based organizations in New York City serving young MSM, particularly young men of color, and the State and City Health Departments, to conduct outreach by specially trained peers to address immediate health and social service needs, HIV testing, and linkage to care and other services.

- ***HIV Impact from Use of Crystal Meth and Other Drugs*:**
  Numerous studies, nationally and in New York State, are documenting methamphetamine use, particularly among gay men and other MSM, noting the increase in use and its relationship to high-risk behaviors. This drug, commonly called "crystal meth," is often used to initiate, enhance and prolong sexual encounters; its disinhibiting effects often lead to unsafe sexual behaviors. Research indicates that methamphetamine is frequently used with other drugs, resulting in increased risks and adverse health outcomes. Since this drug can be administered in numerous ways, including by injection, it can also increase transmission by shared injection equipment. While most research focuses on the use of crystal meth in gay/MSM communities, it is also used outside of those communities. Methamphetamine is the most recent of many drugs known to have both prevention and treatment consequences: HIV transmission increases, treatment adherence decreases, and viral loads rise. Emergence of this latest recreational drug reinforces the need to employ a comprehensive approach to protect the public health, including: outreach and education regarding crystal meth/all drug use and the relationship to HIV transmission and overall health status; a continuum of drug treatment options; and linkage to a full range of health and social services.

- ***Dramatic Increase in Reported Cases Among Women, Particularly Women of Color:*** In 1986, women represented 12 percent of newly reported AIDS cases in New York State. By 2003, this percentage climbed dramatically to 34 percent, compared to 27 percent of new cases nationally. Black and Hispanic women account for 29 percent of the New York female population. However, together they represent 86 percent of New York women living with HIV/AIDS. AIDS cases are also reported among Asian/Pacific Islander and Native American women despite the reality that cultural barriers prevent many women in these communities from being tested and diagnosed. Surveillance data indicates that almost all women contract HIV through heterosexual contact or injection drug use. One-quarter of female HIV cases attributed to heterosexual contact are due to sex with an HIV-infected injection drug user. In addition, men who consider themselves heterosexual but have male sexual partners (a phenomenon referred to as being "on the down low") also put women at risk for HIV and other sexually transmitted diseases. Innovative outreach is needed to ensure that women are aware of their risk and connected to the continuum of HIV services.

- ***HIV-Infected Babies Reaching Adolescence and Beyond*:** The pediatric HIV epidemic has changed dramatically since the mid-1990s due to the introduction of antiretroviral prophylaxis against perinatal transmission and advances in the medical management of HIV infection in children. Significantly fewer HIV-infected babies are being born, and the children who are infected are living longer, healthier lives and aging to adolescence and beyond. As a result, pediatric HIV care programs have had to change their services to address the needs of these children as they become adolescents, and youth-oriented care programs have had to ensure their care settings are welcoming and responsive to the special needs of this group of young people, infected since birth. These programs must meet the complex medical management needs and the unique psychosocial and educational support needs of these children as they grow and develop with HIV and reach the age where they are dealing with issues of sexuality, chronic disease, and bearing children of their own.

- ***AIDS Among Persons 50 and Over:*** Also evident from the data is the significant percentage of individuals living with AIDS who are age 50 or older. As noted in the paper *Public Health and Aging: HIV/AIDS and Older Adults – New York State, 1980-2002* (Document #128), AIDS cases diagnosed among individuals aged 50 years or older totaled 20,600, 13 percent of the state's 157,000 cumulative AIDS cases through December 2002. The authors note further that of the estimated 61,900 individuals presumed to be living with AIDS in New York State, 12 percent are aged 50 or older. Over three-quarters are persons of color; 76 percent are males and 24 percent are females. This data refutes the misperception that HIV-infected older adults are predominantly gay white males who benefited from treatment and who have aged into this group. This information points to the need for effective HIV prevention, primary care and supportive services for the diverse population of older New Yorkers, many of whom have other health care needs that must be met, and for integration with other programs that serve seniors.

Rapid Testing, Treatment Adherence and Resistance Testing

Since 2003**,** rapid testing techniques to identify HIV antibodies have significantly expanded the horizons for conducting testing. Techniques that allow for fingerstick and oral fluid testing, with preliminary results available within 20-30 minutes, have prompted more persons to seek testing and have allowed testing to be done in settings where it was not previously feasible, such as community-based agencies, health fairs, and storefront settings. AIDS Institute data indicates that most persons prefer rapid testing techniques and many previously untested individuals sought testing because test results would be provided at that same visit. While New York State has made rapid testing widely available in State Department of Health and New York City Department of Health and Mental Hygiene-operated testing sites, the full potential of rapid testing has not yet been realized in private physicians' offices, clinics and hospitals.

It is now well documented that non-adherence to HIV treatment regimens can result in an individual patient developing drug resistant strains of HIV. Clinical guidelines address the need for provider education of HIV-infected patients regarding the importance of adhering to medications and avoiding unprotected sex and sharing injection drug equipment that may expose the patient to other strains of HIV that may be drug resistant. When drug resistant strains are present, one or more medications or classes of medications are not effective at controlling the virus, thus limiting treatment options. The clinical guidelines also provide guidance regarding resistance testing so that clinicians have the information needed to tailor the treatment, from the currently available regimens, to most effectively treat the patient.

Stigma and Discrimination

Stigma and discrimination, present since the emergence of the HIV epidemic, continue to play a role in limiting access to care and other services. HRSA, in its August 2003 newsletter, notes that "HIV-related stigma refers to unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as their loved ones, associates, social groups, and communities. Stigma is rooted in prejudices involving gender, sexuality, illness, and race."

In New York State, the HIV Confidentiality Law enacted in 1987 included provisions to protect the privacy of HIV infected persons with the intent of minimizing the effects of stigma and discrimination. That statute, as well as numerous initiatives to provide HIV-related information and education, to develop diverse community leadership on HIV/AIDS issues, and to support specific efforts that prevent and counteract discriminatory acts through partnerships with the State and New York City Offices of Human Rights and with community-based anti-violence projects, has led to increased understanding and tolerance. However, continued vigilance and multiple interventions at both policy and program levels are needed to counter the effects of stigma and discrimination.

Changes in Medicaid and Medicare Coverage of HIV Care

As New York State moved to implement managed care plan coverage for its Medicaid enrollees in the mid-1990s, the AIDS Institute convened a broadly representative planning

group to develop the concept of HIV Special Needs Plans (SNPs) -- Medicaid managed care plans specifically designed to serve Medicaid recipients with HIV/AIDS and their children. The objective was to provide a managed care option that would improve access to high quality health care as well as essential supportive and enabling services, building on the comprehensive continuum of HIV services developed in New York State since the late 1980s. This bold initiative, the first of this scope in the nation, focused on the New York City and Metropolitan New York Region where 30,000 to 40,000 Medicaid recipients with HIV/AIDS and their children reside.

Currently, three SNPs are operational in New York City. Voluntary enrollment to date totals just under 1,600. All operational plans experienced enrollment at a rate slower than originally projected. Outreach and educational efforts have been increased to ensure potential enrollees and providers understand the SNP model and benefits.

In 2004, legislation was enacted at the federal level — the Medicare Modernization Act (MMA) — providing a prescription drug benefit under Medicare. As implementation begins, concerns persist about how the law will affect drug coverage for HIV-infected persons who are "dually eligible" for Medicare and Medicaid. At least 50,000 Americans and an estimated 8,000 – 10,000 New Yorkers living with HIV/AIDS are dually eligible for both programs. Medicare is the primary payer, with Medicaid filling in the gaps and "wrapping around" Medicare coverage. The law forbids states to use federal Medicaid funds to pay for treatment and cost sharing that is not covered by the new drug benefit. However, New York State law requires Medicaid to provide the same service package to all eligible recipients. This means that New York State Medicaid, at State and local expense, must offer the same drug coverage to dually eligible individuals as it does for Medicaid recipients. In addition, assistance must be provided to enrollees in the New York State AIDS Drug Assistance Program (ADAP) who are eligible for this new benefit to ensure they access the most comprehensive drug coverage available to them.

There is also concern that private plans might have formularies that will not include all antiretrovirals and other lifesaving medications needed by people with HIV/AIDS, since these plans can choose to cover only two of the many drugs in each class. However, the final regulations governing the MMA require plans to assure that in the construction of their formularies they do not deter certain classes of individuals, such as persons with HIV or mental illness, from the plan. Specifics will not be known until the private plan formularies are established, which is expected to be in the fall of 2005.

Policymakers at the State level and advocates continue to analyze the federal MMA regulations and work with federal officials to ensure that prescription drug coverage for HIV-infected New Yorkers is not diminished.

Debate regarding "Medicalization" of Ryan White CARE Act-Funded Services

The CARE Act is intended to ensure comprehensive health care and support services for individuals living with HIV/AIDS. Unfortunately, due to lack of sufficient resources, disparities in funding and varying services available through other public health payors from state to state, services for HIV-infected persons differ within and between states.

As a result, there is an escalating debate on the range of services provided with CARE Act funds, with some calling for establishing a set of core medical services available to all CARE Act clients regardless of residency, or "medicalization" of CARE Act services. Thus far, through a mandate in the Title II application guidance, HRSA has defined core services to include primary care, medications, mental health services, substance abuse treatment, dental services and case management, encouraging states to cover these services as a priority.

While states should be encouraged to fund and ensure access to medical services consistent with Public Health Service guidelines, there are dangers in defining a limited core set of services. First, in New York State, many HIV-infected individuals have incomes below or near the poverty level. Support services such as housing assistance, food and nutrition services, transportation and childcare services are absolutely essential elements in helping these HIV-infected persons access care and remain in care. Second, legislators may interpret a core set of services as the only services that are necessary, endangering public support for these "enabling" services that keep people in care. Third, establishing a core set of services could lead to a major redistribution of existing funds among the states leaving many people living with HIV/AIDS without access to the life sustaining services they previously received. Lastly, mandated core services at the national level does not, and cannot, recognize the variations among states in currently funded services, and would likely lead to duplication of some services available through other payers, and create gaps in other areas.

New York State has clearly stated that the CARE Act must continue to support a wide range of services, and that decisions regarding the services to be supported with CARE Act funds must be made, within the parameters set by legislation, at the local level, based on need and availability of other resources.

Status of Ryan White CARE Act Reauthorization

As this document goes to print, reauthorization of the Ryan White CARE Act, which expired on September 30, 2005, has not occurred due to Congressional focus on other matters. It is important to note the while reauthorization has not occurred, the program continues under the existing legislation with budget appropriations. The timeline for reauthorization is not clear at this point although some Congressional staff predict a bill will be passed during Spring 2006, with reauthorization occurring by September 2006.

In late July 2005, the U.S. Department of Health and Human Services issued principles regarding CARE Act reauthorization. The NYS Department of Health has gone on record expressing deep concern about many of those principles. In a letter to the Secretary of Health and Human Services, Commissioner Antonia Novello stated that "while New York State supports several of the principles in areas where we have been a national leader, among them reporting HIV cases as well as AIDS cases and streamlining and simplifying HIV testing, some of the proposed principles, if enacted, will have devastating consequences for people living with HIV and AIDS in New York State and other states with high HIV prevalence. This letter expressed strong concerns about four areas:

1. "The proposed Severity of Need for Core Service Index (SNCSI) will revise funding formulas to take into account the availability of other resources, including local, state, federal and private resources. This approach will disadvantage states like New York that have devoted substantial state resources to caring for residents with HIV and AIDS and will serve as a powerful disincentive for jurisdictions to allocate additional local resources for HIV/AIDS services. In a growing epidemic with escalating costs, this strategy challenges the foundation of fiscal and programmatic partnership already in place between states and the federal government. In addition this principle suggests that the CARE Act is responsible for differences in access to care throughout the country, but such variations are large attributable to differences in the resources each state provides for the care of its residents with HIV disease. The CARE Act should not be viewed as the mechanism for equalizing these differences in commitments by states."

2. "The proposed requirement that 75% of funds be used exclusively for core medical services is inconsistent with the original intent of the CARE Act to give states the flexibility to respond as they see fit to their local circumstances and needs. Since CARE Act dollars are payer of last resort, this approach will further disadvantage states like New York, most heavily impacted by HIV/AIDS, that have devoted significant state resources to support medical services. The proposed principle appears to be inconsistent with the leadership role of the states in determining the best use of both state and federal funds to meet locally defined needs. It is through such local control and determination that the best use of funds can be achieved, as it has been consistently in New York for many years."

3. "With the proposed principle for determining the Title II funding formula, New York stands to suffer a disproportionate reduction in funding. In Title II base formula awards, states receive partial credit for cases in city Title I areas in recognition of the role of the state in effectively coordinating a statewide response to the epidemic. Further, as written, this principle suggests that fair and equitable distribution of CARE Act funds can be achieved through Title I and Title II formula revisions, thus disregarding the role of other titles, including Title III, Title IV and Part F, in the apportionment of CARE Act funds among jurisdictions. Any meaningful national assessment of equity in terms of the distribution of CARE Act resources must include funding from all titles in all states and territories."

4. "The proposed funding principles call for the elimination of a 'hold harmless' provision that limits the loss of resources to a jurisdiction over time. This strategy would create a situation that would destabilize existing services and prevent continuity of care for people with HIV and AIDS. With no ability to control for or anticipate the amount of funding from one year to the next, service providers would be unable to plan for and provide services. While New York supports revisions to the Title II hold harmless clause, the provision must be retained to avoid shifts in funding that would compromise services for persons living with HIV and AIDS."

The Commissioner closes her letter urging the Secretary to "consider other reauthorization strategies, such as those developed by the National Alliance of State and Territorial AIDS Directors (NASTAD). New York worked in partnership with other states in the development of NASTAD reauthorization proposals that reconcile CARE Act issues in an equitable manner…We are seeking continued federal commitment to a process whereby states most affected will maintain federal support proportionate to the extent of their epidemic."

Additional Environmental Considerations and Trends Raised at the SCSN Community Forums

The following additional issues raised by Community Forum participants may impact the priority placed on the HIV/AIDS epidemic and the support it receives at the national and state levels:

- Massive relocation of Americans from the Gulf Coast following Hurricane Katrina. While the exact number of relocated persons is not known, it is estimated that as many as one million people cannot return to their homes for months to come. While most evacuees are spread throughout the South, almost every state has accepted some, including New York. A November 2005 news report from WNYC in New York City indicated that almost 2,500 evacuees came to New York, and while some have moved in with family members or were able to go back home, hundreds more are still living in hotels and waiting to see if they can make a new start in New York, but government assistance programs have been slow to respond to the need for permanent housing and jobs.

- The number of HIV positive Katrina evacuees is also not known, but it is known that they face many challenges, as documented in an article from "The Body," an internet HIV/AIDS resource. In a special report from this source on the hurricane's effect on the AIDS community, it is noted that most evacuees probably were not able to take their HIV medications with them when they left. Even if they did, an additional supply would soon be needed. Without identification, it is difficult for ADAP, Medicaid or private insurance to meet this need. The reports points out "the risk is that evacuees will run out of some medications and end up taking only part of their regimen, risking the creation of HIV drug resistance, which would dramatically limit their future treatment options." State ADAPs that step up to the plate and meet the medication needs of displaced PLWHA will need additional federal assistance to cover unbudgeted costs. In addition, grant-funded programs meeting the needs of uninsured HIV infected evacuees may also need additional resources to cover costs.

- Growth of the federal deficit due to wars in Iraq and Afghanistan, costs of homeland security, and costs associated with hurricane relief/reconstruction and aid for other major natural disasters such as the Pakistan earthquake, may contribute to a reticence to increase, if not slash, domestic spending.

- The diversion of limited public health resources to other health threats including Avian Flu, West Nile Virus, Hepatitis, diseases borne by people fleeing hurricane damaged areas, cryptosporidium, and other STDs will ultimately impact the attention directed to HIV prevention, care and support. This may also exacerbate gaps in critically important public health interventions directed to people engaging in high risk behaviors who do not perceive themselves to be at risk of HIV and are not aware of their status.

SECTION VI:
SPECIAL POPULATIONS

The following special populations are identified in the source documents informing this report, and continue to require focused attention relative to planning, priority setting and resource allocation.

As a backdrop to this Section, it is critically important to note that among all special populations in New York State, persons of color, particularly Blacks and Hispanics, constitute the majority of HIV infected persons. Therefore, needs assessment processes must reflect the unique characteristics and needs of disproportionately affected Blacks and Hispanics, as well as other communities of color — Asian and Pacific Islanders and Native Americans. All program models, service designs and implementation plans must be culturally competent in order to reach and engage diverse subpopulations within communities of color, emanating from ethnic and cultural differences, as well as variations in socioeconomic status, religious beliefs, and sexual orientation.

Substance and Alcohol Users

Substance abuse drives the HIV epidemic in New York State. As of December 2004, nearly 63,000 AIDS cases among injection drug users (IDUs) have been reported; an additional 4,700 cases are among MSM/IDUs. Together these cases represent 42 percent of cumulative AIDS cases in NYS. An additional 18,000 heterosexual AIDS cases have been reported; almost 80 percent of those cases are women. At least 36 percent of female AIDS cases attributed to heterosexual contact are due to sex with an injection drug user. Of the 2,320 AIDS cases reported among children under the age of 13, about 52 percent acquired HIV from a mother who injected drugs or who was the sex partner of a drug injector.

There is, however, some encouraging news. The percentage of new AIDS cases attributable to injection drug use has declined since it peaked in the early 1990s. In 1992, IDUs accounted for 53 percent of all AIDS cases diagnosed; this percentage dropped to 18 percent in 2004. In addition, the proportion of IDU cases appears to be dropping among reported HIV cases, although it is not yet possible to draw conclusions because risk factors are still under investigation in over 40 percent of the cases. Further, HIV data from over 18,600 HIV tests conducted through the AIDS Institute's Substance Abuse Initiative shows a decline in seroprevalence, from 7.3 percent in 1996 to 3.6 percent in 2004.

The twin epidemics of HIV/AIDS and substance use have had a disproportionate impact on communities of color in NYS. Nearly 85 percent of IDU cases are among people of color, (48 percent Black; 36 percent Hispanic; less than one percent Asian/Pacific Islander; less than one percent Native American). The New York State Office of Alcohol and Substance Abuse Services (OASAS) reports that over 55 percent of persons entering drug and alcohol treatment are of color.

OASAS estimates that up to 285,000 New Yorkers are at risk of HIV infection due to current or former substance abuse. It is important to note that while injection drug use directly transmits the virus, non-injecting poly drug use, such as crack/cocaine, and alcohol abuse play a major role in high-risk sexual activity, including trading sex for money or drugs. Numerous recent studies have documented the emergence of a new recreational drug, methamphetamine ("crystal meth"), and its relationship to high-risk behaviors. This drug is often used to initiate, enhance and prolong sexual encounters and its uninhibiting effects lead to unsafe sexual behaviors. In addition to increasing transmission, crystal meth use can decrease treatment adherence, resulting in a rise in viral load.

To respond to the twin epidemics, the NYS Substance Abuse Initiative (SAI) was conceived and developed through a collaboration between the NYS Department of Health and the Office of Alcohol and Substance Abuse Services. SAI encompasses a co-located continuum of comprehensive HIV prevention and primary care services in substance abuse treatment settings throughout NYS. This Initiative has been instrumental in broadening the mission of the substance abuse treatment community from a focus on rehabilitation to the provision of public health, and is a national model for effectively engaging a very high-risk population in care.

Men Who Have Sex with Men

About 30 percent of New York State's newly diagnosed HIV and cumulative reported AIDS cases are among men who have sex with men (MSM). It is important to note that MSM include distinct subpopulations: men who openly identify as gay, men who prefer sex with other men but do not self-identify as gay, and men who self-identify as heterosexual but also have sexual encounters with other men. The latter group is sometimes referred to as "men on the down low." MSM cases are diverse in terms of race/ethnicity. Among cumulative AIDS cases, 26 percent are Black, 21 percent are Hispanic, 52 percent are White, one percent are Asian/Pacific Islander, and one percent are Native American. Gay men and other MSM are also very diverse in terms of cultural and social ties, age, socio-economic status, residence in rural, suburban and urban settings, and many other dimensions.

Despite public health and community level interventions that slowed the rate of new infections among MSM in the mid-1990s, recent data and other trends are causing concern about a potential resurgence of HIV among MSM. There is a documented resurgence of syphilis cases among these men indicating unprotected sex. Other concerns include the reported increase in recreational drug use – particularly methamphetamine – among gay men and the increasing importance of the Internet as well as other venues in facilitating sexual encounters. Other phenomena documented in the literature such as "prevention fatigue," "barebacking" (sexual penetration without a condom), and media and advertisements portraying HIV as a treatable chronic disease may be contributing to a rise in new infections among MSM.

Findings from the Young Men's Study (YMS) confirm that significant numbers of HIV-positive men are unaware of their serostatus. National YMS data indicate that of the 249 men who tested positive, only 18% already knew they were HIV positive. Accessibility and

issues of stigma and shame are often barriers to testing among MSM. Campaigns promoting HIV testing (such as Project WAVE radio promotion of HIV testing) and making testing more accessible in community settings (such as peer outreach associated with mobile medical vans and "testing-in-the-park" events) are examples of methods shown to reach MSM who do not perceive themselves as at-risk.

Gay men seeking services in mainstream health care facilities may be reluctant to disclose their sexuality or risk behaviors out of fear of discrimination. Homophobia and stigma within the medical establishment can perpetuate mistrust and may prevent MSM from disclosing personal, often relevant information, leading to misdiagnosis or late-stage diagnosis of life-threatening illness. A comprehensive approach to health care for MSM should address at a minimum: preventive care, primary and specialty health care, HIV and sexually transmitted diseases, substance and alcohol use, violence, and mental health services.

Women

HIV and AIDS among women have increased dramatically. The proportion of newly reported AIDS cases among women has more than doubled in New York, rising from 12 percent in 1986 to over 30 percent in 2003. The increase in HIV infection among young women and teens is even more alarming. In New York, females now account for 48 percent of new HIV infections among adolescents ages 13-19, and 43 percent of new infections among young adults, ages 20-24. An increasing number of HIV/AIDS cases are also being seen in women over 50 years of age.

The concentration of HIV among women of color is striking. African American and Hispanic women together represent 86 percent of the 53,500 women diagnosed with HIV/AIDS in New York. The rate of HIV infection is 27 times higher for Black women than white women and 13 times higher for Hispanic women. Also at increased risk for HIV infection are Asian/Pacific Islander women, Native American women, and immigrant women from regions where HIV is endemic, including Africa and the Caribbean.

Women often face significant barriers to care. Published studies indicate a higher proportion of women than men with HIV report postponing medical care for reasons such as competing needs or lack of transportation. The largest group of women affected by HIV are poor women and women who are marginalized in society. Many of the women at greatest risk for HIV are also struggling with drug and alcohol use, mental illness, low educational levels, poor nutrition, sexually transmitted diseases, or teen pregnancy. Many are homeless, victims of domestic violence, incarcerated, mentally ill or engaged in prostitution to meet subsistence needs for themselves and their families. A major challenge in this third decade of the epidemic is ensuring that culturally appropriate HIV prevention, care and support services are truly accessible to these high-risk women. (Excerpts from *Women in Peril – HIV & AIDS: The Rising Toll on Women of Color*, Document #41).

Children and Families

Over the past decade the number of new cases of HIV infection among children has declined dramatically in NYS due to multiple factors, including a lower rate of HIV infection among childbearing women (0.27% in 2004 from a high of 0.66% in 1989 based on NYS Health Department Newborn Seroprevalence Data) and a lower perinatal transmission rate resulting from therapeutic regimens that reduce passing the virus from mother to child (2.8% in 2004; preliminary Newborn Seroprevalence Data). The number of pediatric deaths attributable to AIDS has also significantly declined as a result of advances in medical management of the disease. Approximately 2,400 children and youth are living with maternally transmitted HIV or AIDS in NYS; nearly 45% are 13 years of age or older. While there are fewer infected infants entering care, children with HIV are living longer, some to adolescence and beyond. Perinatally acquired HIV infection is, for most infected children, a chronic disease that requires complex medical and psychosocial management.

HIV is often a disease that affects families with multiple needs: poverty, substance use, domestic violence, mental illness, lack of employment opportunities and health insurance. HIV may affect several generations and extended family members. In addition to immediate health care concerns, families often face issues such as custody arrangements, daily childcare, elder care, and the emotional needs of infected and uninfected children, youth and adults. Traditionally, women have primary responsibility for care of children, and they often put the needs of their children ahead of their own. Health care may not be a high priority as they struggle to meet the basic subsistence needs of their families for shelter, food and clothing. It is also acknowledged that in some cases, fathers assume the role of primary caregiver and may face unique challenges in obtaining needed benefits, supports and services.

Children and adolescents who are orphans of the HIV/AIDS epidemic, both infected and affected youth, need multiple services including medical care and support, as well as education and skills building to prevent further transmission. Primary caretaking of these youth often falls to grandparents, other extended family members or foster parents who need HIV-related education and a broad range of family support services to carry out this responsibility. There are often challenges associated with disclosure to the child as some, maybe many, are not told about their own HIV status until 12-13 years of age. These young people also need special support in transitioning from pediatric to adult care settings in large health care facilities.

A family-centered approach to HIV health care recognizes and supports family members in their caregiving roles. The hallmark of family-centered care is integration and coordination of services. Multi-cultural, multi-disciplinary teams that integrate medical care, including specialty care, with mental health, substance use treatment, case management and other HIV-related support services can best manage the complex medical and social issues faced by HIV affected families. Ideally, services are co-located or, at a minimum, strong working relationships are forged between adult medicine, obstetric, pediatric and adolescent programs to address the health needs of all family members.

Adolescents and Young Adults

New York State surveillance data reported and confirmed through December 2004 indicates that 4,688 AIDS cases have been reported among young people 13 through 24 years of age. An additional 3,201 youth are living with HIV. Young people of color are disproportionately affected, with the overwhelming majority of cases (80 percent) occurring among Black and Hispanic youth. As expected, when comparing HIV to cumulative AIDS cases, there are more cases in the 13-24 age range among those with HIV. Alarming data from the New York City Young Men's Study indicates very high rates of seroprevalence among young men 15-22 years of age who have sex with men: 12 percent overall, 18 percent among young black men, 16 percent among those with mixed race, and 9 percent among Hispanics.

The predominant route of transmission in young people is sexual intercourse although many youth who were perinatally infected are living to adolescence and beyond. Counseling and psychological services need to be tailored to the varying needs of young people who have been infected since birth and those who have acquired HIV through behavioral risk factors.

Youth infected since birth have to deal with a continuing life threatening disease and complex treatment while going through the psychological and emotional changes that are part of adolescence and young adulthood. This can result in rebellious behavior that manifests in the young person refusing to take medications or keep medical appointments. Often, parents and other primary caretakers need professional help to effectively communicate with their children during this phase.

Young people in general avoid health care. Outreach networks are needed to reach the highest risk adolescents and young adults who may be socially isolated and marginalized by homelessness, sexual identity, substance use and survival sex. To engage high-risk young people in care, services must be designed to meet their immediate health care and social service needs. This requires an approach which includes partnerships of health providers, youth-serving organizations, the social networks of youth and trained peers, and other community resources to facilitate access to the concrete services at-risk youth need before addressing issues relating to HIV testing and treatment. Adolescents may avoid health care because they fear disclosure of confidential information to parents or guardians and/or because the delivery system is daunting to a young person. Providers must be sensitive to these concerns by offering clinical services in accessible community-based settings at unconventional hours, and developing trusting relationships by providing services which are non-judgmental, culturally sensitive, developmentally appropriate and youth-friendly.

Homeless Persons

As indicated in the 2004 Housing Needs Assessment Reports (Document # 36-NYC and #119-Upstate and Long Island), homeless people are at greater risk of HIV infection than the general population, and people with HIV/AIDS are significantly more likely to become homeless. The Reports further indicate that housing for people with HIV/AIDS is a public health intervention that promotes stability and connection to health care for people with

multiple and complex needs. This intervention is critical to address the public health threats posed by the co-occurring and inter-related epidemics of homelessness, HIV, chronic drug use, mental illness, tuberculosis and, more recently, Hepatitis C.

The consumer survey conducted for the NYC assessment indicated 45 percent of respondents reported a history of "literal" homelessness, sleeping in a shelter or on the streets. Co-morbidities are common — 80 percent report a substance use problem or mental health issue in the past or present, and more than 40 percent have a history of incarceration. The report indicates that despite these histories and the potential barriers to securing and maintaining housing, the overwhelming majority of people surveyed were stably housed through HIV/AIDS housing programs sponsored by New York City, and had a relationship with a primary health care provider. (Given the growing number of persons living with HIV, significant unmet and projected housing needs across the State are described in the Needs section of this report.)

The Needs Assessment report further indicates that much of this unexpected stability can likely be attributed to "wrap around" support. Medicaid and grant-funded support services, such as case management, medical and social day programs, harm reduction programs for active substance users, and mental health care, provide the supports that keep many people in independent housing stable and connected to care. These services are increasingly important as consumers' health status changes because of aging, prolonged HIV treatments, and co-occurring substance use and mental health issues.

Stable affordable housing and related supportive services for persons living with HIV/AIDS were noted as critical unmet needs in all regions of NYS. The Upstate New York and Long Island Housing Needs Assessment notes that while existing HIV/AIDS housing resources have significantly improved the health status of many persons with HIV/AIDS, their limited availability leaves an increasing number of persons without necessary housing and supports. Research and key informant interviews conducted as part of this assessment indicate that a large percentage of the more than 4,000 people with HIV/AIDS in Upstate New York and Long Island who are currently in need of housing supports live in inadequate housing situations, and would be considered homeless under definitions employed by many housing programs.

A continuum of housing services is needed across the state that includes at a minimum: housing placement assistance; scattered site housing; transitional and independent housing with supportive services such as case management, transportation and nutrition assistance, child care, peer support groups, etc.; congregate housing; transitional and long-term group housing and supportive services; enhanced rental subsidies; emergency rental and utility assistance; and enhanced supportive services, such as home meal delivery, mental health services, substance abuse counseling, crisis intervention and partner notification assistance.

Immigrants, Both Documented and Undocumented

New York State is home to the second largest immigrant population in the nation. Twenty percent (3.8 million) of the State's population is foreign-born, twice as high as the national average. Immigrants living in New York represent 150 ethnicities and speak almost as many languages and dialects. The most foreign-born New Yorkers live in New York City (2.9 million) where they represent 36 percent of the City's population. Many immigrants come from areas of the world where HIV is endemic (Africa, Asia, the Caribbean) and access to HIV testing and treatment is limited.

Approximately 15 percent of all documented AIDS cases in New York State occur among foreign-born residents. However, it is likely that this represents a significant undercount since country of birth is frequently not recorded on HIV/AIDS reports.

Changes in laws relating to eligibility for public entitlements, linguistic isolation and distrust of service providers result in lack of access to care and essential support services for these subpopulations Recent immigrants, such as those from countries in West Africa, Eastern Europe, and Asia, face formidable barriers. As noted in the New York City Community Forum Report (Document #8), many of the new arrivals are undocumented, unemployed, lack access to medical care and face issues of cultural integration, poverty, language, illiteracy, and substandard housing. Although many are able to survive through street peddling and restaurant work, they are often unable to access needed services, particularly medical services. At the Community Forums, participants noted that a significant and growing number of undocumented immigrant workers engage in the day labor industry for economic survival, making HIV services to infected day laborers an emerging need requiring targeted services. Ryan White CARE Act funded services, such as ADAP, ADAP Plus, and grant-funded supportive services, are critically important for immigrants who most often do not qualify for Medicaid or other entitlement programs.

Inmates and Releasees from Criminal Justice Settings

According to United State Department of Justice statistics, the New York State prison system has the highest number of prisoners infected with HIV, including the largest number of HIV positive female inmates, of all prison systems in the country. NYS AIDS/HIV surveillance system data indicates there are 3,481 cumulative AIDS cases and 3,001 HIV cases among state prison inmates through December 2003. Criminal justice settings are important for the provision of HIV prevention, care and supportive services because: 1) incarcerated populations are at high risk for HIV, STDs and other communicable diseases; 2) inmates can be provided education and care in these settings; and 3) inmates will eventually be released back to their communities.

There are three specific subpopulations involved with criminal justice in particular need of HIV-related services — those with a history of reported substance and/or alcohol abuse, women and Spanish-dominant speakers. In 2003, the State Department of Correctional Services (DOCS) reported that almost 65 percent of the total population under custody had a history of reported substance and/or alcohol abuse. Women entering state prisons were three

times more likely than men to be infected with HIV and hepatitis C (HCV) based on seroprevalence studies conducted by NYSDOH. Nearly 14 percent of women versus 4.7 percent of men were HIV positive, and 23 percent of women and 13 percent of men were infected with HCV. Finally, inmates who are Spanish-dominant speakers represent about 8.4 percent of the DOCS inmate population, and require linguistically and culturally appropriate HIV prevention and care.

Locally operated jails, which have the capacity to house over 36,000 individuals, should also be involved in providing HIV-related services. While data on HIV/AIDS cases in local jails is not available, local jails report a significant proportion of their total census to be from communities of color, which are disproportionately affected by HIV/AIDS in NYS. In addition, since local jails house individuals who are sentenced to terms of less than one year, many releasees are returning back to their communities from these settings.

The NYC Community Forum Report indicates that HIV/AIDS stigma, very pronounced within correctional settings, follows releasees "outside" and is compounded by societal stigma against ex-offenders. This stigma often forces individuals to withhold their status in and out of prison, thereby keeping them away from needed treatment. A continuum of prevention, care and supportive services is needed to reduce HIV transmission and to improve the health and well-being of HIV infected inmates and releasees. Multiple strategies, including accessible HIV counseling and testing, linkage to and continuity of comprehensive health care, transitional and on-going case management, are essential to adequately serve this high risk subpopulation.

Mentally Ill, and Mentally Ill and Chemically Addicted (MICA) Persons

Many people with HIV/AIDS are now living longer and facing new challenges and difficulties. Research reflects the connection that often exists involving HIV infection, mental illness and substance use. Studies of psychiatric patients in the mid-1990s indicated a range of HIV infection from 4 to 23 percent, with a large proportion involved in substance use. Recent studies in New York indicate 4 to 8 percent of persons living with HIV are also diagnosed with psychiatric disorders. It is likely that specific subgroups have substantially higher rates but these conditions are undiagnosed. There are numerous factors that affect persons who are multiply diagnosed with HIV, mental illness and chemical addiction. These include: diminished access to regular health care, reduced adherence to psychotropic medication leading to increased risk of harm to self and others, reduced adherence to antiretroviral therapy, inadequate treatment of other medical conditions, and increase in drug and alcohol use.

A continuum of health, mental health and supportive services is necessary to address the full range of conditions among persons who are triply diagnosed. This service continuum includes screening, assessment and evaluation, psychological testing, a comprehensive care and behavioral health plan addressing individual needs and co-existing disorders, psychiatric, psychological, medical and substance abuse treatment, crisis intervention and support services. The HIV primary care provider has a critical role in assessing mental health status

and recognizing substance abuse problems, and then ensuring the patient has access to needed services.

The linked epidemics of HIV infection, substance abuse and mental illness call for greater coordination and integration of the mental health, substance abuse treatment and HIV service delivery systems. It is critical that these systems of care and the providers in each work together to minimize harm and maximize successful outcomes for at risk and infected persons. This goal translates into an on-going need for cross-training and outstationing of staff, co-location of services wherever feasible, and frequent case consultation.

Persons Aged 50 and Over

The NYS HIV/AIDS Surveillance Semiannual Report for cases diagnosed through December 2003 indicates the following: persons aged 50 and over account for 14 percent of cumulative AIDS cases, 13 percent of persons living with AIDS, and 11 percent of persons living with HIV. Over 75 percent are persons of color. These substantial percentages underscore the need to integrate culturally sensitive HIV/AIDS prevention, care and supportive services with services for older persons.

The New York EMA Addendum to the 2004 Needs Assessment (Document #66) summarizes issues and challenges related to the 50 and over population. These include: denial of risk among seniors; lack of education about HIV; HIV infection not considered a possibility by clinicians; diagnosis and treatment of co-morbidities and age-related illnesses, and how these affect treatment options; HIV services not targeted to seniors; seniors' hesitation or refusal to share an HIV diagnosis with family and other members of their personal support network; and the compounding of age and HIV stigma and discrimination.

A published article on HIV/AIDS Prevention and Care Services for the Aging (Document #139) notes that as HIV-infected individuals live longer, this group of long-term survivors will join those who become infected in their later years. To better reach and serve this growing group, service models should include culturally sensitive HIV education targeted to persons in the 50 and over age range and better integration of HIV prevention, care and supportive services with other programs serving seniors. Written comments emphasize that the reality of living with AIDS as a chronic illness requires focused attention and resources to address the complex needs of this aging group, including co-morbidities associated with aging, increased isolation from broader social networks, and the negative impact of HIV stigma and ageism.

Transgender Persons

Transgender persons are individuals whose gender identity, expression, or behavior is not traditionally associated with their birth sex. Some transgender individuals experience gender identity as incongruent with their anatomical sex and may seek sex reassignment surgery, take hormones, or undergo other cosmetic procedures. Others may pursue gender expression (masculine or feminine) through external self-presentation and behavior.

Transgender persons are often extremely socially isolated, rejected by family and the community, and face stigma and discrimination that exacerbates their HIV risk. This stigma is associated with lower self-esteem, increased likelihood for substance abuse and survival sex work, and lessened likelihood of safer sex practices. Social marginalization of this subpopulation can result in denial of educational, employment and housing opportunities.

Transgender persons often require on-going hormone therapy. Medicaid and most insurance companies specifically exempt hormone therapy coverage despite the medical necessity of this treatment documented by health care professionals. Since most transgender persons cannot afford to pay for this treatment out of pocket, they engage in behaviors, such as trading sex for money and sharing syringes, that greatly elevate the risk of HIV transmission.

Prejudice against transgender individuals is pervasive. There is a long-held view on the part of U.S. medical providers and researchers, as well as the public at large, that transgenderism is pathological. This constitutes one of the most significant barriers to care. As a result of this labeling, transgender individuals underutilize health and social services. A survey of transgender men and women in San Francisco reported that many in this population are chronically underserved with regard to basic medical and psychological support services. Few resources exist that address their special needs or provide necessary consumer education and regular medical follow-up (Excerpt from *Transgendered People, HIV and Access to Care Course Syllabus (Document #164).*

A large scale San Francisco study describing HIV risk, health care use and mental health status of transgender individuals (Document #163), found that male-to-female transgender persons were more socioeconomically disadvantaged and had higher HIV prevalence. The study also found a particular need to intervene with African American male-to-female transgender persons in their study group, two-thirds of whom had positive HIV test results. This study also confirmed that many transgender persons enter the medical system in pursuit of hormones. This gateway to services allows health providers the opportunity to counsel and refer transgender patients in need of HIV, substance abuse, and mental health services. The authors cite the particular need to assess the potential for depression and suicide, noting that the prevalence of suicide attempts among transgender persons in this study was much higher than that found in other population samples.

In summary, access to health care in general and to HIV care is limited for transgender persons due to low socio-economic status, lack of insurance, fear of one's transgender status being revealed, provider lack of knowledge about caring for transgender persons, and discrimination. To more effectively address their needs, the following need to occur: improve data collection on transgender persons and HIV infections; educate health and human service providers regarding their unique needs and barriers to service; build provider competency to address transgender health concerns including HIV; and increase understanding about this subpopulation to address stigma and discrimination and eliminate barriers to receipt of services by transgender persons (US Department of Health and Human Services Fact Sheet on HIV/AIDS and Transgender Persons; Document #140).

Lesbians

The Centers for Disease Control and Prevention (CDC) indicates that female-to-female transmission of HIV appears to be a rare occurrence. However, case reports of female-to-female transmission of HIV and the well documented risk of female-to-male transmission of HIV indicate that vaginal secretions and menstrual blood are potentially infectious and that mucous membrane (e.g., oral, vaginal) exposure to these secretions has the potential to lead to HIV infection.

The *Women in Peril Report* of the NYS AIDS Advisory Council (Document #41) indicates that since CDC has categorized female-to-female sexual transmission as very low risk, some lesbians perceive that they are at low risk for HIV infection regardless of their behavior. In fact, surveys have shown that up to 75 percent of lesbians have sex with men at some time, including unprotected vaginal and anal intercourse with gay and bisexual men. Some lesbians are also at high risk due to injection drug use. Others make the point that lesbians are made invisible in the AIDS epidemic through the risk factor reporting methodology. If a lesbian acknowledges that she has ever had sex with men, she is counted under heterosexual transmission; if she has ever used intravenous drugs, that becomes her risk category.

Due to fear of discrimination and judgment, many lesbians are reluctant to seek medical care or to acknowledge their sexual orientation. Those who do seek medical care are frequently not asked questions about their lifestyle that would inform the practitioner about HIV risk. There is a clear need for accessible, high quality, non-judgmental health care and supportive services for lesbians and women who partner with other women but do not identify as lesbian.

Deaf and Hard of Hearing Populations

The unique needs of the deaf and hard of hearing persons relative to both HIV prevention and care was noted at numerous community forums throughout the State. Meeting these needs includes: 1) developing strategies for effective communication with deaf and hard of hearing persons about HIV prevention, care and supportive services, including sign language when needed; 2) ensuring access to the full continuum of HIV services; 3) preparing HIV service providers to help deaf and hard of hearing patients adhere to antiretroviral therapy; and 4) using a relay service to phone deaf and hard of hearing persons.

Residents of Rural Areas

Based on the 2000 U.S. Census, about 3.4 million NYS residents, over 18% of the State's total, live outside of urbanized areas (this includes rural residents as well as persons living in urban clusters that have at least 2,500 but fewer than 50,000 people). Lower rates of HIV infection in these areas may translate into less awareness of HIV, limited availability of HIV counseling and testing, and few or no providers experienced in HIV diagnosis and treatment. This can result in late diagnosis and limited access to state-of-the-art medical care. Major medical centers that provide comprehensive HIV/AIDS health care services are primarily

located in urban areas with high rates of HIV. Infected persons living in rural areas often have to travel hundreds of miles to reach medical providers who have the expertise to treat their complex medical conditions. In addition, case management and other enabling or supportive services such as transportation and nutrition assistance, essential for maintaining a person in care, are often not easily accessible in rural areas. The need to develop broader networks of service providers, including satellite offices, and home-based services covering rural areas was emphasized in community forums held across New York State.

Migrant Workers

Cornell Migrant Program data indicates that approximately 47,000 migrant workers come to rural New York State each year. New York State ranks tenth in the nation in the use of migrant farm workers. Information in the Finger Lakes Region draft Service Delivery Plan (Document # 102) indicates that housing for this population varies from barracks to people living in vans, cars or abandoned houses. Code enforcement is minimal and many live without basic facilities such as potable running water and toilets. Nationally, nearly 90% of migrants make less than $10,000 a year. There is no mandatory day of rest, nor is there a standard eight hour work day with additional work compensated at a higher rate. Migrant workers have no sick or vacation time and have no benefits, including health care insurance.

To reach this subpopulation, grant-funded services must be brought to them in mobile health vans or easily accessible community settings. Migrant health service programs must include multi-lingual staff who are sensitive to cultural issues and equipped to provide “in camp” health screening and treatment of minor acute conditions before HIV testing and care can be addressed. Continuity of care for HIV-infected migrant workers presents a major challenge because they frequently relocate in connection with growing seasons.

SECTION VII:
SERVICE NEEDS AND BARRIERS BY REGION

A. Introduction

Over one hundred fifty documents were received and reviewed in preparation of this report. These documents addressed service needs, barriers to service, targeted subpopulations infected and affected by HIV, local and regional strategic plans for addressing needs, policy and coordination issues. The types of documents received include: statewide, regional or population-specific needs assessments; local and regional comprehensive service plans; reports from consumer groups; epidemiological reports and profiles; published articles; research studies; evaluation and topic-specific reports; strategic plans; letters; documents from federal, state and local health departments and other public agencies. All documents received are briefly described in Appendix A.

This report summarizes all needs — both "documented" and "perceived." Documented needs are those supported by specific evidence and/or quantitative information from creditable sources. Perceived needs are statements of need or concern made by creditable sources that are not accompanied by specific quantification or documentation. Most often, perceived needs are expressed by consumers or caregivers with direct experience accessing the delivery system, or by providers and case managers on the frontline of service delivery. Reviewers used a checklist developed to capture needs, barriers, subpopulations, and other issues addressed in the source documents. A database was created to aggregate this information. This Section is organized to present summary information from the database and illustrative narrative from the source documents by each geographic area listed below. The service needs described for each geographic region are not listed in priority order; however, some regions and boroughs identified certain needs as the most commonly identified or most pressing needs.

- Statewide
- New York Citywide
- Bronx
- Brooklyn
- Manhattan
- Queens
- Staten Island
- Upstate (New York State, excluding New York City)
- Albany (Northeastern) Ryan White Region – Counties of: Albany, Clinton, Columbia, Delaware, Essex, Franklin, Fulton, Greene, Hamilton, Montgomery, Otsego, Rensselaer, Saratoga, Schenectady, Schoharie, Warren and Washington
- Binghamton Tri-County Ryan White Region – Counties of: Broome, Chenango and Tioga
- Buffalo (Western) Ryan White Region – Counties of: Allegany, Cattaraugus, Chautauqua, Erie, Niagara, Genesee, Orleans and Wyoming
- Lower Hudson Ryan White Region – Counties of: Putnam, Rockland and Westchester

- Mid-Hudson Ryan White Region – Counties of: Dutchess, Orange, Sullivan, and Ulster
- Nassau/Suffolk Ryan White Region – Counties of: Nassau and Suffolk
- Rochester (Finger Lakes) Ryan White Region – Counties of: Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne and Yates
- Syracuse (Central) Ryan White Region – Counties of: Cayuga, Cortland, Herkimer, Jefferson, Lewis, Madison, Oneida, Onondaga, Oswego, St. Lawrence and Tompkins

B. Statewide Needs and Barriers

New York State is the epicenter of the HIV epidemic in the United States. The following facts are noteworthy:

- New York State has far more total AIDS cases than any other state -- 28,000 more than the next highest incidence state of California (CDC cumulative AIDS case data through December 2003).
- New York State's epidemic affects a greater proportion of persons of color than the nation as a whole -- 73.5 percent in NYS compared to 57.6 percent in the U.S. (CDC cumulative AIDS case data through December 2003).
- In terms of estimates of Persons Living with AIDS at the end of 2003, CDC data indicates that New York State has 66,660 PLWHA or nearly 17 percent of all PLWHA in the country. New York has 7 percent of the U.S. population.

Service Needs and Barriers

The following is a summary list of needs and barriers identified statewide. This list includes items that were identified across regions, but may not be inclusive of all items identified in every region. It is important to note that some services, such as home-delivered meals, home health care, and hospice, are in much lower demand due to treatment success. However, there are some regions that indicate a need for these services in certain localities. The region and borough summaries, which follow in this section of the report, include more detailed descriptions of service needs and barriers, and affected subpopulations.

Medical and Dental Care and Related Needs

- Comprehensive Health Care, integrating Primary Care (for HIV, STDs, Hepatitis, and TB), Medication Assistance, Treatment Adherence Support, and Specialty Care for all persons including those who are uninsured, underinsured, or enrolled in Medicaid or ADAP Plus
- HIV Testing
- Treatment Adherence Education and Support
- Dental Care
- Vision Care
- Financial Assistance for Uninsured and Underinsured
- Access to Clinical Trials
- Clinical Research
- Alternative/Complementary Therapy

Housing and Related Support Services

- Emergency Shelter/Placement Assistance
- Permanent Housing
- Transitional Housing
- Emergency Financial Assistance
- Supportive Housing Services

Substance/Alcohol Abuse Related Services

- Substance/Alcohol Abuse Prevention Education and Counseling
- Residential Treatment, particularly for women and women with children
- Harm Reduction, including Syringe Exchange and expanded access to syringes

Mental Health Services

- Individual and Group Counseling
- Residential Care for Serious Mental Illness
- Psychiatric Services
- Services for the Mentally Ill and Chemically Addicted (MICA)

Linguistically and Culturally Competent Services

- Translation Services
- Provider Training

Outreach

- At Community Events and in Neighborhoods for Case Finding and Linkage to Care, particularly among subpopulations at high risk of HIV
- Broad scope outreach campaigns to encourage HIV testing and linkage to care

Case Management at varying levels of intensity based on the complexity of the client's needs, and in a variety of settings

Food/Nutrition

- Food Banks/Pantries
- Congregate Meals
- Home Delivered Meals
- Nutrition Counseling

Transportation and Legal Assistance were consistently identified as key supportive services that enable linkage to and retention in care for HIV positive persons.

Other Supportive Services:

- Peer Education and Support
- Emergency Financial Assistance
- Vocational Training and Job Placement
- Client Advocacy, including entitlements and benefits assistance
- Family Support Services, including permanency planning for families in transition and child care
- Information and Referral
- Caregiver Support
- Day/Respite Care
- Buddy/Companion
- Bereavement/Grief Support

Service Delivery Models

- Evening and Weekend Services
- Enhanced Continuity of Care and Service Integration, particularly for families

- Improved Service Coordination in terms of linkages and referrals, and between prevention and care
- Co-Located Services
- Mobile Medical Vans
- Neighborhood Service Sites
- More Accessible Services for Rural Residents

HIV Prevention and Education

- HIV Risk Reduction Education and Counseling
- Community-Based Consumer Education to Improve Health Literacy
- Prevention with HIV Positive Persons
- Youth-Specific HIV Prevention
- Condom Distribution
- Prevention of STDs
- Peer Education
- General Health Education
- Education Addressing Stigma and Discrimination
- Social Marketing Campaigns
- Microbicide Research

Training and Technical Assistance for Providers

- Cultural Competency
- Clinical Education
- Capacity Building to Improve Quality of Care

Chronic Care

- Adult Day Treatment
- Home Health Care
- Hospice

Policy Issues

- ADAP – Full Funding and Expanded Formulary
- Medicaid Reform and changes in coverage
- Ryan White Reauthorization, including ADAP funding and continued coverage of supportive services
- Infrastructure and Administrative Support for Community-Based Organizations (CBOs)
- Gap Health Care Coverage for Uninsured
- Equitable Distribution of Resources and Funding Levels that allow services to keep pace with increasing demands
- Improved Data Collection/Reporting and Outcome Evaluation
- Rate Reform for AIDS Adult Day Care
- Increased Resources for HIV Prevention
- Comprehensive Health and Sex Education for Youth

Targeted Subpopulations

The following subpopulations were consistently mentioned in the source documents received. The characteristics and unique needs of many of the subpopulations are described in the Special Populations section of this report.

- Persons of Color, including Black, Hispanic, Asian/Pacific Islander, and Native American
- Substance/Alcohol Users, particularly Injection Drug Users (IDUs)
- Men Who Have Sex With Men (MSM), particularly Men of Color Who Have Sex with Men (MCSM), including gay men and men who do not identify as gay
- Women
- Adolescents/Youth
- Immigrants
- Homeless
- Mentally Ill and Chemically Addicted Persons (MICA)
- Persons Co-infected with HIV and Hepatitis
- Persons Co-infected with TB
- Criminal Justice System Releasees/Parolees
- Victims of Domestic Violence
- Migrants and Seasonal Workers
- Perinatally Infected Infants/Children/Youth and Family Members
- Seniors
- Transgender Persons
- Lesbians
- Deaf Persons
- Residents of Rural Areas
- Persons with STDs

The unique needs of Asians/Pacific Islanders and Native Americans across the State were addressed in several source documents and are summarized below.

Asians/Pacific Islanders

Four source documents were submitted by the Asian and Pacific Islander Coalition on HIV/AIDS (APICHA) (Document #s 78-81) specifically addressing the needs of Asians and Pacific Islanders (A/PIs). According to 2000 census data, A/PIs now comprise over 10 percent of New York City's population. They come from 49 distinct ethnic groups and speak over 100 languages and dialects. Nearly 80 percent are immigrants, of which an estimated 20 percent are undocumented. A/PIs' perceptions of health promotion and disease and how to take care of their health often differ markedly from perceptions and practices of Westerners and allopathic medicine.

NYCDOHMH presented data in 2002 to the New York City HIV Planning Council showing that A/PIs had a rate of "delayed access" to care that is almost twice as high as the rate for other racial groups. APICHA notes that A/PIs have one of the lowest rates of HIV testing

and that too often, A/PIs learn of their HIV status in the emergency room when they are being treated for AIDS-related complications. APICHA reports that the relatively low HIV/AIDS case count among A/PIs may be due to under-reporting and misreporting of cases among A/PIs, as well as lack of access to testing, care and other services.

The literature indicates that A/PIs face significant barriers to accessing comprehensive, culturally acceptable primary care services. Language barriers, lack of culturally competent providers, traditional beliefs and practices, social stigma, lack of insurance, immigration status, mistrust of institutions, and HIV-sensitive provision of care affect A/PI patterns of service utilization and medical adherence. All of the factors influencing access to primary care services are also complicated by the immense diversity of the A/PI population.

The most commonly identified needs for A/PIs include:

- Linguistically and culturally competent services, including translation
- Financial and geographic access to comprehensive, confidential health care, HIV testing, treatment adherence education and support
- Community Outreach to establish linkages to care and services, and use of mobile medical vans
- Training and Technical Assistance for providers
- Health Education, including HIV prevention and education to reduce stigma
- Mental Health Services
- Supportive Services, including case management, peer education and support groups
- Education and services focused on A/PI youth, empowering A/PI women, and building self-esteem among A/PI gay men

Native Americans

Three source documents were submitted by the American Indian Community House (AICH) (Document #s 135-137) specifically addressing the needs of Native Americans. There are eight different Native American nations located within New York State, each with its own government, land base and membership. This includes the Haudenosaunee ("People of the Longhouse") Confederacy, located in Upstate New York, and comprised of six separate nations: Mohawk, Oneida, Onondaga, Cayuga, Seneca, and Tuscorora. The Shinnecock Nation and Unkechaug Nation are located on Long Island.

The literature documents that significant health disparities exist between Native American populations and the general U.S. population. While the number of reported HIV/AIDS cases is relatively low among Native Americans, many believe the case count reflects underreporting due to limited access to HIV testing and care, as well as misidentification of Native Americans by non-Native American providers. Native American access to general health care is limited, as its federal funding is not based on entitlement appropriations, as Medicare and Medicaid are, but on discretionary funding from the DHHS budget. Also, some traditional nations do not accept federal funds for health care. These factors result in barriers to care for many Native Americans who do not have the resources or insurance coverage to seek health care.

The Native American Leadership Commission on Health and AIDS, facilitated by AICH, conducted community forums to identify top HIV-related needs of Native American communities as follows:

- Promote awareness of the presence and risk of HIV in NA communities, and of HIV facts to reduce stigma and facilitate effective prevention. Develop educational campaigns using multi-media and behaviorally-based intervention strategies. Target NA youth in particular.
- Encourage increased HIV testing in NA communities, testing by NA providers, and promote the benefits of knowing one's status and access to early, comprehensive care. Ensure confidentiality to engender trust, and follow-up to ensure connection to and retention in care.
- Develop strategies for increased involvement of NA leadership and elders and for bringing NA HIV infected speakers to Native communities.
- Housing for NA HIV infected persons and supplemental emergency assistance for housing/rent/utilities.
- Culturally sensitive substance and alcohol abuse-related services.
- Develop and manage volunteer programs and peer-based services, including a drop-in center for gay and lesbian NAs.
- Culturally competent services, training and educational materials.
- Increase funds supporting HIV-related services targeted to NA communities.
- Promote networking and service coordination among agencies serving NA communities.

C. New York Citywide

Through 2003, New York City reported more cases than were reported by the state of California -- the second highest prevalent state in the nation. Although the City has only three percent of the U.S. population, almost 16 percent of people living with AIDS in the U.S. reside in New York City, and 24 percent of the perinatally infected children. In addition, 17 percent of AIDS deaths in the U.S. have occurred in New York City. The map below depicts the five boroughs of New York City.

New York City's epidemic overwhelmingly affects people of color. About 77 percent of all persons living with AIDS and HIV in New York City are persons of color (NYCDOHMH HIV/AIDS Surveillance Statistics 2003) (Document #158). Analysis of this data indicates that Blacks and Hispanics are disproportionately affected:

Race	Percentage of NYC's Population	Percentage of all PLWHA
Blacks	24%	44%
Hispanics	27%	32%
Whites	35%	21%
Asian/Pacific Islanders	10%	1%
Native Americans	Less than 1%	Less than 1%

The New York City Department of Health and Mental Hygiene HIV Epidemiology Program April 2005 report highlights the following important facts:

- 81 percent of new HIV (non-AIDS) diagnoses and 80 percent of new AIDS diagnoses were in Blacks and Hispanics in 2003.
- Black women accounted for 61 percent of AIDS cases in women in 2003.
- Men and women showed different patterns of HIV transmission in 2003:
    - Heterosexual sex was the predominant risk factor for HIV among women with known risk, accounting for 75 percent of new HIV (non-AIDS) diagnoses.
    - Among men with known risk, sex with men accounted for 71 percent of new HIV (non-AIDS) diagnoses.

Service Needs and Barriers

This summary of service needs and barriers in the New York City Region is informed by various comprehensive documents issued recently, including a 2004 Comprehensive Needs Assessment for the New York Metro Area, a 2002-05 Comprehensive Strategic Plan, Consumer and Community Forum Reports, a Housing Needs Assessment, CHAIN Study reports (Community Health Advisory Information Network, Columbia University), and a 2005 report from the Women's HIV Collaborative. (All are described further in the Appendix to this report.) Based on these documents, the service needs and gaps most often identified citywide are the following:

- Housing
- Mental Health Services
- Substance and Alcohol Abuse Related Services
- Outreach, Early Intervention (Counseling, Testing and Linkage to Care), Comprehensive Health Care, and Treatment Adherence Education and Support
- Linguistically and Culturally Competent Services
- Case Management, including benefits/entitlements assistance
- Food and Nutrition Counseling
- Transportation

The following summarizes issues related to the above needs and barriers from various source documents. It is noted that these services must be tailored to meet the varying needs of the affected racial and ethnic groups and special subpopulations described in this report.

Housing:

Based on needs assessment documents and consumer input surveys, stable, affordable and medically appropriate housing is the most significant need not being met for individuals living with HIV/AIDS in New York City. The following data, information and recommendations are taken from the January 2004 NYC EMA Housing Needs Assessment Report (Document #36):

Housing resources have expanded in response to the epidemic – nearly 23 percent of New Yorkers with HIV/AIDS now receive some type of public support to meet their housing

needs. New York City's system for housing persons with HIV/AIDS has served as an extremely effective public health intervention, improving the health status of New Yorkers with HIV/AIDS, while simultaneously reducing overall homelessness, caring for the homeless mentally ill, and providing housing to persons with substance use and other issues.

This unprecedented investment has demonstrated remarkable success in promoting stability and connection to health care for a group of people who might not otherwise find housing at all. Of more than 2,000 New Yorkers with HIV/AIDS surveyed as part of the Needs Assessment study, 64 percent are stably housed, having moved one or fewer times in the last three years, and more than 70 percent are satisfied with their housing. These findings are particularly impressive in light of the multiple and complex issues faced by these consumers, who report extremely high levels of past homelessness, co-occurring mental health and substance use issues, and histories of incarceration.

Housing stability leads to improved health: of those surveyed during the Assessment, 95 percent reported a relationship with a primary care provider, and 75 percent reported participation in life sustaining Highly Active Anti-Retroviral Treatment (HAART). Conversely, housing instability is associated with disruption of HIV care. A quarter of all respondents report that a lack of appropriate housing has at some point interfered with their ability to adhere to HAART and other HIV medications. The Assessment report notes that much of the stability can likely be attributed to "wrap around" support services, such as case management, medical and social day programs, harm reduction programs for active substance users, and mental health care, as they help keep people in independent housing and connected to care.

However, the housing system faces significant challenges in both the short and long terms. Many of these challenges are driven by population growth associated with improved treatment and decreased mortality. Data presented in the Needs Assessment report indicates that the current unmet need for housing among the 127,000 persons currently living with HIV/AIDS is 2,400 additional units. By 2010, the system will require a total of more than 15,000 additional housing units, a 53 percent increase from current capacity.

The Housing Needs Assessment Report indicates further that the homeless shelter population has increased by 82 percent since 1998, from 21,100 persons in shelters on a given night to 38,400 currently. The number of emergency housing placements made by the HIV/AIDS Services Administration (HASA) has also increased dramatically. In December 2003 alone, HASA made almost 3,000 emergency housing placements in transitional programs and commercial single room occupancy (SRO) hotels. If this trend continues, it would represent a nearly 300 percent increase in emergency placements since 2001.

The Report notes that New York City's HIV/AIDS housing system is particularly fragile as a result of its reliance on the private housing market with 86 percent of persons supported by the system receiving rental assistance or residing in subsidized scatter site units in the private housing market. The private market is becoming increasingly unaffordable in New York City, making it nearly impossible to locate apartments renting for the $480 per month standard enhanced rent provided to persons with HIV/AIDS.

The private market is also inhospitable to many groups of persons living with HIV/AIDS who have significant unmet housing needs, including people leaving jail and prison and those with past felony convictions, undocumented immigrants, persons of transgender experience, families with children, adolescents and youth aging out of foster care, persons in need of harm reduction services, and persons over age 50. Many persons with HIV/AIDS, moreover, experienced discrimination in securing and maintaining housing based on race/ethnicity, HIV/AIDS, and income source, among other factors.

The Needs Assessment Report details concrete recommendations necessary to improve New York City's existing HIV/AIDS housing system, and to meet the growing need for more housing. These recommendations relate to converting commercial SRO hotels to permanent affordable housing; increasing rental assistance; ensuring supportive services for clients in greatest need; creating a "land trust" to secure sites for future housing; and establishing a "bridge to work" for persons in the housing system to work without losing housing benefits.

Mental Health Services:

The 2004 Comprehensive Needs Assessment Report (Document #6) indicates that mental health needs persist across the EMA. Among CHAIN study participants, mental health service gaps are reported in all boroughs and across all racial groups. A November CHAIN presentation indicated a 42 percent mental health services gap for CHAIN participants across New York City.

The CHAIN Report 2004-1 on Service Gaps and Utilization in the NYC Continuum of Care (Document #124) indicates professional mental health services to be one of the top five service gaps for the newly recruited CHAIN cohort. (The original CHAIN cohort was recruited in 1994-95, and the refresher cohort was added in 1998.) A key finding of this analysis was that individuals with very low mental health scores are more likely to experience comprehensive medical care and housing gaps.

Substance and Alcohol Abuse Related Services:

The 2004 Comprehensive Needs Assessment Report indicates that service gaps continue to exist among persons with HIV/AIDS in New York City in need of alcohol and drug treatment services, with gaps distributed proportionately across boroughs and racial groups.

A November 2003 CHAIN presentation indicates a 60 percent substance/alcohol abuse treatment services gap for CHAIN participants across New York City. CHAIN study data indicates that exposure to trauma and violence among persons abusing alcohol and other drugs is a predictor of not maintaining continuous medical care.

The need for expanded access to syringes and for harm reduction services to engage substance and alcohol users in treatment are frequently noted.

Outreach, Early Intervention (Testing, Counseling and Linkage to Care), Comprehensive Health Care, and Treatment Adherence Education and Support:

The January 2004 HIV/AIDS Surveillance Quarterly Update (NYCDOHMH) indicates that although HIV surveillance data provide an incomplete picture of people living with HIV in

the New York EMA, the available data shows that a large proportion of persons newly diagnosed with HIV infection have evidence of advanced infection at the time of diagnosis. In 2002, 25 percent of these individuals had an AIDS defining event within 90 days of their HIV diagnosis. Late diagnoses do not vary substantially by gender, race/ethnicity, mode of transmission, or residence, although individuals age 40 and above had a disproportionately high percentage of late diagnoses.

CHAIN and NYCDOHMH data on delayed entry into care demonstrate a significant gap in seeking care. HIV/AIDS surveillance data found 38 percent of individuals newly diagnosed with HIV in 2002 lacked evidence of entry into care within 12 months of their HIV diagnosis, and 20 percent of CHAIN participants were found to have delayed entry into medical care by at least four months.

The 2004 Comprehensive Needs Assessment Report includes policy recommendations resulting from the above findings, which include providing more realistic treatment information at the time of test counseling; improving the ease, speed and convenience of HIV testing; assuring better linkages to medical care for HIV positive persons; and addressing such factors as housing, prior experience with medical care, and social isolation during test counseling. The New York State Department of Health 2005 modifications to HIV testing policies and processes are intended to increase access and streamline procedures. The need for broad scope outreach campaigns regarding HIV testing and linkage to care has also been identified.

Studies have found that patients participating in programs providing treatment adherence education and support strategies have maintained and even increased adherence to HAART over time. It is noteworthy that the need for enhanced treatment adherence education and support was frequently mentioned among service gaps, and that the 2004 CHAIN report (Document #124) identifies "patient/provider communication" among the top five service gaps for the newly recruited cohort. CHAIN study participants expressed the need for better explanation of treatment options, and the study report noted the absence of treatment adherence services among non-adherent study participants.

Comprehensive health care is needed to address the full range of medical needs of persons living with HIV associated with aging, effects of medications, and other medical conditions such as hepatitis, sexually transmitted diseases, tuberculosis, cancer, heart disease, diabetes and mental illness. The need for complementary and alternative therapies is noted, recognizing, in particular, the cultural beliefs of specific communities. To improve quality of care, the need for clinical education on standards of care and quality management provider training and technical assistance is noted.

Linguistically and Culturally Competent Services*:*

Diversity is the hallmark of the HIV epidemic in New York City, in terms of racial/ethnic composition as well as sexual orientation. The May 2004 CHAIN document (Document #125) indicates that 15 percent of the original study cohort and 13 percent of the new study cohort report delaying or not getting medical or social services because staff did not speak their language, were not competent, were disrespectful, did not understand clients' problems or were not good at listening.

Source documents representing the perspectives of African Americans, Latinos, Asian/Pacific Islanders, Native Americans, Caribbean Islanders and other immigrant groups commonly identified the need for cultural competency training of health and social service providers, more diversity among agency staff and languages spoken, and translation services as barriers to obtaining needed services, especially for recent immigrants.

Case Management:

According to a November 2003 CHAIN presentation, case management service gaps exist across all boroughs and racial groups. A November 2003 CHAIN report indicated a 20 percent case management service gap for CHAIN participants across New York City.

The Women's HIV Collaborative Report (Document #138) notes that the confluence of poverty, race, family responsibilities and stigma, coupled with poor health and fragmented service provision, represents major barriers to service access for HIV infected persons.

The CHAIN study documents the central role played by comprehensive case management, citing it as the linchpin to linking individuals to the services necessary to access and maintain them in care. Case managers often play a key role in benefits advocacy and entitlements assistance. Data from the 2004 CHAIN report indicates that individuals who do not have comprehensive case management have significant service gaps in comprehensive medical care, supportive mental health, permanent housing, and transportation. The report indicates this data suggests that if the comprehensive case management service gap is addressed, some of the other service gaps might also diminish.

The Title I Consumer Advisory Group Survey Report (Document #5) ranks case management as the Number 1 service category that promotes access to and maintenance in HIV-related primary care.

It is important to recognize that not all geographic areas have a shortage of case managers given current grant support for this service and case management available through approved providers participating in the Medicaid-reimbursed COBRA Community Follow-up Program. It is also important to recognize that case management should be provided at the appropriate level of intensity based on clients' needs. For example, in some cases a case manager will focus on empowering the client by imparting knowledge and contacts the client needs to negotiate the health and human service delivery system. Other clients with complex needs and periodic crises require more intensive case management, which results in more frequent contacts. In addition, if multiple case managers are involved with a single client, efforts must be made to communicate and establish distinct roles to eliminate duplicative efforts, and to ensure the client understands those distinctions.

Food and Nutrition Counseling:

The May 2004 CHAIN (Document #125) document notes that 58 percent of the new CHAIN cohort reported needing assistance with food, groceries and meals, and other concrete needs including childcare and legal matters.

The Title I Consumer Advisory Group Survey Report identifies Food/Nutrition among the top five gaps in HIV-related services, and among the top seven Title I service categories that promote access to and maintenance in HIV-related primary care. Consumers note the need for well-balanced, nutritious meals, nutrition counseling related to taking medications and associated food requirements, and more food pantries.

Transportation:

The need for enhanced transportation assistance is commonly mentioned by consumers, noting in particular the need for such assistance for persons with multiple disabilities. The Ryan White Title I Consumer Advisory Group Survey Report (Document #5) identifies transportation as one of the top five gaps in HIV-related services, and as one of the top ranked Title I services categories that promote access to and maintenance in HIV-related primary care.

The 2004 Needs Assessment Report documents a continuing transportation assistance need among CHAIN study participants — 45 percent among the original cohort, and 38 percent among the new cohort.

Additional service needs and barriers commonly mentioned by consumer groups and in other source documents include:

Medical:

- Dental and Vision Care
- Provider Training and Technical Assistance
- More Women-Centered Treatment and Female Providers
- Financial Assistance for Uninsured and Underinsured
- Clinical Research
- Home Care

Supportive Services and Education:

- Peer Education and Support Groups
- Legal Assistance
- Family Support, including Permanency Planning for Families in Transition, Child Life Services and Child Care
- Counseling, Individual and Group
- Community-Based Consumer Education to Improve Health Literacy
- Education Addressing Stigma and Discrimination
- Vocational Rehabilitation and Workforce Re-Entry
- Housekeeping Assistance
- Disclosure Assistance and Counseling
- Consumer Training
- Improved Discharge Planning for Prison/Jail Releasees

Service Delivery Models:

- Evening and Weekend Services, and More Timely Appointments
- Enhanced Service Integration, particularly for families

- Improved Service and Agency Coordination in terms of linkages and referrals, and between prevention and care
- Co-located Services
- Neighborhood Service Sites
- Mobile Medical Vans

Prevention:

- HIV Prevention Education, particularly for youth
- Prevention with HIV Positive Persons
- Social Marketing Campaigns (e.g., regarding increase in HIV among women of color)
- Microbicide Research

Policy Issues:

- ADAP – Full Funding and Expanded Formulary
- Medicaid Cuts
- Ryan White Reauthorization, including ADAP funding and continued coverage of supportive services
- Equitable Distribution of Resources among Boroughs
- Infrastructure and Administrative Support for CBOs
- Gap Health Care Coverage for Uninsured and Underinsured
- Improved Data Collection and Outcome Evaluation
- Rate Reform for AIDS Adult Day Care

Targeted/Special Needs Subpopulations

The Needs Assessment Report presents data associated with the following subpopulations identified in the 2004 Title I application as those disproportionately affected by the AIDS/HIV epidemic: injection drug users and other substance users; men who have sex with men (including those who identify as gay and those who do not), women, and youth ages 13-24. Among each of these subpopulations, the disproportionate impact on persons of color, particularly Blacks and Hispanics, is well documented.

The various source documents commonly identify specific subpopulations requiring special attention in addressing HIV-related service needs: immigrants, including recent arrivals and undocumented persons; adolescents and youth, particularly young persons of color; victims of domestic violence; incarcerated persons and releasees; women; seniors; perinatally infected children aging into adolescence; families; deaf persons; transgender persons; lesbians; and the multiply disabled. (See Section VI of this report, Special Populations, for more detail.)

D. Bronx

The Bronx ranks fourth among the five boroughs of New York City in terms of total population — 1.36 million representing 17 percent of New York City's total. Its population is very diverse: 51.3 percent are Latino, 31.2 percent are African American, 13.0 percent are White, 1.0 percent are two or more races or other, 3.2 percent are Asian/Pacific Islander, and 0.3 percent are Native American (US Census estimate for 2003). Cases diagnosed through December 2003 indicate that the Bronx has a disproportionate share of the epidemic — over 19,000 persons living with HIV/AIDS, representing 23 percent of total living cases in New York City. Of all living HIV/AIDS cases in the Bronx, 94 percent are among persons of color, with the overwhelming majority among Blacks and Hispanics.

Service Needs and Barriers

The Steering Committee of the Bronx HIV CARE Network selected the following as the top ten needs, emphasizing that all must be provided in a culturally and linguistically appropriate manner:

- Housing
- Treatment Education and Adherence Support
- Services for Inmates and Releasees from Criminal Justice Settings
- Services for Active Drug Users: Treatment Adherence, Access to Services
- Substance Use Treatment
- Job Training and Job Readiness Education
- Services for Young Gay Men of Color to address the rise in HIV cases
- Funeral and Burial services
- Peer Education and Support Groups
- Harm Reduction, including Syringe Exchange

Selected commentary from the Bronx HIV CARE Network Service Delivery Plan (2001) (Document #34) and other source documents regarding these needs includes the following.

Culturally Competent Services:

This is a critical need supported by the census and epidemiological data described above which shows the diversity of racial/ethnic groups and cultures in the Bronx. For example, treatment options must be clearly presented to patients in understandable language and with sensitivity to cultural issues.

Housing:

As noted in the Dominican Sisters Needs Assessment document (Document #120), the number of housing units, the presence of low income individuals and families, waves of immigrants, vulnerabilities to health issues, and more recently the gentrification of some areas have impacted the number and availability of affordable housing units. The Service Delivery Plan indicates there are not enough housing units available, and many of those that are on the market are in substandard condition. Because of the existing housing shortage and the procedures required to obtain housing, it is very difficult for people living with

HIV/AIDS to find permanent housing. Housing-related needs came up in all interviews and focus groups conducted to prepare the Service Delivery Plan, as well as at the SCSN/CP Community Forum. Forum participants emphasized the need for more housing specifically for PLWHA so that residents can address care and prevention issues, and the need for oversight of available housing to be sure it is in good condition and safe.
Also, the need for CARE Network involvement in housing advocacy was noted.

Serving Substance Users:

Injection drug use is the number one risk factor in the Bronx. More substance abuse treatment providers and modalities are needed; in particular, treatment programs tailored to the needs of women and women with children. Many substance users receive short-term treatment; more follow-up is needed once they leave treatment. Many agencies refuse to provide services to active drug users, and they often are discriminated against when seeking housing and other services. Treatment adherence education and support for this population was emphasized.

Job Training and Job Readiness Education:

Focus group participants noted that job training and job readiness education have become very important components due to the improved health and increased longevity of people living with HIV/AIDS. The need for vocational training for women and youth was noted in particular.

Peer Education and Support Groups*:*

More resources are needed for peer education and support groups to provide the facts relating to HIV transmission and risk reduction, influence behaviors and support maintenance in care. This need was emphasized at the SCSN/CP Commuity Forum. In particular, the need for the following support groups was mentioned in source documents: gay men of color; lesbians, bi-sexual and transgender persons, and harm reduction for substance/alcohol users.

Services for Young Gay Men of Color:

Young gay men of color have one of the most rapidly increasing rates of infection. Services targeted to their needs, including outreach, easily accessible counseling and testing, crisis intervention, and linkage to comprehensive health care, must be enhanced.

Additional service needs and barriers addressed in the Bronx Comprehensive Service Delivery Plan, the Planning Council Community Forum Report (Document #8), other source documents, and the SCSN/CP Community Forum can be summarized as follows:

Medical and Dental Care:

- Increased Access to Rapid HIV Testing to facilitate casefinding and early intervention
- Comprehensive Primary and Specialty Health Care, and reduction in waiting times when patients arrive for appointments
- Increased Access to Dental Care
- Treatment for HIV+ Persons Co-Infected with TB and Hepatitis

- Better coordination of services: health (e.g., HIV, STDs, Hepatitis, TB, Asthma) mental health, and substance use
- More clinical research

Mental Health:

- Continuum of mental health services for the following: all HIV+ persons, women, adolescents, families, those newly diagnosed with HIV, and mentally ill/chemically addicted (MICA) persons
- Better referral and follow-up system to keep persons in need of mental health services from falling through the cracks
- Education regarding mental illness to increase awareness and alleviate stigma and discrimination
- Need for care coordination that involves health, mental health and support service providers

Supportive Services:

- Domestic violence services for women, seniors and gay men of color
- Advocacy for entitlements
- Financial assistance for PLWHA
- Case Management that is culturally appropriate for immigrants; geared to needs of women and families
- Transportation assistance for medical and supportive service appointments, including Metrocards and car fare
- Legal assistance and advocacy
- Child care, particularly for young HIV+ mothers
- Bereavement support and financial assistance for funeral/burial expenses
- Services for families: permanency planning and families in transition
- Services targeted to and combined with other services for seniors

Other:

- Services located in Bronx neighborhoods to make them more accessible, preferably in community-based agencies that offer low-threshold services
- Co-located services that include prevention, treatment and support geared to the needs of women, children, youth and families
- Provider training related to cultural competency and gender sensitivity to improve customer service and help providers empathize with PLWHA
- Employment of HIV positive persons as case managers in community-based agencies and at the NYC HIV/AIDS Services Administration (HASA)
- HIV prevention education, particularly for youth
- Ensuring various methods for on-going consumer input and advocacy to ensure services are relevant, appropriately delivered, and meeting the needs of PLWHA.

The Bronx includes many subpopulations in need of targeted HIV/AIDS services. Some subpopulations highlighted in the source documents include:

Homeless Persons:

A CHAIN study indicated that "within a six-month period an estimated 3l of persons living with HIV in the Bronx reported that they had been homeless or unstably housed."

Adolescents:

Infants born to HIV infected women before the advent of AZT are now adolescents. They must cope with the ordinary challenges of teenage years while adhering to complex drug regimens. They are also at an age where mood disorders such as depression can occur. The greatest concern is for those who have grown up poor and exposed to drugs.

Participants at the SCSN/CP Community Forum noted that the needs of perinatally infected youth and those infected as adolescents are different, and services must be tailored to their distinct needs. HIV case data indicates that among young people under age 24, females are infected at higher rates than among older age groups, highlighting the need for focused prevention efforts.

Women*:*

One study in the South Bronx showed that 59 percent of women in the study had a diagnosis of post-traumatic stress disorder due to violent trauma such as assault, rape or witness to murder, and non-violent trauma such as homelessness, loss of children or serious accident. HIV case data indicates that women represent 42% of new cases among those diagnosed in 2003 from the Bronx, highlighting the need for prevention, care and supportive services that are women and family-focused.

Immigrants*:*

A significant number of Bronx residents are undocumented immigrants or have resident-alien status. Lacking language skills and knowledge of formal systems, they often face significant challenges and health risks, especially when they are undocumented. Even immigrant families who are eligible for benefits are reluctant to be tested for HIV or to seek out human services because they fear deportation. The following immigrants were identified as growing groups and underserved subpopulations due to the lack of agencies able to offer culturally competent services: Mexicans, West Africans, Asians, Dominicans, Venezuelans, and Columbians. It was also noted that newly arrived Puerto Ricans have difficulty accessing services.

Men of Color Who Have Sex with Men:

Enhanced agency and peer services are needed to reach these men, particularly those who do not identify as gay.

Inmates/Parolees/Releasees:

Coordination with outside services is a critical need as there is currently inadequate or nonexistent discharge planning for HIV+ releasees from jails and prisons. Treatment for Hepatitis C was also noted as an unmet need for this subpopulation.

Seniors:

The data gathering process for the Bronx Service Delivery Plan identified older adults as a population in need of services, including both HIV+ people who are aging and newly diagnosed older adults. Participants at the SCSN/CP Community Forum emphasized the need for targeted outreach to persons aged 50 and over, and education of providers regarding the need to address risk factors with clients/patients in this age group.

Additional comments from the SCSN/CP Community Forum:

- The need for more treatment education was noted, as well as the importance of HIV Prevention with positive persons.
- Two subpopulations not specifically mentioned above are in need of targeted services in the Bronx: transgender persons and Spanish-speaking immigrants.
- The distinct needs of transgender persons and lesbians need to better articulated in the Special Populations section of the document.
- Gaps in insurance coverage were noted, particularly for the working poor who are HIV+ and uninsured or underinsured but whose income is just above eligibility levels for programs like ADAP Plus Insurance Continuation (APIC). These individuals may not be able to obtain all prescribed medications because of lack of coverage.
- Education and training is needed for consumers and case managers to ensure PLWHA understand various options for coverage, such as mainstream Medicaid Managed Care, Special Needs Plans (SNPs) and new complicated Medicare Part D prescription drug coverage, as well as specific issues for persons dually eligible for Medicaid and Medicare. Participants are very concerned about the potential for disruption in accessing medications when Medicare Part D takes effect.
- The need for mental health services specifically tailored to the needs of adolescents under age 18 was noted.
- One participant recommended that peer education/services be included in virtually every category of service, and be included as a principle. Peers can be helpful with every aspect of HIV prevention and support, and through continuing training and fielding of peer educators that communities are empowered and develop leadership to fight the epidemic.
- Concern was expressed about the large number of orphans of the epidemic and what will happen to them when grandparents who have become their primary caretakers die. Concern was also expressed about the significant number of children and youth, both affected and infected, who have grown up in “HIV+ families.” The need for enhanced community-based family services and mentoring to help family functioning and stabilization was noted.
- Consumers expressed concern regarding the disparity in services provided by HIV/AIDS Services Administration (HASA) to persons who are HIV+ and those with AIDS, noting that HIV+ persons who are asymptomatic receive fewer services. They noted that more services earlier in the course of infection can serve as a form of prevention.

- The importance of consumer advocacy was emphasized. The critical role of the PWLHA Leadership Training Institute (LTI) in empowering consumer advocates was noted, as well as the need to expand its availability in the Bronx and throughout New York City. The LTI also fosters peer education on many topics, including prevention with positive persons.
- Participants expressed deep concern about potential disruption in services resulting from funding cuts; there was discussion regarding the need to be educated about CARE Act reauthorization issues and the need for advocacy. The important role played by CARE Networks on this and other issues was emphasized.

E. Brooklyn

Brooklyn ranks first among the five boroughs in terms of total population – 2.47 million or 31 percent of New York City's total. Its population is diverse: 20.3 percent are Latino, 34.5 percent are White, 35.2 percent are African American, 8.6 percent are Asian/Pacific Islander, 0.2 percent are Native American, and 1.1 percent are two or more races (US Census estimate for 2003). Cases diagnosed through December 2003 indicate that Brooklyn has over 21,600 persons living with HIV/AIDS, representing 26 percent of the total living cases in New York City. Of all living HIV/AIDS cases in Brooklyn, 87 percent are among persons of color, with the overwhelming majority among Blacks and Hispanics.

Service Needs and Barriers

A review of source documents, including Service Delivery Plans (Document #s 86, 97, 100) from three Ryan White CARE Networks (Williamsburg/Greenpoint/Bushwick; East New York/Brownsville; and Bedford Stuyvesant/Crown Heights) as well as numerous community data profiles and fact sheets, identified a wide range of HIV-related needs for this borough. Those identified across the three Brooklyn CARE Networks as the top service needs include:

- Housing and Related Supportive Services for Special Populations
- Comprehensive Medical Care (Primary and Specialty)
- Treatment Education and Adherence Support
- Mental Health Services, including services tailored to the needs of MICA population
- Substance/Alcohol Abuse Treatment
- Linguistically and Culturally Competent Services, particularly Spanish speaking services
- Case Management (assessing where gaps exist) and periodic training for case managers on clinical updates and methods to better serve clients
- Supportive Services, such as child care, legal assistance, transportation, peer education and support groups, job readiness programs, and permanency planning for families in transition
- HIV Prevention Education

The following service needs were identified by special population, and are supplemented by specific commentary regarding these special populations from the Brooklyn Service Delivery Plans:

Women:

Brooklyn has one of the highest HIV infection rates among Black and Latina women in the country. Needs assessments found that women in Brooklyn had significant unmet need for concrete supportive services, which often overshadowed their ability to connect to HIV providers and to benefit fully from available services. Service needs for women include: housing; transportation; case management and entitlements advocacy; comprehensive primary care co-located with OB/GYN care, family planning and STD treatment; legal assistance; permanency planning and family supportive services; domestic violence services; mental health and substance abuse treatment; on-site child care; and other supportive services.

***Substance/Alcohol Users and MICAs**:*

Over 40 percent of Brooklyn's cumulative AIDS cases are directly attributable to injection drug use, and many more heterosexual and MSM cases are indirectly attributable to substance use. Service needs identified for substance/alcohol users include: more outpatient and residential drug and alcohol treatment programs; more drug treatment programs that focus on the needs of women, pregnant women, and women with children; comprehensive drug treatment and case management for HIV infected substance users, with emphasis on benefits and entitlements assistance; scattered site housing programs for HIV positive recovering addicts; innovative treatment models for the MICA population; more effective linkages between medical, mental health and drug treatment providers; treatment programs that offer "after hours" services; extensive range of harm reduction services, including access to syringes, to provide gateway to substance abuse treatment; integration of Hepatitis C screening and treatment into all programs serving substance users; substance/alcohol use prevention education and counseling; expanded relapse prevention programs; and education on managed care policies and procedures regarding coverage and referrals for substance abuse treatment. Community Forum participants noted the need for enhanced education regarding safe injection and maintenance of wellness.

Men Who Have Sex with Men, particularly Men of Color (MCSWM):

This population accounts for slightly more than one-third of cumulative AIDS cases among African Americans and Latinos. Men of color who do not identify as gay often do not respond to prevention messages targeting gay men and are unlikely to seek testing and other HIV-related services. Service needs identified for this population include: increasing community awareness and understanding of MCSWM issues; culturally and linguistically competent services; prevention and health promotion messages that specifically target both gay and non-gay identified MSM; outreach and easy access to counseling, HIV testing and care, STD treatment, drug and alcohol treatment, and mental health services.

***Homeless Persons**:*

Quality affordable housing continues to be one of the most pressing unmet needs for HIV infected and affected persons in Brooklyn. In particular, the housing needs of pregnant women, women with children, active substance users including the MICA subpopulation, and persons dually diagnosed with HIV and TB were noted. There is unmet need for supportive housing programs that offer crisis intervention and linkages to address immediate needs and health issues. Participants at Community Forums noted that development of luxury housing in Brooklyn is pushing out long-time residents, mostly people of color, and is forcing more people into the shelter system.

Prison Releasees, Parolees and Probationers:

Epidemiological data indicates this population is at elevated risk for HIV, Hepatitis, and STDs, and Brooklyn is home to a significant number of releasees from the criminal justice system. Service needs identified for this population include: transitional housing with comprehensive supportive services; peer support groups; increased coordination between Corrections and Parole, particularly related to the unique needs of MCSWM; and case management and social support systems to ensure continuity of care and facilitate integration

back into communities upon release from incarceration. Participants at the SCSN/CP Forum emphasized the need for better release planning from prisons.

Immigrants, both Documented and Undocumented:

Brooklyn is home to numerous immigrant communities. These subpopulations have difficulty accessing services and systems due to language barriers and concerns regarding deportation**.** Service needs identified for immigrants include: linguistically and culturally competent health, case management and social service programs; more translation services; expanded outreach to link to HIV counseling and testing and needed services; legal assistance on issues of importance to immigrants; better coordination and more effective linkages among agencies that serve immigrant communities; and more enumeration and in-depth needs assessments of emerging immigrant populations. Participants at the SCSN/CP Community Forum emphasized the importance of ADAP and ADAP Plus for immigrants, and the need to ensure providers are trained regarding the services these programs provide for immigrant populations.

Adolescents and Youth:

HIV is increasingly a disease of the young and sexually active. To address HIV risk among young persons, programs are needed that address low self-esteem, sexual abuse and gang violence. HIV-related service needs identified for this population include: community-based, easily accessible "one-stop shopping" models for young people ages 13-24; integration of HIV prevention and service messages into settings that serve youth (e.g., schools, teen pregnancy programs, youth-focused minority organizations, and other CBOs that attract young people); programs to train and support youth as peer health educators; education, support and training for youth providers.

Seniors*:*

Approximately 25 percent of PLWHA in Brooklyn are 50 years of age or older. This proportion will continue to rise as HIV treatments result in increased life spans. This population presents unique challenges related to adherence, multiple diagnoses and medication contraindications, HIV and menopause, and the psychological effect of HIV on persons over 50. Service needs identified for this population include: integration of HIV messages into other programs serving seniors; capacity building and training for geriatric providers addressing sexuality and drug use; culturally sensitive HIV prevention, education, counseling, testing and linkage to health and other services; and more detailed surveillance of this population.

Additional specific service needs identified in the Brooklyn source documents for all populations include:

Medical:

- HIV Counseling and Testing
- Expanded Outreach to Link Persons to Care and ADAP
- Treatment of Hepatitis C, STDs and TB
- Clinical Trials
- Clinical Education and Cultural Competency Training for Providers

Supportive Services and Education:

- Food/nutrition services
- More faith-based initiatives
- HIV social marketing campaigns, particularly targeting Blacks and Hispanics
- Peer support groups, particularly for gay/lesbian/bi-sexual and transgender populations
- STD and Hepatitis C prevention education
- Consumer education regarding housing, immigrant rights and partner notification
- Updated information and referral services

Service Delivery Models:

- Co-located and better integrated and coordinated services
- One-stop medical and social services
- Services provided at night and on weekends

Policy Issues

- Enhanced funding for HIV-related services
- Equitable distribution of resources to Brooklyn

Additional comments received at the SCSN/CP Community Forum:

- Written comments were received emphasizing concern regarding the number of HIV positive people in Brooklyn who are not in care – either because they do not know their status, or are aware and not accessing care. To illustrate this concern, the writer noted that in a major Brooklyn hospital, patients are frequently diagnosed through the OB/GYN service, emergency room or inpatient services who are surprised by their HIV diagnosis. Greater emphasis on broad-based HIV awareness-raising, counseling, testing and linkage to care is very important in such settings.
- Supportive services are essential to link HIV+ persons to care and maintain them in care, particularly individuals who are living in poverty and struggling to meet basic subsistence needs. Testing needs to be tied directly to care connection.
- Transportation often presents a barrier to accessing care.
- The distinct needs of transgender persons and lesbians need to be better articulated in the Special Populations section of the document. Additional targeted services are needed for transgender persons, often extremely isolated and at high risk of HIV.
- The increasing number of Asian/Pacific Islander immigrants was noted, as well as the need to provide targeted prevention, care and services to these communities.
- Participants expressed their belief that Brooklyn is underfunded given their share of the epidemic. To the extent possible, limited available funding should support direct services based on community needs assessments with a minimum allocation for administrative costs.
- The importance of the role of the CARE Networks as a vehicle for community input should be more prominent in the SCSN and CP.

- Better agency coordination is needed to improve efficient delivery of services. In addition, improved adult education and health literacy services are needed to help HIV+ persons successfully navigate delivery systems, and to help with job readiness so that individuals can become more self-sufficient.
- The critical role of the PWLHA Leadership Training Institute (LTI) in empowering consumer advocates was noted, as well as the need to expand its availability in New York City and upstate. This training helps PWLHA with many issues, including disclosure and accessing services.
- "One-stop shopping" service models are important but clients should be allowed to choose if they want to obtain all services at one location or multiple locations. Options for accessing services help to ensure that confidentiality will be safeguarded.
- The need for expanded needle exchange services was emphasized. On-going training of law enforcement personnel is needed to prevent harassment of clients using this service.

F. Manhattan

Manhattan ranks third among the five boroughs in terms of total population – 1.56 million or 19 percent of New York City's total. Its population is primarily White (46.1 percent), but there is also considerable diversity: 27.4 percent Latino, 14.8 percent African American, 1.1 percent Mixed Race or other, 10.4 percent Asian/Pacific Islander, and 0.2 percent Native American (US Census estimate for 2003). Cases diagnosed through December 2003 indicate that Manhattan has over 27,750 persons living with HIV/AIDS, representing 34 percent of total living cases in New York City. Of all living HIV/AIDS cases in Manhattan, 63 percent are among persons of color, with the overwhelming majority among Blacks and Hispanics**.**

Service Needs and Barriers

A review of source documents, including Service Delivery Plans from two HIV CARE Networks (East Harlem and Central Harlem) (Document #s 105, 107), reports from Community Forums (Document #8) and providers identified a wide range of HIV-related needs for this borough. Those identified as the top service needs include:

- Housing
- Culturally Competent and Linguistically Appropriate Services
- Comprehensive Health Care, Treatment Education and Adherence Support
- Food and Nutrition Services
- Supportive Services, including transportation, legal assistance, case management, client/benefits advocacy, job training/readiness, and family support such as permanency planning and child care
- Mental Health Services
- Substance/Alcohol Abuse Related Services, including Harm Reduction, Detoxification and Treatment
- HIV Prevention Education, particularly for Youth
- Services for Special Populations, including Women, Families, Youth, MSM, Immigrants, Formerly Incarcerated Persons and Persons over 50

Selected commentary from the various source documents and the SCSN/CP Community Forum regarding high-risk populations and the above needs includes the following:

Housing:

The homeless population in Manhattan cuts across all age, gender and ethnic groups. The living conditions in shelters, SROs, and inadequate public housing are often breeding grounds for repeated exposure to TB and to behaviors that lead to transmission of Hepatitis C and HIV. Many housing units in poverty stricken areas of Manhattan are being extensively renovated to sell at huge profits. Most available scattered site housing is for single adults; there is a need for more placement assistance and supportive housing for PLWHA with families. Much of the available permanent housing is substandard and very often rejected even by those in dire need. After-hours emergency housing was also identified as a critical need.

Substance Users and Service Delivery:

The needs for this population focused on improved coordination among primary medical care and substance abuse treatment providers, screening and treatment for Hepatitis C, and expansion of needle exchange, particularly in East Harlem.

Mental Health Services:

Mental health service needs were consistently identified as an unmet need for all subpopulations affected by HIV/AIDS. The lack of sufficient mental health service programs for all PLWHA was highlighted, as was the need for programs that focus on the special needs of the MICA population and of families affected by HIV.

Food and Nutrition:

Community Forum participants emphasized the fundamental need for food and nutrition for persons with HIV/AIDS, noting that adequate nutrition is needed to stay healthy and to help prevent opportunistic infections. Nutrition education is very important, especially relating to what and when to eat while taking medications. The importance of nutrition education for persons with multiple diagnoses was also noted.

Women-Focused Services:

Women of color in Manhattan are disproportionately affected by HIV and are more likely to delay seeking care for themselves because they focus on survival needs for their families. The need to develop non-traditional services tailored to the needs and diversity of subpopulations of infected and affected women was underscored in community forums. The lack of childcare at service sites and the high cost of professional childcare were cited as barriers to care for many women. Outreach programs are needed that help high risk women meet immediate survival and health care needs, understand their HIV risk, and realize the importance of knowing their HIV status and seeking early care.

Men Who Have Sex with Men*:*

Men who have sex with men make up a significant proportion of AIDS/HIV cases in Manhattan. Programs targeted to address the specific needs of subpopulations of MSM are needed: MSM who identify as gay, men who identify as heterosexual but have sex with other men, and young MSM of color. These programs must be tailored to provide services that engage MSM, establish trust to allow for open communication between providers and clients, and provide a comprehensive array of services that address emerging needs that include increases in STDs, use of recreational drugs such as crystal meth and alcohol, and "prevention/treatment fatigue" among older MSMs.

Immigrants and Culturally Competent Services:

New arrivals in Manhattan include Hispanics from the Dominican Republic, Cuba, Mexico, Central and South America, West Africans, and Asians. Many new immigrants are undocumented, unemployed, without social support networks, lack access to medical care and face issues of cultural integration, poverty, language, illiteracy and substandard housing. Legal assistance services are essential for undocumented/new immigrants. More multi-lingual services are needed to better engage non-English speaking persons in care. The need for services in Spanish was particularly noted.

Formerly Incarcerated Persons:

This population in Manhattan faces many challenges as they transition from prison back into the community and many barriers to accessing medical care. For example, nearly 75 percent of the state's entire prison population comes from just seven zip codes, of which East Harlem is one. Wards Island Men's Shelter in East Harlem is home to 1,000 homeless men, many of whom are formerly incarcerated persons from throughout NYC who are often released without resources, benefits or appropriate access to health care. Transitional planning and case management are essential for this subpopulation.

Additional service needs and barriers identified in Manhattan source documents include:

Medical:

- More comprehensive medical care including: Vision, Prenatal, GYN, Hepatitis C, and TB
- HIV testing and assistance with notifying partners of HIV status
- Training and technical assistance for providers, especially cultural competency
- Developmental assessments/early intervention for children
- Home care and related supportive services

Supportive Services:

- Bereavement/grief support
- Domestic violence-related services
- Buddy/companion services
- Emergency financial assistance
- Pastoral counseling
- Peer education/support groups

Service Delivery Models:

- Evening and weekend services
- Integrated care and services for all, particularly families
- Intensive community outreach to high risk populations with HIV prevention messages and to increase linkage with and retention in care
- Enhanced pharmaceutical services
- Improved service linkages and referral, including hotlines

Prevention:

- HIV and general health education
- STD prevention education
- Education to reduce stigma and discrimination
- Social marketing campaigns

Policy:

- Increased resources to enhance HIV services
- Rate reform for AIDS adult day care
- Client advisory boards at more agencies

Additional comments from the SCSN/CP Community Forum:

- Participants expressed concern about potential funding cuts causing disruption in services and possible elimination of essential services that are not deemed to be the highest priority.

- The disproportionate impact on communities of color in general, and on Black men and women in particular, was emphasized. Discussion ensued regarding a meeting held by the Centers for Disease Control and Prevention (CDC) with prominent Black leaders to discuss why this is happening and preventive strategies.

- The need for targeted outreach and services for the increasing number of Asian/Pacific Islanders was noted.

- The distinct needs of transgender persons and lesbians need to be better articulated in the Special Populations section of the document.

- Perinatally exposed youth who are now aging into young adulthood face many challenges and are in need of targeted services.

- The negative effects of stigma and discrimination were emphasized, noting the need to enhance PLWHA and diverse community leadership as a way to combat stigma and discrimination. Education, skills-building and leadership training are needed to build capacity, ensure consumer input on policies and programs, and help PLWHA with disclosure issues and techniques. The Leadership Training Institute (LTI) was cited as an excellent model.

- The training and technical assistance needs of small Community-Based Organizations (CBOs) providing HIV prevention and support services were emphasized, especially in the areas of: grant writing and financial management, program planning, logic models and implementing scientifically proven interventions such as Diffusion of Effective Behavioral Interventions (DEBI), and process and outcome evaluation. The commenter felt the document should address organizational issues relating to the differences between larger, better-funded AIDS Service Organizations (ASOs) and smaller Community-Based Organizations (CBOs). His belief is that CBOs, despite their good work, suffer from lack of funding to hire grant writers and development directors which negatively impacts their ability to successfully compete for new grants that would allow them to deliver enhanced services -- effectively "shutting them out." As an example, the commenter noted that the shift toward scientific-based interventions impacts funding for CBOs since they are unable to develop these interventions and use them as examples of success when applying for funds. CBOs need a "stronger place at the table" to make their needs known and to better position themselves in competing for funds.

- The need to develop a two-page fact sheet drawing key facts from this document that describe the burden of New York's epidemic to educate decision makers and policymakers, particularly as it relates to reauthorization of the CARE Act, was noted.

G. Queens

Queens ranks second among the five boroughs in terms of total population – 2.23 million or 28 percent of New York City's total. Its population is diverse: 26.2 percent are Latino, about 31.5 percent are White, 19.9 percent are African American, 20.5 percent are Asian/Pacific Islander, 1.5 percent are Mixed Race or other, and 0.4 percent are Native American (US Census estimate for 2003). Cases diagnosed through December 2003 indicate that Queens has approximately 11,850 persons living with HIV/AIDS, representing about 15 percent of the total living cases in New York City. Of all living HIV/AIDS cases in Queens, 79 percent are among persons of color, with the overwhelming majority among Blacks and Hispanics.

Service Needs and Barriers

A review of source documents from the HIV CARE Network (Document #108) and Community Forums (Document #8) and the Regional Gaps Analysis (Document #113) identified the following as the most pressing needs in Queens:

- Housing
- Mental Health Services
- Harm Reduction Services
- Linguistically and Culturally Competent Services
- Transportation
- Food/Nutrition Services
- Comprehensive Health Care, Treatment Education and Adherence Support
- Substance and Alcohol Abuse Treatment Services
- Services for Women and Children
- Services for Immigrants
- HIV Prevention – Outreach and Education, particularly for youth and seniors

Selected commentary from the various source documents and the SCSN/CP Community Forum regarding high-risk populations and the above needs includes the following:

The Homeless and Need for Housing and Supportive Services

Queens faces tremendous challenges over the next several years with the growing demand for housing and supportive services for persons living with HIV/AIDS. The availability of affordable, appropriate housing was raised as one of the greatest unmet needs by over one-third of consumer survey respondents. The vague and often misunderstood regulations regarding housing are of great concern. The issue of survivor housing for family members and children, the inability to work and maintain housing, and the fear of losing medication assistance outside of scattered site, non-independent living are among the concerns for both consumers and providers. In addition, many persons with HIV in housing programs need very strong supportive services that meet immediate needs and help foster adherence with medical care and treatment regimens. Community Forum participants noted that many homeless residents of Queens have to leave the borough to find available housing and emphasized the need for more scatter site housing in Queens.

Mental Health Services:

HIV disease prompts a wide range of emotional and cognitive problems as infected adults and adolescents cope with the implications of infection, face changes in personal and work relationships, and negotiate the system of care and services. The stress associated with HIV infection typically exacerbates pre-existing mental health problems. Accessing a full continuum of mental health services is a primary concern for both HIV infected and affected Queens residents. Community Forum participants emphasized the need for services targeted to Mentally Ill/Chemically Addicted (MICA) persons.

Substance Users and the Need for Harm Reduction and Treatment Services:

There is a need for more harm reduction approaches in Queens, especially needle exchange programs. Treatment modalities demanding total abstinence often create barriers that prevent clients from accessing needed services. A research study conducted by the New York Academy of Medicine revealed that half of new injection drug users tested positive for Hepatitis C virus. This highlights the need for an increase in "low threshold" programs like needle exchange in Queens to reach substance users and link them to health care, substance and alcohol abuse treatment and other services.

Immigrants and the Need for Linguistically and Culturally Competent Services:

Queens is a community of immigrants, including many from Central and South America, the Caribbean, Africa and Asia, who cannot access services due to linguistic isolation and changes in entitlement laws. The Queens PLWHA community is culturally diverse and complex with over 140 languages spoken there. Specific knowledge and resources are needed for the development of effective intervention strategies because these subpopulations are hard to reach through traditional service delivery systems and require specialized and culturally competent services.

Transportation:

Persons dependent on public transportation in Queens, the City's largest borough by landmass, frequently find schedules and routes inadequate, and often have to pay more than one fare. In addition, handicapped transportation is not universally available. Transportation has been consistently identified as a barrier to care and to participation in support programs. Community Forum participants emphasized that mass transit needs to be available during later hours so that clients can access services during the evening.

Food/Nutrition:

HIV infected persons have nutrition-related needs that are a direct result of their disease. Those who are poor and/or who have a history of serious alcohol/substance abuse typically have nutrition-related problems pre-dating their HIV infection. Food requirements associated with complicated treatment regimens highlight the need for food distribution and nutrition counseling programs that ensure an adequate supply of food and help PLWHA understand the dietary requirements related to their medications.

Comprehensive Care, Treatment Education and Adherence Support:

Persons with HIV and AIDS, like all other community residents in Queens, should be able to obtain a full range of medical care with minimal difficulty. Available care should cover a continuum of care running from prevention through primary care to specialized services and long term care. The dramatic availability of different treatment options and further research has created a critical need for patient and provider support regarding treatment education, including potential side effects, contraindications for medications, and strategies to help with treatment adherence.

Women, Children, Adolescents and Families:

The face of HIV/AIDS in Queens indicates growing numbers of women of childbearing age living with HIV/AIDS and, consequently, a growing number of families with children and adolescents who are either infected or affected by HIV/AIDS. Meeting the needs of women, children and families affected by HIV has become a priority in Queens. Needs identified for this population include entitlements advocacy, childcare, respite care, and permanency planning.

Additional service needs identified in Queens source documents include:

Education:

- Training for health and human services providers, particularly related to cultural competency. SCSN/CP Community Forum participants emphasized the need for a training site located in Queens to improve access and participation
- Education to reduce stigma/discrimination
- Media campaigns – culturally and linguistically appropriate

Supportive Services:

- Family support services, including permanency planning
- Peer education/support groups
- Prevention Case Management
- Transitional services for Criminal Justice releasees

Service Delivery Models:

- Enhanced Outreach to High Risk Populations, particularly to MSM, Immigrants, Criminal Justice releasees, MICA persons
- Enhanced coordination of services
- Co-located services
- Mobile Medical Vans

Policy Issues:

- Continued Funding for Support Services
- Better Surveillance Data relating to risk factors
- Comprehensive Sex Education and Condom Distribution

H. Staten Island

Staten Island is the smallest of the five boroughs with nearly 460,000, or about 6 percent, of New York City's total population. Its population is primarily White (68.2 percent), but there is also considerable diversity: 14.3 percent Latino, 9.6 percent African American, 6.7 percent Asian/Pacific Islander, 1.0 percent Mixed Races or Other, and .2 percent Native American (US Census estimate for 2003). Cases diagnosed through December 2003 indicate that Staten Island has approximately 1,600 persons living with HIV/AIDS, representing 2 percent of total living cases in New York City. Of all living HIV/AIDS cases in Staten Island, 62 percent are among persons of color, with the overwhelming majority among Blacks and Hispanics.

Service Needs and Barriers

A review of source documents from the HIV CARE Network (Document #83) and Community Forums (Document #8) and the Regional Gaps Analysis (Document #114) identified the following as the most pressing needs in Staten Island:

- Housing and On-Site Supportive Services
- Harm Reduction, including Access to Syringes through Syringe Exchange and ESAP, and Substance/Alcohol Abuse Treatment Services
- Mental Health Services, including services for MICAs
- Food and Nutrition Services
- Dental Care
- Supportive Services, including Transportation, Client and Entitlements Advocacy, Case Management, Counseling, Legal Assistance, Child Care and Respite Care for Children of Infected Adults

As part of the SCSN/CP Community Forum Process, the Coordinator of the Staten Island CARE Network provided written comments indicating the Network is currently updating the Staten Island Service Delivery Plan for release in 2006. Findings from consumer focus groups held to date validate major concerns and service needs in the following areas: housing, transportation, continuum of mental health services (the need for counseling and therapy was emphasized, in addition to prescription medications), food and nutrition, and a needle exchange program located on Staten Island to improve access.

Selected commentary from the various source documents and the SCSN/CP Community Forum regarding high-risk populations and the above needs includes the following:

The Homeless and Housing:

Chronic homelessness among PLWHA results in little or no access to health care. Exposure to the elements produces more medical complications, and high-risk behaviors continue in order to survive on the streets. Homeless people need a range of housing options that provide access to, as well as maintenance in, health care. Specific subpopulations in need of housing include IDUs, immigrants, women, children and domestic violence victims.

In focus groups held by the Network, consumers indicate that homelessness tends to disrupt their treatment, raises their risk of developing drug resistance, jeopardizes their mental well-being, and leads to relapse in abusing substances.

Comments received at the SCSN/CP Community Forum indicate that affordable and appropriate housing remains the most critical need noted by consumers and providers. Over the last three years, a continuum of housing services has begun to be established on Staten Island to help PLWHA smoothly transition from the street or substandard living. This continuum includes some emergency housing in hotels, congregate housing, and scatter site transitional housing, as well as three AIDS-specific housing placement assistance programs. HOPWA funding supports some hotel placements for Staten Island families while transitioning to permanent housing. Although a 24-unit supportive housing program was added in 2005, Staten Island needs additional scatter site supportive apartments (HASA Scatter Site I model) to sustain clients in housing linked to care for the duration of their lives. Staten Island still lacks long-term congregate HIV housing for people with multiple needs, as well as adequate supported SROs and emergency HIV housing for families.

It is important to note that in a tight housing market that consists primarily of one and two-family homes, it is difficult to locate affordable, appropriate housing for any person living on a fixed income. The shortage will be exacerbated by a plan to demolish Markham Gardens, a low income housing complex, and replace it with less units of mixed income housing. Adequate resources to support a comprehensive housing continuum would allow movement into emergency, transitional or permanent housing based upon choice, severity of need and personal capacity.

Housing-related supportive services are essential. Comments received at Community Forums indicate that Staten Islanders served in scatter site apartments benefit greatly from available supportive services such as case management, through which individuals access needed entitlements, medical, mental health and substance abuse services, resulting in improved overall health and well-being. Many improve to the extent that they are engaging in vocational training and learning new skills that strengthen and support the gains they have made.

Injection Drug Users and Syringe Access:

Staten Island has one of the highest rates of infection due to intravenous drug use in NYS. While 40 percent of cumulative AIDS cases in NYC reported IDU as the risk factor, in Staten Island IDU accounted for 48.8 percent of all male cases reported, and 45.4 percent of all female cases. Yet, Staten Island is the only borough with no approved syringe exchange program. There is an extreme need on Staten Island for a Syringe Exchange Program which offers IDUs sterile syringes free of charge, coupled with other services such as counseling, HIV testing and access to drug treatment. Comments from the SCSN/CP Community Forum indicate the need for comprehensive strategies for access to clean syringes, which includes continued support of the Expanded Syringe Access Program (ESAP) to ensure persons are knowledgeable about this option for syringe access. Harm reduction services must include safe injection information, HIV testing, treatment options and referrals, hepatitis screening and vaccination, and overdose prevention.

Food/Nutrition Services:

The Food Bank for New York City reported in 2002 that Staten Island had the greatest unmet need in terms of feeding programs among the boroughs; 66 percent of Staten Island soup kitchens and 71 percent of the food pantries experienced an increased demand for emergency food assistance. The HIV-specific food programs in the borough noted this same increased demand. Clients have expressed a need for fresh fruits and vegetables, which are generally in short supply at emergency food programs.

Despite valiant efforts to increase food donations in the community, the food pantry cannot continue to provide an array of necessary food to the hundreds of HIV-positive people who use the service. Additional funds for food must be allocated to meet the growing food needs of Staten Island clients. It is imperative for the sake of improved health outcomes that food required in connection with medication adherence is provided to everyone in need. In focus groups held by the Network in 2005, consumers reiterated that pantries have not increased the quantity and nutritional quality of products to meet increased demand.

Dental Care:

While some dental care is provided through hospital-based programs, access to dental care on Staten Island for people with HIV, both uninsured and those with Medicaid, needs to be expanded.

Supportive Services:

Limited public transportation options (i.e. no subway and insufficient bus routes) present a formidable barrier to accessing care in terms of both availability and affordability. Despite transportation needs on Staten Island, there has been a recent reduction in funds supporting transportation services. This barrier makes it even more important that consumers have the ability to obtain HIV services in neighborhoods where they live.

Community Forum comments indicate that funding for another important service was recently eliminated — a day care program providing comprehensive on-site services to active drug using and mentally ill homeless people living with HIV and AIDS on Staten Island.

There is a continuing need for support of legal assistance as the number of HIV+ persons seeking such services increases. These services include attorneys specializing in family law and housing law, and a Spanish speaking attorney addressing immigration issues.

Additional service needs identified in Staten Island source documents include:

Medical:

- Comprehensive Health Care, including Hepatitis Screening and Treatment
- Outreach to high risk communities and broader access to HIV Counseling and Testing and Early Intervention
- Treatment Education and Adherence Support for Patients
- HIV Prevention and Harm Reduction Training for health care providers
- Home Delivery of Medications

- Alternative/Complementary Therapy

Supportive Services:

- Family Support Services
- Vocational and Job Training/Placement
- Clothing Bank
- Emergency Financial Assistance
- Therapy for Children Affected by HIV
- Peer Advocacy and Support Groups
- Day Treatment Programs
- Hospice

Service Delivery Models:

- Better integration of prevention and care services and use of mobile vans
- Outreach at community and sporting events
- Better coordination of mental health, substance abuse and HIV services
- Improved information and referral services
- Faith-based initiatives
- Linguistically and culturally competent services for immigrants, including Bi-lingual services and targeted outreach to Latino communities
- Neighborhood-based services and evening hours

HIV Prevention:

- HIV education campaigns through media, speakers bureau and community outreach and education initiatives
- Prevention case management
- Behavioral-based counseling
- Condom distribution
- Peer outreach and education
- Adolescent-focused education

Policy Issues:

- Increased funding for Staten Island
- More information regarding "men on the down low"
- Rate reform for adult day care

Additional comments from the SCSN/CP Community Forum:

- Immigrants living on Staten Island, including those who are undocumented, are in need of targeted outreach and linkage to prevention and services.

- Written comments from Community Health Action of Staten Island indicates that in 2001 and 2002, Staten Island had the highest age-adjusted death rate from HIV and the highest percentage of people diagnosed concurrently with HIV and AIDS in New York City. In 2003, these trends appear to be improving, but this data suggests the need for expanded and aggressive outreach, HIV testing and early intervention programs.

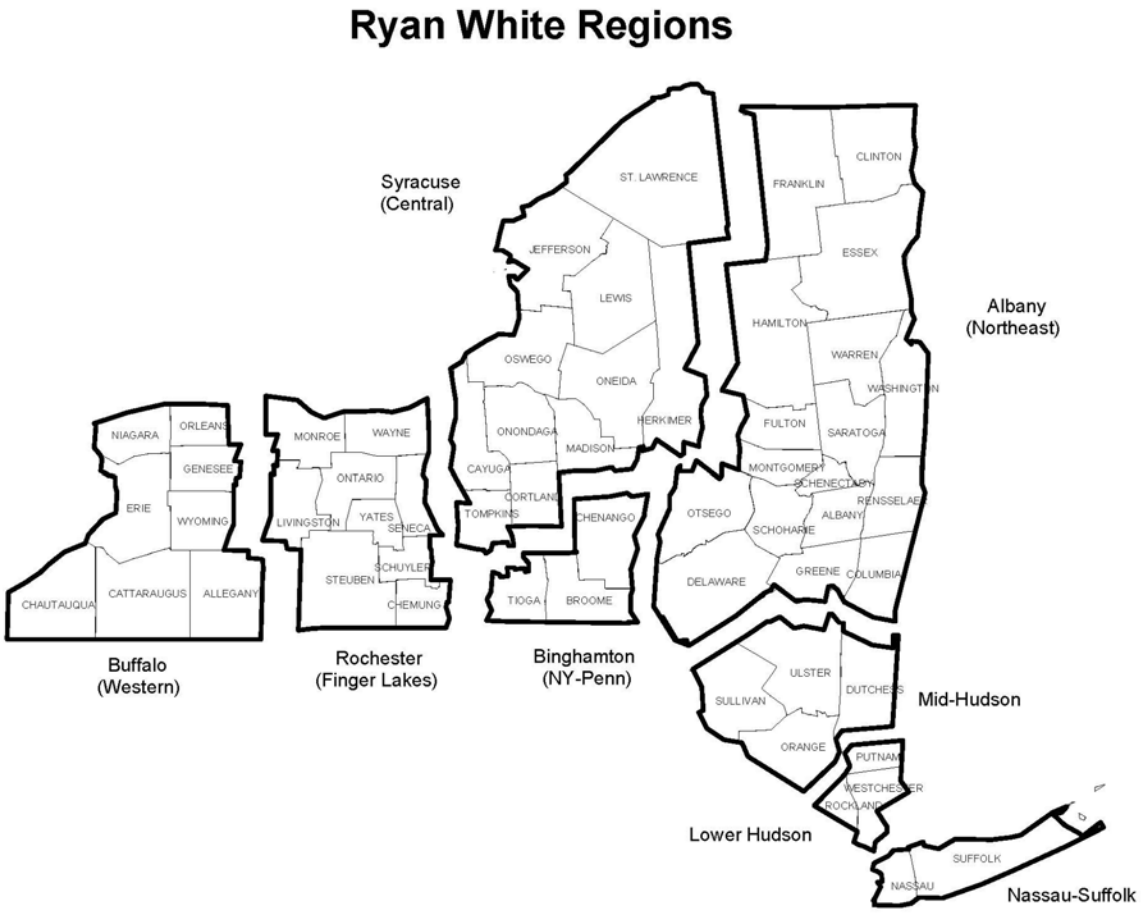
- There are still pockets of ignorance and prejudice that prevent lesbian, gay, bi-sexual and transgender (LGBT) persons on Staten Island from seeking and obtaining both HIV care and prevention services. In 2004, the percentage of new HIV cases on Staten Island with MSM reported as the transmission risk increased by 50%. This speaks to the continued need for targeted, culturally competent LGBT prevention and service programs to reach and serve these communities.

- Concern was expressed at the Community Forum regarding future access to care for the uninsured since the major provider of uninsured care and the only AIDS Designated Center on Staten Island, St. Vincent's Catholic Medical Center, is in bankruptcy and for sale. There are no City Health and Hospital Corporation (HHC) facilities or Federally Qualified Health Centers (FQHCs) on Staten Island.

- Major concerns were expressed about threats to the Ryan White CARE Act and to Medicaid, accompanied by the perception the epidemic is "controlled". Education and advocacy are needed to prevent "dismantling" the systems built over the last 20 years with the goal of providing comprehensive, accessible, and respectful services for all.

I. Upstate (New York State, Excluding New York City)

The 57 counties outside of New York City are generally referred to as "Upstate." These counties include both urban and rural areas resulting in needs that vary widely depending on place of residence, socioeconomic status, risk factors, and cultural heritage. There are eight multi-county Ryan White CARE Network Regions outside of New York City depicted on the map below.



Service Needs and Barriers

Since service needs and barriers are described in more detail for each Region, a summary listing is provided here of the identified service needs across Upstate Regions, gleaned from the source documents. It is important to note that some services such as home-delivered meals, home health care, and hospice are in much lower demand due to treatment success. However, there are some regions that note a need for these services in certain localities.

Medical and Dental Care and Related Needs:

- Comprehensive Health Care, including Primary (HIV, STDs, Hepatitis, TB) and Specialty Care for all persons including those who are uninsured, underinsured or enrolled in Medicaid or ADAP Plus
- HIV Testing
- Treatment Adherence Education and Support
- Dental Care
- Vision Care
- Financial Assistance for Uninsured and Underinsured
- Access to Clinical Trials
- Alternative/Complementary Therapy

Housing and Related Support Services:

- Emergency Shelter/Placement Assistance
- Permanent Housing
- Transitional Housing
- Emergency Financial Assistance
- Supportive Housing Services

Substance/Alcohol Abuse Related Services:

- Substance/Alcohol Abuse Prevention Education and Counseling
- Residential Treatment, particularly for women and women with children
- Harm Reduction, including Syringe Exchange and expanded access to syringes

Mental Health Services:

- Individual and Group Counseling
- Residential Care for Serious Mental Illness
- Psychiatric Services
- Services for the Mentally Ill and Chemically Addicted (MICA)

Linguistically and Culturally Competent Services:

- Translation Services
- Provider Training

Outreach:

- At Community Events and in Neighborhoods for Case Finding and Linkage to Care, particularly among subpopulations at high risk of HIV.
- Broad scope outreach campaigns to encourage HIV testing and linkage to care

Case Management at varying levels of intensity based on the complexity of the client's needs, and in a variety of settings

Food/Nutrition:

- Food Banks/Pantries
- Congregate Meals
- Home Delivered Meals
- Nutrition Counseling

Transportation and Legal Assistance were consistently identified as key supportive services that enable linkage to and retention in care for HIV positive persons.

Other Supportive Services:

- Peer Education and Support
- Emergency Financial Assistance
- Vocational Training and Job Placement
- Client Advocacy, including entitlements and benefits assistance
- Family Support Services, including permanency planning for families in transition and child care
- Information and Referral
- Caregiver Support
- Day/Respite Care
- Buddy/Companion
- Bereavement/Grief Support

Service Delivery Models:

- Evening and Weekend Services
- Enhanced Continuity of Care and Service Integration, particularly for families
- Improved Service Coordination in terms of linkages and referrals, and between prevention and care
- Co-Located Services
- Mobile Medical Vans
- Neighborhood Service Sites
- More Accessible Services for Rural Residents

HIV Prevention and Education:

- HIV Risk Reduction Education and Counseling
- Community-Based Consumer Education to Improve Health Literacy
- Prevention with HIV+ Persons
- Youth-Specific HIV Prevention
- Condom Distribution
- Prevention of STDs
- Peer Education
- General Health Education
- Education Addressing Stigma and Discrimination

Training and Technical Assistance for Providers:

- Cultural Competency
- Clinical Education
- Capacity Building to Improve Quality of Care

Chronic Care:

- Adult Day Treatment
- Home Health Care
- Hospice

Policy Issues:

- ADAP – Full Funding and Expanded Formulary
- Medicaid Reform and changes in coverage
- Ryan White Reauthorization, including ADAP funding and continued coverage of supportive services
- Infrastructure and Administrative Support for Community-Based Organizations (CBOs)
- Gap Health Care Coverage for Uninsured
- Equitable Distribution of Resources and funding levels that allow services to keep pace with increasing demands
- Improved Data Collection and Reporting and Outcome Evaluation
- Rate Reform for AIDS Adult Day Care
- Increased Resources for HIV Prevention
- Comprehensive Health and Sex Education for Youth

Targeted Subpopulations:

The following subpopulations were consistently mentioned in the source documents received. The characteristics of many of the subpopulations are described in the Special Populations section of this report.

- Persons of Color, including Black, Hispanic, Asian/Pacific Islander, and Native American
- Substance/Alcohol Users, particularly Injection Drug Users (IDUs)
- Men Who Have Sex With Men (MSM), particularly Men of Color Who Have Sex with Men (MCSM), including gay men and men who do not identify as gay
- Women
- Adolescents/Youth
- Immigrants
- Homeless
- Mentally Ill and Chemically Addicted Persons (MICA)
- Persons Co-infected with HIV and Hepatitis
- Persons Co-infected with TB
- Criminal Justice System Releasees/Parolees
- Victims of Domestic Violence
- Migrants and Seasonal Workers
- Perinatally Infected Infants/Children/Youth and Family Members
- Seniors
- Transgender Persons
- Lesbians
- Deaf Persons
- Residents of Rural Areas
- Persons with STDs

J. Albany (Northeastern) Ryan White Region

There have been nearly 4,000 AIDS cases reported in this 17-county region since the beginning of the epidemic, and nearly 3,450 persons are living with HIV or AIDS. Of the newly diagnosed HIV cases (2001-03), 55 percent are among persons of color. This region covers the largest geographic area in the State, stretching from the Hudson Valley to the Canadian border. Albany County, the most populous county, has 27 percent of the region's AIDS cases, but every one of the 17 counties has reported AIDS cases. Among Black and Hispanic males living with HIV/AIDS in the region, IDU is the primary risk factor but is closely followed by MSM. Among White, Asian/Pacific Islander and Native American males, MSM is the predominant risk factor. Among females living with HIV/AIDS, heterosexual transmission is the primary risk factor across racial/ethnic groups, with the exception of Native Americans where IDU is the primary risk factor.

Service Needs and Barriers

The following list identifies the top service needs for this Region based on CARE Network Service Delivery Plans, including the most recent Plan developed and approved in 2005 (Document #161), Regional Gaps Analysis (Document # 115) and other information provided for this region:

- Case Management
- Dental Care
- Outpatient and Specialty Care
- Housing
- Mental Health and Psychosocial Support
- Transportation
- Nutrition
- Substance Abuse Services

As part of the 2005 Service Delivery Plan process, the following summaries and recommendations were developed by the CARE Network to directly correspond to the above top service needs for this Region.

Case Management:

- As the incidence of HIV and AIDS continues to increase in the region and people are living longer, case management services must be increasingly flexible as clients' needs fluctuate over the course of their illness. The AIDS Institute's current efforts to address this concern through the development of an integrated, flexible case management model should be sustained.

- Flat funding for grant-supported case management services, as well as proposed cuts in Medicaid, limit the ability of service providers to increase the number of staff available to address the growing demand for services. Increased funding,

and more flexible funding, for case management services is necessary to ensure that people do not have to wait for help when they need services.

- While providers of AIDS-specific case management services in the region have developed mechanisms for coordinating service delivery and reducing duplication of services, the difficulties related to fully coordinating care for infected individuals who also require mental health and/or substance abuse services have yet to be resolved satisfactorily. The Coalition for Coordinated Care's effort to establish and coordinate effective multidisciplinary communication to eliminate barriers to serving the HIV-infected and affected population in Northeastern New York should be sustained and supported by the AIDS service delivery system.

Dental Care:

- The practice of good preventative dental care is related to positive health outcomes. Both consumers and health care providers need to be better educated about the value of good oral hygiene for those infected with HIV/AIDS.

- There is limited access to Medicaid funded dental care throughout the Network region, as low reimbursement rates present a major barrier to the widespread provision of these services. Enhanced Medicaid reimbursement for dental services is essential if the availability of these services throughout the region is to be increased.

- The Ryan White HIV Dental Care Clinic at Albany Medical Center provides the only HIV-specific oral care in the Network region. This service is constantly threatened by loss of funding and is difficult for clients to access from outside the Capital Region. Long-term funding for HIV specific dental services needs to be assured and dentists in private practice should be both encouraged and trained to treat HIV infected individuals.

Outpatient and Specialty Care:

- The ease of access to outpatient medical care varies across the Network region. The Regional Designated AIDS Center in Albany treats the majority of PLWHA in the region, but many consumers are unable to utilize these services on a regular basis due to the distance they must travel to come to the center. This leads to many clients using a primary care physician to provide some of their care, with occasional visits to an HIV specialist. Strengthening and enhancing the transportation options available to consumers would help ease some of the difficulties related to consistently accessing AIDS-specific medical care.

- Implementation of routine rapid HIV testing and case finding is expected to increase the already heavy burden on the existing medical care system. Trends in

service demand and barriers to service access should be continuously monitored, and this data should be utilized to support service expansion as necessary.

- Many specialty care providers do not accept Medicaid or ADAP Plus insurance reimbursement. Enrolling in Medicaid Managed Care plans would allow PLWHAs access to certain specialty care services, but may limit access to others. Case managers need to be trained to help educate consumers about their insurance and medical care options in order to help them make informed choices and select the coverage that best meets their needs.

Housing:

- Safe, affordable, appropriate housing is difficult to find throughout the region and HOPWA funding and Section 8 programs are operating at capacity in the region's urban areas. Funding support for housing assistance programs that are not specifically designed to address homelessness should be increased.

- While ADM-90 (rental assistance for persons with disabilities, including HIV/AIDS) has been implemented at the state level and is theoretically available through county Departments of Social Services (DSS), this program has not been utilized effectively in the Network region. This may be due to inadequate information and/or staff training at the county DSS level, or to lack of sufficient time at the case manager level to advocate with DSS for approval of the ADM-90 rental assistance stipends.

Mental Health and Psychosocial Support Services:

- Access to HIV-specific mental health care is limited throughout the region. Funding for HIV-specific mental health services should be increased and training should be made available to providers of mental health services to support their ability to appropriately treat PLWHA.

- Bundled reimbursement rates limit access of PLWHA to mental health treatment due to concerns about the inability of capitated rates to accommodate the high cost of required medications. Efforts should be directed toward identifying mechanisms that allow for more flexible funding of mental health services for HIV infected individuals.

- Coordinating care for infected individuals who also require mental health and/or substance abuse services continues to be an ongoing challenge for the service delivery system. The Coalition for Coordinated Care's effort to establish and coordinate effective multidisciplinary communication to eliminate barriers to serving the HIV-infected and affected population in Northeastern New York should be sustained and supported by the AIDS service delivery system.

- Drop-in community centers have shown to dramatically impact the availability of social support and meal programs, especially in the evenings and on weekends. Peer-based support and referrals have shown to increase collaboration of providers and consumers in having needs met faster and more efficiently. Efforts should be made to increase support to existing peer-based community centers and increase availability of such centers in areas that do not have them.

- Strengthening and enhancing the transportation options available to consumers would help ease some of the difficulties related to participating in support groups as well as in accessing appropriate and consistent AIDS-specific mental health care. Developing alliances with Area Agencies on Aging and faith based organizations, many of which have vehicles and drivers who may be able to alleviate some of the transportation issues, is an avenue that should be explored.

Transportation:

- Transportation barriers limit access to services as well as to activities that support healthy living for many consumers in the region. These barriers are related both to the region's wide and varying geography as well as to restrictive funding guidelines and funding limitations. Expanded funding, more flexible funding, and partnerships with other transportation providers should be sought to enhance the transportation options available to PLWAs in the region.

Nutrition:

- A healthy balanced diet is essential to health maintenance for individuals with HIV/AIDS. Consumers, treatment facilities, and emergency food providers should be educated about the specialized nutritional needs of infected individuals and how these can be addressed through appropriate food selection, meal preparation, and food storage. Additionally, baseline and periodic Bio Impedance Analysis (BIA) should be encouraged at medical facilities throughout the region as a standard of care to assist clients in maintaining a healthy body mass.

- Congregate meal programs for HIV infected individuals are available in some areas of the Network, but require the ability to travel to the site of the meal, thereby limiting access to those affected by transportation barriers. As previously noted, the transportation options available to PLWHA in the region need to be strengthened and enhanced.

Substance Abuse:

- HIV and substance use are closely linked; and substance abuse and MICA treatment facilities have been identified as a high priority setting for HIV prevention education. Support for prevention education programs targeted toward these facilities should be sustained and opportunities to provide testing and counseling in these facilities should be expanded.

- Harm reduction efforts, including syringe exchange programs, are essential to the prevention as well as treatment of HIV/AIDS. Although the Network region is actively promoting ESAP and has placed needle disposal kiosks in some communities, the region lacks a syringe exchange program. Options for establishing a syringe exchange program in the region should be explored.

- As previously noted, coordinating care for infected individuals who also require substance abuse and/or mental health treatment continues to be an ongoing challenge for the service delivery system. The Coalition of Coordinated Care's effort to establish and coordinate effective multidisciplinary teams that eliminate barriers to serving the HIV-infected and affected population in Northeastern New York should be sustained and supported by the AIDS service delivery system.

Legal Services:

- Enhanced availability of legal services is needed to assist HIV infected persons to secure and maintain entitlements, address issues of discrimination, strengthen case managers' roles as advocates, and restore availability of permanency planning programs.

- Compelling comments regarding the need for expanded resources to support legal assistance for low income PLWHA were received at the SCSN/CP Community Forum and are included in full in Section IX of this document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans. Citing specific data, the commenters note that comparing available program resources to Health Department statistics on PLWHA in the Albany Region, "the Legal Aid Society of Northeastern New York has one lawyer to serve 3,400 people living with HIV or AIDS." Cited program data confirm that the legal needs of low income PLWHA most often involve protecting basic survival needs, including housing, income, health and family matters – 79% of cases in 2004.

Albany region documents also identified service needs and barriers by specific population groups:

- **Inmates/releasees** require the following services:
  - Transitional housing assistance
  - Case management
  - Long term counseling services
  - Services to the families of inmates
  - Anonymous counseling and testing in facilities
  - Support groups in institutions
  - Increased collaboration between outside specialists and primary care providers inside institutions

- There is a continuing need for services targeted specifically toward **women** in recognition of their unique needs. In particular, outreach and education to women who are planning a pregnancy, especially young women, is needed. Many teen mothers in the region have late third trimester or no prenatal care. In addition, adult women may not enter prenatal care early or at all, placing themselves and their babies at risk.

- More services for **children, adolescents and families,** including at a minimum:
  - Subsidized child care to allow families to access needed services
  - Respite care for families, both planned and on an emergency basis
  - Outreach and social supportive services
  - Permanency planning programs
  - Anonymous counseling and testing for youth.

- **Migrants/seasonal workers** are generally unaware of methods of preventing STDs and HIV infection. Focused efforts to reach this population require innovative approaches by outreach educators, involving collaboration with employers.

- Special considerations must be given to providing outreach, prevention education and clinical intervention to **mentally retarded/developmentally disabled** individuals that live communally and within the community.

Other service needs and barriers in this region were described in source documents and at the SCSN/CP Community Forum:

- Increased **outreach/education and counseling and testing efforts** must be targeted to the following at-risk populations: adolescents, females, persons of color, men who have sex with men, intravenous drug users, the homeless, and older adult populations.

- More physicians trained in HIV/AIDS care services for adults and youth in rural areas are necessary to ensure adequate **comprehensive primary care**.

- The availability of **specialty care** providers who accept Medicaid and ADAP Plus and are trained to diagnose and treat HIV-specific problems is crucial, particularly care for those with Hepatitis C co-infection, gynecological/women's health care, dermatology and eye care.

- Increased access to **clinical trials, alternative/complementary therapies,** and **treatment adherence education** are needed. These programs should reflect the cultural and linguistic needs of the population to be served.

K. Binghamton Tri-County Ryan White Region

There have been over 350 AIDS cases reported in this three-county region, and there are about 330 persons living with HIV and AIDS. Providers in the region believe that these numbers underestimate the true numbers of persons living with HIV/AIDS in the region since the AIDS surveillance system is based on a person's residence at time of initial diagnosis. Service providers note an increase in the number of persons seeking services who have moved into the region from other areas.

The Binghamton Tri-County HIV CARE Network analyzed risk transmission data and found the most significant increases in MSM and IDU cases when comparing AIDS cases from 2000 to 2002. Among White males living with HIV/AIDS in the region, MSM is the primary risk factor; among Hispanic males, IDU is the predominant risk factor; and among Black males, IDU is followed closely by MSM. Among females living with HIV/AIDS in the region, IDU is the primary risk factor for Hispanics; among White and Black females, heterosexual transmission is the primary factor but is followed closely by IDU.

Service Needs and Barriers

The following is a list of identified service needs and barriers for this region based on the Network Service Delivery Plan (Document # 89), the Regional Gaps Analysis (Document #52), and information provided at the SCSN/CP Community Forum:

- **Dental services** are limited due to the lack of an adequate number of dentists in the region enrolled in Medicaid or ADAP Plus. There is only one ADAP Plus dental clinic in the tri-county region, and although there are 38 dentists currently enrolled in Medicaid, there remains a long waiting list for new clients. The shortage of dental services, including oral specialists, for HIV infected persons was noted as a serious problem at the SCSN/CP Community Forum.

- Awareness among all populations regarding how to prevent transmission of HIV infection is crucial. **HIV Risk Reduction Education and Counseling for PLWHA** is needed so they can maintain as healthy a lifestyle as possible and reduce the spread of infection to others. In addition, these services are necessary for persons who are HIV negative but at high risk. Effective prevention messages need to be developed and delivered in a culturally sensitive, age-appropriate manner.

- **Nutritional services and counseling** including home delivered meals and food banks that offer food choices for those with special dietary needs are needed in the region. Nutrition consultants with knowledge about HIV/AIDS, medication and related nutrition needs, and general consumer and provider education regarding how diet can improve health are also lacking.

- Although there does not appear to be a lack of **case management** services, the level of services offered by different providers is sometimes confusing to consumers. There is a need to educate both consumers and providers about the differences between supportive case management and medical case management services offered

by area organizations. Comments at the SCSN/CP Community Forum confirmed that with the addition of COBRA case management in the region, additional **consumer education is needed to improve understanding about different levels of intensity of case management services**. There continues to be confusion regarding expectations about what case managers can and cannot provide. In addition, new case managers need a stronger orientation to assist them with gaining necessary knowledge regarding community resources and services for PLWHA.

- **Transportation services** are needed for medical and non-medical services, especially in rural areas.

- **Outreach and comprehensive health care services**, including ambulatory and specialty care, as well as complementary therapies, is crucial. The need for specialty care in Broome County was noted in particular. The need for rehabilitative services in the region was also identified.

- Adequate **supportive services**, including direct emergency financial assistance, client advocacy to assist with navigating the social services system, legal assistance, counseling, and buddy/companion services, are lack in this region.

- More **services for women and families,** including permanency planning, adoption and foster care assistance, are needed.

- Better access to **chronic care services,** including day treatment, respite care, home health care and hospice care (home-based and residential), is needed in certain locations in the region.

- Outpatient services for **substance abuse treatment and counseling** may not be readily accessible due to factors such as lack of transportation and lack of insurance.

- **Housing** that is safe and affordable, especially in handicapped accessible buildings, and placement assistance, is needed.

- Expanded availability of **mental health therapy and counseling** is needed, especially in Broome County, due to lack of psychiatrists and other mental health providers.

- **Provider education services** are needed, as many health care providers do not fully understand the impact of HIV on the clients they serve. Physicians and other health providers need to be better educated regarding the health and psychosocial needs of the HIV-infected and affected population, including technical knowledge of HIV counseling and testing procedures, legal and confidentiality issues, and sensitivity to cultural issues.

- At the present time, the nearest **syringe exchange program** is located outside this region in Ithaca, approximately a one-hour drive from the nearest area in the tri-county region and is open from 1 – 5 pm only. The need for this service was emphasized at the SCSN/CP Community Forum.

Special Populations

The following were identified as special populations in need of targeted services in this region:

- Persons with sexually transmitted diseases
- Persons who inject drugs
- Young people with a history of multiple sexual partners
- Men who have sex with men
- Persons who are homeless
- Mentally ill and chemically addicted persons

Comments received at the SCSN/CP Community Forum:

- The CARE Network Coordinator emphasized the serious shortage of covered dental services for HIV+ persons in this region, and in Broome County in particular. She recommended that consideration be given to allowing private dentists to become ADAP Plus providers. (Note: ADAP Plus covers limited dental services (12 visits per year) through Article 28 licensed clinics. This policy is a result of overall funding limitations and is intended to provide some basic dental coverage for ADAP Plus participants.)

- One participant emphasized that the impact of the epidemic on communities of color is a reality in Upstate New York, including in the Binghamton Tri-County Region.

- Rapid testing offered in the local health department two days a week has been extremely successful. The commenter noted that unfortunately private medical providers are not offering rapid testing, apparently because not all costs associated with providing the test are reimbursed. So that more persons can learn their HIV status, the recommendation was made to change reimbursement mechanisms to encourage private providers to offer rapid testing.

L. Buffalo (Western) Ryan White Region

There have been nearly 3,200 AIDS cases reported in the eight-county Buffalo Ryan White Region since the beginning of the epidemic. Nearly 2,800 persons are living with HIV or AIDS in the region. Sixty-four (64) percent of HIV/AIDS cases in the region are from Erie County, which has sixty percent of the region's population. However, each of the other more rural counties has reported HIV and AIDS cases.

The Network also compiles an estimate of the total number of individuals living with HIV/AIDS in the region – 4,700 in the AIDS Network of Western New York 2004-05 Service Delivery Plan Update. This estimate significantly exceeds the official case count as it includes an estimate of individuals who are infected but unaware of their status, and persons diagnosed outside of the Region but now residing and obtaining care in the Region. This estimate is reformulated periodically using available databases.

The Service Delivery Plan Update notes that as of 2003, Erie County has the highest cumulative AIDS case rate, 188.9 per 100,000 (excluding State prisoners). In comparison, the other counties in the region ranked from a low of 5.5 to 77.7 cumulative AIDS cases per 100,000. The Network Plan Update further indicates that analysis of newly diagnosed 2003 case data reflects 65% of those receiving an initial HIV or AIDS diagnosis were male and 35% were female. The greatest number of newly diagnosed cases is among people between 30 and 49 years of age (63%), followed by those over 50 (19%) and persons aged 20-24 (18%). Blacks comprised 54% of those newly diagnosed cases; Whites 31%; Hispanics 13%; Native Americans, Asian/Pacific Islanders and those of multi-race each less than 1%.

Service Needs and Barriers

The following summarizes service needs and barriers identified based on Network Service Delivery Plans, including the 2004-05 Update **(**Document #162), Regional Gaps Analysis (Document #2), a PLWHA consumer survey, and other information extracted from documents submitted for the Buffalo Region. The top five service delivery gaps identified in the 2004-05 Update by the AIDS Network of Western New York are:

1. **"The Unconnected"** — There is widespread concern in the region that there are significant numbers of people living with HIV infection who are not connected to services. The unconnected are defined as people who have never accessed services or who have accessed services, and then for a variety of reasons, dropped out of care. In April 2004, the AIDS Network Data Collection Committee reported that approximately 69% of individuals living with HIV/AIDS in the region were not receiving primary medical care. This report was based on actual enrollment data received from primary HIV/AIDS medical care providers.

2. **Case Management** — There is still a regional need for recruitment and retention of experienced and culturally competent case managers and support staff to meet the ever changing and complex needs of people living with HIV/AIDS and other diagnoses.

3. **Housing and Related Services —** There is a lack of safe, affordable and stable housing and supportive housing services in the region. High cost utility rates were also noted as a significant problem. Homeless shelters are overburdened, discrimination persists in private sector housing, and there are gaps in the social support systems that assist people in retaining housing. These barriers influence consumer ability to access the multiple HIV-related medical and support services that are necessary to stabilize their health and become independent. Community Forum participants noted that housing funds most often do not flow to rural counties so their housing needs are not addressed.

4. **Discrimination and Stigma —** Fear of discrimination related to HIV status and the related sense of stigma about being HIV positive are significant concerns in the region. These fears constitute a barrier to accessing services.

5. **Transportation** — Given the large distances included in the region, the inclement climate, and high rates of poverty among people living with HIV/AIDS, transportation is a major issue. This impacts the ability of PLWHA to access and maintain comprehensive services. People living in rural areas have particular problems: not only are the distances longer and public transportation less available, but they have to travel into urban areas to access specialized state of the art health care.

Other service needs and barriers identified in this region include:

Access to Primary and Specialty Medical Care:

The AIDS Network has identified service gaps in the availability of primary and specialty medical care for people living with HIV and AIDS in both urban and rural areas of the region. The service system cannot efficiently and effectively meet the needs of the current population, and the situation is expected to worsen in the next few years if current trends continue. The two major provider sites have had great difficulty recruiting and retaining HIV specialist physicians, physician assistants and nurse practitioners. In addition, the Network has identified service gaps in the following medical specialties:

- *Dermatology*: Currently there are no HIV experienced Dermatologists in the area and only two clinics provide dermatology consultations for Medicaid recipients. Therefore, the waiting time for consultations can be several months.
- *Pain Management*: The region is without a pain clinic that addresses HIV issues or accepts Medicaid patients.
- *OB/GYN Care*: Only one OB/GYN, assisted by two nurse practitioners, provides HIV care in the region, and future grant funding for these services is uncertain.
- *Pediatric Care*: There is only one physician and one nurse practitioner providing HIV pediatric/adolescent specialty care in the region.

Access to Care and Supportive Services for Rural Residents:

The majority of service providers are located in the vicinity of the city of Buffalo where the epidemic in this region is centered, making it difficult for rural residents in the region to easily access comprehensive care. Rural communities have been faced with a shortage of HIV specialists for many years. The one dedicated physician who provides HIV care at rural clinics took a one year leave from practice as of July 2005; a Nurse Practitioner is covering during the leave.

Participants in the SCSN/CP Forum emphasized the major challenges faced by residents of rural counties in accessing care and supportive services. Residents of Genesee and Orleans Counties were cited as examples; HIV+ persons from these counties have to travel to either Buffalo or Rochester for care and services. The need to outstation additional services in rural counties was emphasized. A range of services was mentioned, including outreach and casefinding, easy access to medical care by physicians, specialty care, transportation, case management, and other supportive services. The lack of comprehensive health insurance was also noted as a barrier for rural residents.

Services for Substance Users and Mentally Ill, Chemically Addicted (MICA) Persons:

Residential treatment beds, including HIV-targeted substance abuse and MICA beds, and harm reduction-oriented housing, were specified as service needs.

Mental Health Services:

Medical and social work professionals have reported that mental illness in substance using patients is often undiagnosed as their clients bounce between community-based counseling services and chemical dependency programs. The Network established a Mental Health Workgroup that is considering how mental health needs are being addressed and where gaps exist. The Workgroup has created a guide to help PLWHA access mental health services in various settings.

Outreach*:*

This was identified as a significant need as it impacts the ability to identify underserved people living with HIV/AIDS and to connect them to care, and to provide counseling and testing to persons who may not be aware of their HIV positive status. New strategies to reach highest risk populations are needed. In its 2004-05 Service Delivery Plan Update, the Network noted the value of resources supporting a dedicated counselor talking with patients and providing counseling and rapid testing in settings that serve high risk populations, such as Emergency Rooms of urban hospitals.

Expanding and Improving Human Resources:

Lack of incentives to recruit and train experienced, diverse and culturally competent health and human service providers to meet the complex needs of increasing numbers of people living with HIV/AIDS, many with co-morbidities, was noted. At the SCSN/CP Community Forum, a commenter noted that it is very difficult to recruit qualified multi-cultural staff in all positions.

Specific recommendations were also made at the Community Forum about the need to orient and train both local Social Services staff and county public health nurses, particularly in rural counties, about available HIV services so they can help clients link with those services, particularly case management and supportive services. Currently, clients often have to find out about available services and then advise county staff about options.

***Health Insurance**:*

Lack of health insurance was found to be a major impediment to maintaining good health and quality of life.

Access to Benefits and Entitlements:

Almost 45 percent of respondents that participated in a consumer survey indicated they had problems in obtaining benefits or entitlements.

Supportive Services and Peer Education:

Clients identified the need for enhanced legal assistance, peer support groups and pastoral care. The need for more involvement of faith-based agencies in providing HIV education and services was noted. Community Forum participants noted that more peer education is needed to empower consumers in addressing such topics as nutrition, harm reduction, phone and other general life skills.

Special Populations identified in Western Region documents:

Substance abuse remains a major problem in this area. Injection drug use is attributable to about a third of cumulative and living AIDS cases in the region and has increased as a percentage of total cases over the past ten years. Blacks comprise more than half of the living cases where injection drug use is the identified risk factor. People with histories of injection drug use face additional risk factors, including Hepatitis C. Western New York has seen an alarming number of Hepatitis C (HCV) cases among persons living with HIV/AIDS. More opportunities for HCV screening and third-party coverage of treatment are needed.

Persons triply diagnosed -- with HIV infection, mental illness and chemical addiction (MICA) -- were frequently identified as presenting significant needs that have not been addressed. The need for a broader understanding of harm reduction in general HIV-related services and for harm reduction-oriented housing was noted.

Other population groups identified as having a high rate of unmet service needs were: PLWHA who were homeless or tenuously housed; men who identify as gay and other men who have sex with men, specifically adolescents and men of color; and parents, specifically young mothers and single parent families. Lack of coordination between general women's health and family services and HIV wellness was also addressed as a need in this region.

Additional groups mentioned as having significant needs include: Native Americans, individuals in the criminal justice system, Hispanic women, the under/uninsured, people living with AIDS and dementia, migrant workers, and the mentally ill.

The Western New York region attracts a large number of immigrants and a significant number of migrants. Barriers to health care and social services, including lack of insurance and language issues, creates the potential for HIV infection to go unmonitored and untreated among these populations in New York State. The need for culturally and linguistically competent outreach, health care and supportive services was identified.

Members of the deaf community were also identified as a special subpopulation. Community providers' lack of understanding of their special needs, as well as lack of up-to-date and appropriate outreach strategies and literature, was noted as barriers blocking effective treatment access.

Documents from this region expressed concern that youth were not receiving sufficient HIV/AIDS education and prevention, and that services available to them were limited both by provider capacity and their ability to address the immediate needs of at-risk young people.

Other Comments Received at the SCSN/CP Community Forum:

- One existing transportation grant limits assistance to residents of Erie County; this limitation prohibits serving persons from more rural counties in need of such services.

- The service needs of persons who use crack/cocaine and marijuana must not be ignored as resources are directed to crystal meth users. Persons using any of these substances are at increased risk for acquiring and transmitting HIV.

- Consideration should be given to creating streamlined "Single Point of Access" procedures for HIV+ persons who need multiple services, such as housing, intensive case management, mental health and supportive services.

- Important to acknowledge that the reported number of infected Native Americans is likely an undercount due to persons not being tested, inability to access services, and/or not self-identifying as Native American.

- The needs of transgender persons should be addressed more specifically in the Special Populations section, including issues relating to Medicaid coverage of hormone therapy, needle sharing, self-identification and resulting stigma and discrimination.

- Need to track trends relating to HIV+ persons aged 50 and over, and develop strategies to reach and serve this age group.

- Science-based HIV Prevention service models need to target communities of color. Those models need to be adapted and tailored to address diverse subpopulations within communities of color.

M. Lower Hudson Ryan White Region

There have been nearly 6,100 AIDS cases reported in the three-county Lower Hudson Ryan White Region since the beginning of the epidemic. Over 4,000 persons are living with HIV or AIDS in the region. People of color represent 66 percent of cumulative AIDS cases and 73 percent of living AIDS cases. African Americans, who represent less than 13 percent of the Tri-County population, account for 49 percent of cumulative AIDS cases. Nearly 82 percent of cumulative cases are from the largest county – Westchester. Rockland County accounts for 15 percent of cases, and Putnam County the remaining 3 percent. Among Black and Hispanic males living with HIV/AIDS in the region, IDU is the major risk factor followed by MSM; the reverse is true for white males. Heterosexual contact is the major risk factor for females living with HIV/AIDS across racial/ethnic groups, followed by IDU.

Service Needs and Barriers

The most commonly identified service needs in the Network Service Delivery Plan (Document #103), other source documents for the Lower Hudson Ryan White Region, and at the SCSN/CP Community Forum are:

- Housing, Rent Subsidies, and Related Support Services
- Substance Abuse Treatment/Harm Reduction Programs
- Transportation
- Outreach and Early Intervention Services, including Counseling and Testing, and Linkage to Comprehensive Health Care for HIV, TB, Hepatitis and STDs
- Treatment Education and Adherence Support
- Mental Health Services
- Linguistically and Culturally Competent Services, including translation and related provider training
- Legal Assistance
- Supportive Services, including case management and assistance in accessing health insurance and entitlements; counseling and peer support; child care; emergency financial assistance; vocational training and job placement
- Health Education and HIV Risk Reduction
- Service Delivery Models, including mobile medical vans, co-located services, and coordinated care across addiction and mental health service programs

Other important concerns identified in this region's source documents:

- The Lower Hudson has a high prevalence of sexually transmitted diseases, which tend to be an indication of unprotected sexual activity and high risk for HIV infection. It was reported that gonorrhea and chlamydia case rates for this region, especially among women 20-39 years of age, are troubling.
- Tuberculosis remains a public concern for this region, especially given that a large proportion of the population growth in the region is attributed to immigration; therefore, this is an area in need of close monitoring.

- Because of improved medical treatments, people with AIDS are living longer. In this region, more than 40 percent of people living with AIDS are over 40 and almost 10 percent are over 50 years old.

- The wide geographic distribution of specific populations in this region, combined with a limited number of HIV/AIDS service providers, restricts the number of specialized programs that are funded.

Populations with special needs that have been identified include the following:

Women:

This population continues to constitute a significantly higher percentage of new AIDS cases in this region than earlier in the epidemic. Women tend to access the region's health care services later in their progression of HIV infection than males. Women are one of the fastest growing populations with HIV and AIDS in this region, and women of color are disproportionately affected by HIV/AIDS. It is difficult for women to access services that do not offer childcare, meal programs or other services that address their familial needs. Unless transportation is provided between service providers or the services are co-located, women often are unable to meet all of their needs. Skilled case managers and legal advisors are necessary as advocates in order to help navigate complicated service systems such as drug treatment, Medicaid, workfare, childcare and foster care, as well as other public assistance programs. Documentation also noted that as a result of high teenage birth rates in parts of this region and the growing rates of STDs, data specific to the newborn seroprevalence study suggest that sexually active young women and their sexual partners may be increasingly vulnerable to HIV transmission.

Men of Color Who Have Sex with Men (MCSM):

It has been well established nationally that the MCSM population experience barriers in entering the care system because of stigma and discrimination associated with acknowledging that they are 'gay.' Ethnic and cultural barriers may cause many non-white MSM, particularly Hispanics, to identify only with the heterosexual population, making the delivery of appropriate services difficult. This indicates the need for services that are identifiable as services for men who are sexually active, regardless of the gender of their partner, and that are culturally sensitive, credible, and appropriate.

Injection Drug Users:

Injection drug users are often described as "hard-to-reach" and are unwilling to travel or seek out health and support services. Injection drug use continues to be the leading cause of new infections in the Tri County region. As the AIDS and HIV population ages, people living with AIDS in this region who have injection drug histories will be at an increased risk for Hepatitis C infection and disease. Service implications identified for this population are: 1) the identification of service providers who employ harm reduction approaches; 2) co-location of HIV primary care and substance abuse services; and 3) integrating substance abuse services and HIV-related services. Service needs include supportive residential housing, childcare, MICA programs, outreach and transportation. Harm reduction approaches in case

management and other health and social services can be key strategies in addressing needs of people who continue to inject drugs while in treatment.

Homeless:

There are many factors that complicate the lives of the homeless who are at risk for or living with HIV/AIDS and may be infected with TB. These factors include addiction, having multiple sex partners and using sex for drugs and survival. There is a lack of awareness of programs for people with HIV/AIDS among homeless people in the region. Documented service needs for this population includes the following: intensive case management; rental assistance; coordinated referrals to entitlements; mobile services for basic needs; and other needed referrals.

Mentally Ill and Chemically Addicted (MICA):

Lack of coordination between mental health and addiction services are challenges to serving this population. This "disconnect" tends to exacerbate the acute needs of MICA patients. It is reported that linkages among referral agencies, treatment programs and housing facilities for this population need continuous monitoring and reinforcement, especially between jurisdictions. Documented service needs for this population include: coordinated care across addiction and mental health services; supportive housing for MICAs who are HIV infected; and continuity of benefits for newly released individuals from the criminal justice system.

Criminal Justice Populations:

Ex-offenders and parolees face a complicated and difficult set of circumstances upon release from prison, many of which can increase HIV risk. These issues include: immediate homelessness, substance abuse, and health issues, in particular tuberculosis, HIV/AIDS and other sexually transmitted diseases. Documented service needs for this population include: effective discharge planning to ensure linkages with community-based organizations; housing; day care; job training programs; services specifically for female parolees and their families; access to coordinated HIV care, substance abuse and mental health services.

Immigrants, Undocumented and Recently Arrived:

There is no definitive data on the incidence of HIV among immigrants in this region. This is due in part to the number of undocumented and illegal immigrants for whom no data is collected. A survey by the Tri-County EMA of various HIV/AIDS social service providers in the area revealed that between 8 and 15 percent of their clients were non-legal permanent resident immigrants. Findings in this region identified a strong need for culturally appropriate alcohol and drug services for this population. Community forum participants emphasized the need for outreach to immigrant populations and for access to the full continuum of health and supportive services, and indicated that there is a large undocumented population in Rockland County that requires targeted services. The need for expanded ADAP Plus coverage was also noted so that undocumented immigrants have broader access to services, such as diagnostic testing and ongoing drug and and alcohol treatment. Among undocumented persons, there is tremendous fear of deportation and reluctance to access health care and social services, especially HIV-related.

Adolescents:

Adolescents (13-19 years of age) comprise about one to two percent of people living with HIV/AIDS in this region. A number of these young people are long-term survivors of perinatal transmission. HIV/AIDS risk for young people remains significant in light of chlamydia rates, pregnancy rates and drug-related behaviors. School settings, community-based, regional and national organizations geared to serving youth, have been identified as resources to reach youth with HIV prevention messages and services.

Participants at the SCSN/CP Community Forum emphasized the following:

- There is a noticeable lack of medical and dental providers in the region who accept Medicaid and ADAP Plus.

- The need for additional resources to support legal services for PLWHA. Compelling comments regarding the need for expanded resources to support legal assistance for low income PLWHA were received at the Community Forum and are included in full in Section IX of this document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans. Citing specific data, the commenters note that comparing available program resources to Health Department statistics on PLWHA in the Lower and Mid-Hudson Valley regions, "to serve over 7,100 people living with HIV and AIDS, Legal Services for the Hudson Valley has two lawyers and the Legal Aid Society of Rockland County one." Cited program data confirm that the legal needs of low income PLWHA most often involve protecting basic survival needs, including housing, income, health and family matters – over 80% of cases in both 2004 and 2005. The need for additional non-restricted funding for crucial legal services, such as eviction defense, is described given recent policy decisions regarding the unavailability of Title I funds for such services.

- With dramatic increases in costs associated with housing, gas and utilities, there needs to be greater emphasis on resources to support emergency financial assistance for basic subsistence.

- Helpful comments were received regarding the need to clarify differences in the data presented for this region in the Epidemiology section of the report and in the Appendix tables, and suggestions for more accurate descriptions of the data presented in the various tables for all regions. Edits have been made in accordance with these suggestions.

N. Mid-Hudson Ryan White Region

There have been nearly 4,400 AIDS cases reported in the four-county Mid-Hudson Ryan White Region since the beginning of the epidemic. Over 3,100 persons are living with HIV or AIDS in the region. People of color represent 59 percent of cumulative AIDS cases and 63 percent of living cases. In Orange, Dutchess, Sullivan and Ulster Counties, Blacks and Hispanics are disproportionately affected by AIDS. Blacks comprise 5-9 percent of each county's population, but represent 23-41 percent of total county AIDS cases. Similarly, Hispanics comprise 6–12 percent of each county's population, but represent 20-25 percent of total county AIDS cases. Among Black and Hispanic males living with HIV/AIDS in the region, IDU is the major risk factor followed by MSM; the reverse is true for White males. Heterosexual contact is the major risk factor for females living with HIV/AIDS across racial/ethnic groups, followed by IDU.

Service Needs and Barriers

The following services have been identified as the most pressing needs in the Network Service Delivery Plan (Document #46), the Regional Gaps Analysis (Document #47), other source documents submitted for the Mid-Hudson Region, and community forum comments:

Housing Assistance and Housing Related Services:

These services are considered a critical need in the Mid-Hudson region. Limited HOPWA funds through Housing and Urban Development (HUD) are available in the region but the scope of covered services has diminished over the years. Currently, there is very limited scattered site housing – 17 sites currently serving about 40 persons, and one group home setting in Ulster County. There are waiting lists in all counties covered by HOPWA funding, and access to housing becomes available only upon the death of current clients and the subsequent re-location of surviving family members. Community members noted that HOPWA income standards are stringent and often PLWHA in need of housing do not meet them. Section 8 housing is also not uniformly available throughout the region. More housing resources are urgently needed to ensure a full complement of housing-related services, including more low income housing; emergency financial assistance to obtain housing and support other basic needs such as food and utilities; client-level needs assessment, advocacy, and placement in housing.

Transportation:

Transportation remains an urgent, critical need in this region. Medicaid restricts the use of medical transport and will not provide taxi service to appointments outside the consumer's county of residence. This is problematic for patients seeking specialty care that is unavailable in the Mid-Hudson region and can prevent a patient from receiving necessary care. In addition, physician certification of need is required to obtain Medicaid covered transportation.

Comprehensive Health Care, Co-Located Services, and Case Management:

At the SCSN/CP Community Forum, commenters noted that some areas of the region lack a full continuum of comprehensive health care for PLWHA. Specific examples provided include: community health centers are struggling; there is a noticeable lack of medical providers who accept Medicaid and ADAP; providers have moved away from Middletown and Newburgh (Orange County); there is no infectious disease physician in Middletown; and the need for more specialty providers so that patients do not have to travel long distances. Community members also noted that additional co-located services would facilitate access to care and treatment in the region. Case management must be readily available for client advocacy, care coordination and linkage to vital services.

Dental Care:

There is a lack of dentists in the region who accept Medicaid and ADAP Plus. More geographically accessible and culturally competent dental services for PLWHA are needed.

Legal Services:

The expansion of legal services is essential. Legal assistance is needed to address a range of issues including entitlements, welfare reform, housing and immigration. Compelling facts regarding the need for expanded resources to support legal assistance for low income PLWHA were received at the SCSN/CP Community Forum and are included in full in Section IX of this document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans. Citing specific data, the commenters note that comparing available program resources to Health Department statistics on PLWHA in the Mid- and Lower Hudson Valley regions, "to serve over 7,100 people living with HIV and AIDS, Legal Services for the Hudson Valley has two lawyers and the Legal Aid Society of Rockland County one." Cited program data confirm that the legal needs of low income PLWHA most often involve protecting basic survival needs, including housing, income, health and family matters – over 80% of cases in both 2004 and 2005.

Food/Nutrition:

Nutrition services are available on a severely limited basis in the region. There are two service agencies that can provide meals to the homebound, but only within a small radius of their program base and in small numbers. Congregate meals and food pantry services are available in urban areas of each county through churches and other social services agencies. These are, in general, services meant for the general public – there are no specific accommodations to meet the nutritional needs of the HIV infected.

Mental Health Services:

Participants at the SCSN/CP Community Forum noted that mental health services in the region are generally limited, and that family counseling, including services for children who are affected family members, is needed. In addition, HIV training is needed for mental health providers as few have experience with HIV/AIDS.

In addition to the needs listed above, the following needs have been identified through regional needs assessments:

Outreach to High-Risk Youth:

Gay male adolescents in the Mid Hudson region are especially at risk. Outreach programs that engage members of young gay networks are needed to reach this subpopulation, as well as faith-based HIV programs that minister to gay youth

Pre/Post Counseling and Testing:

With the closure of a testing program in the region, there is a gap in counseling and testing services in this region.

HIV/Hepatitis Co-Infection:

Anecdotal information in this region is emerging that indicates a fairly high level of co-infection among intravenous drug users in treatment settings. The regional Network is encouraging all people to get counseling and testing for both HIV infection and Hepatitis C regardless of risk factors. Hepatitis screening and treatment are needed.

STDs/Co-Incidence of HIV:

A partnership with service providers and county health departments has been implemented to address the rise in STDs/co-incidence of HIV. A website has been developed to provide resources and link HIV and STD services in the region. Education regarding STDs, screening and treatment is needed.

Training:

Mental health issues, domestic violence and talking to children about coping with HIV in the family are areas that have been identified in which training is needed.

This region also identified the following service needs and barriers by specific populations.

Men Who Have Sex with Men (MSM):

Unprotected sex among MSM accounts for nearly 50 percent of White men living with HIV/AIDS, and about 20 percent of Black and Hispanic men living with HIV/AIDS in this region.

- **Outreach:** Effective outreach strategies are needed because of the stigma associated with homosexuality and fear of recrimination in suburban/rural communities that impede access to services by many MSM.
- **Comprehensive Health Care Services:** Many clients travel outside their counties of residence to seek medical services, including ambulatory care. Specialty care services are insufficient to meet demand.
- **Training:** The need for appropriate staff training in organizations that provide services to HIV-infected MSM has been identified. Educated and sensitive providers are essential to ensure effective assessment of needs and appropriate referrals.
- **Education:** HIV prevention education that targets younger MSM who engage in risky behaviors is urgently needed, and reinforced prevention education efforts are also needed for older MSM.
- **Support Services and Substance Abuse Treatment:** There is a need for support services, especially case management and one-on-one counseling, as well as substance abuse treatment.

Men of Color Who Have Sex with Men (MCSM):

MCSM may not identify as gay and therefore not receive messages targeted to the gay community. There is a lack of education and prevention programs that effectively address the ethnic and cultural influences that affect their behaviors and beliefs, and the double stigma of being a man of color engaging in same sex behavior and possibly using alcohol and drugs.

- **Outreach and Education**: Outreach and prevention education efforts targeting younger MCSM who engage in risky behaviors and that address ethnic and cultural biases.
- **Support Services**: Appropriate support services essential for a population that feels isolated from their ethnic communities and discriminated against by society at large, and who do not wholly identify with the white MSM population.
- **Coordinated Services**: One-on-one counseling and coordinated services for dually and triply diagnosed MCSM, including comprehensive health care, case management, mental health services, and substance abuse treatment.

Women:

Women are the fastest growing HIV-infected population in the Mid-Hudson region. Injecting drug use is a primary transmission factor — either directly or through sexual contact with an injecting partner. Women of color are disproportionately affected.

- **Comprehensive Health Care:** Women tend to seek health care later in the progression of HIV infection. Specialty care services are insufficient to meet demand. Clinical trials for women are also limited.

- **Childcare:** Limited availability of childcare hinders access to care and services. This is particularly true in substance abuse treatment settings.
- **Other Support Services**: There are needs for housing, transportation, emergency financial assistance, permanency planning, and case management that addresses the entire family.

Injecting Drug Users:

Injecting drug users living with HIV/AIDS make up the highest risk group in this region, comprising over 54 percent of total adult and adolescent AIDS cases. Crack-cocaine has long been the dominant drug in the Mid-Hudson region, but heroin use is on the rise. With the availability of heroin at very high purities in New York State, the mode for using heroin has changed to inhalation/sniffing. Because this new form of drug taking does not involve needles, heroin use has spread to the middle class, especially among women and adolescents. This behavior may appear to reduce risk, but in fact, sniffing heroin may eventually lead to injection use, and affects judgment relating to other high-risk behaviors. Other health concerns for IDUs include Hepatitis C infection, new forms of treatment-resistant STDs and tuberculosis. Services listed below should be bi-lingual.

- Treatment services: Additional drug treatment modalities are needed throughout the region to make them more easily accessible..
- **Transportation:** Little or no transportation available to access health care services.
- **Co-located services:** The need for "one-stop shopping" or co-located services (health, HIV and Hepatitis testing and case management) onsite at substance abuse treatment programs, and enhancement of services for the MICA population.
- **Outreach and Comprehensive Health Care:** Targeted outreach for the purpose of linkage to comprehensive health care is limited. Specialty care services are insufficient to meet demand.
- **Case Management and Supportive Services:** Housing, transportation, childcare, and intensive case management, particularly for mentally ill, chemically addicted (MICA) persons.
- **HIV Prevention**, including syringe exchange programs, harm reduction services, and safe injection education.
- **Training and Education**: More frequent provider training regarding substance use and MICAs, and HIV training for law enforcement personnel.

Adolescents:

The number of HIV cases among adolescents in this region is relatively low. Yet, many adolescents are at risk precisely because they do not perceive they are and engage in risky behaviors.

- **Stigma:** Adolescents are usually unwilling to disclose their feelings and fear the stigma associated with having an HIV positive parent or being positive, thus relationships take time to be developed.
- **Targeted Services**: Services that integrate HIV must be tailored to engage adolescents in general, and subpopulations of youth at highest risk, e.g., young men who have sex with men, young men of color, and youth using crystal meth.

- **Transportation:** Lack of transportation is a barrier to service in all areas of the region.
- **Counseling:** Services that address the aftermath of sexual trauma are needed.
- **Family-Centered Case Management:** for infected and affected youth and their family members.

Other Subpopulations in Need of Targeted Services:

Participants in the SCSN/CP Community Forum identified other subpopulations and issues in need of focused attention:

- **Communities of Color:** Given the demographics, communities of color, particularly Blacks and Hispanics, must be targeted for outreach, diagnostic testing and linkage to care and services. Faith-based organizations are a major resource in communities of color and should be supported as active partners in providing HIV services.
- **Immigrants:** Outreach and a full continuum of health and supportive services are needed for immigrants, many of whom are undocumented and fear accessing services where they must provide identifying information. Expanded ADAP Plus coverage is needed so that undocumented immigrants have broader access to services, such as diagnostic testing and ongoing drug and alcohol treatment.
- **Rural and Transient Populations:** More culturally competent and co-located services are needed to address the needs of this largely Latino population, including bi-lingual service providers. Additional support for peer education is needed, particularly for Latinas. Cultural sensitivity training for providers would help shape prevention message and techniques to assist this population with behavior change.
- **Deaf and Hard of Hearing:** This is a frequently misunderstood and underserved population with unique cultural and linguistic needs. Health provider training is needed to assure sensitivity regarding their needs.
- **Homebound:** There is a growing number of multiply disabled, homebound persons who require more intensive services. Service intensity should be reflective of the individual's degree of illness and disease progression. Since co-morbidities are often involved, multiple funding sources are needed to address the full range of needs as it is not realistic to finance exclusively with HIV funds.
- **Elderly and Long-Term Survivors:** Long-term survivors in their 60s with multiple diagnoses present a new population with very complex needs. As people live longer, ongoing care and services must continue to be provided based on individual needs assessments.

In terms of policy and board program issues, the following comments were received at the SCSN/CP Community Forum:

- From a consumer perspective, three broad areas of need in this region were expressed: housing, medical care, and transportation.

- Consumer needs were elaborated upon in a written document, "Living with AIDS – A Hudson Valley Consumer-Based Observance," which is included in full in Section IX of this document. Highlights of emerging needs addressed in this document include: additional funding to meet the increasingly complex needs of PLWHA whose health is deteriorating and who have become homebound, semi-homebound or temporarily incapacitated, which includes more intensive case management, additional caregiver time, and adequate time with physicians during office visits to address multiple care needs and medical complications; need for human contact, communication and home-based services for isolated persons who are symptomatic and living alone and/or in rural areas; need for future planning and more resources to assess and address the full range of needs of PLWHA who are growing weaker and challenged by the effects of cumulative illness; and concern that reductions in dedicated resources and service cuts might result in despair, nonadherence, and an increase in high risk behaviors.

- With dramatic increases in costs associated with housing, gas and utilities, there needs to be greater emphasis on resources to support emergency financial assistance for basic subsistence.

- Condom distribution within correctional facilities is required to assure HIV prevention. Community members noted that the misperception that prisoners are not sexually active or use drugs must be halted, and measures taken to address drug use and sex in prisons. They recommended that DOCS policy prohibiting condom distribution be changed. It was noted that DOCS policy does allow distribution of condoms for conjugal visits.

- Providers spoke of the importance of respecting an individual's wish to die with dignity and how that often involves the need for personal advocacy when family members are not available, challenges from health institutions, and the need for legal assistance.

O. Nassau/Suffolk Ryan White Region

There have been nearly 7,600 AIDS cases reported in this two-county region since the beginning of the epidemic. Over 4,500 persons are living with HIV or AIDS in Nassau and Suffolk Counties, commonly called Long Island. The disproportionate impact on communities of color is very evident in this region -- 67 percent of newly diagnosed HIV cases (2001-03) are among persons of color. It is informative to note that the Nassau/Suffolk Region alone has more total cumulative AIDS cases than 26 states in the US. Among White, Hispanic and Asian Pacific/Islander males living with HIV/AIDS in this region, MSM is the major risk factor followed by IDU. Among Black males living with HIV/AIDS, IDU only slightly exceeds MSM as the primary risk factor. Heterosexual contact is the major risk factor for females living with HIV/AIDS across racial/ethnic groups with the exception of Native Americans where IDU is the primary risk factor.

Service Needs and Barriers

The following is a list of identified needs and barriers based on the Network Service Delivery Plan (Document # 70), Regional Gaps Analysis (Document #s 76, 77), and other information provided in source documents and at the SCSN/CP Community Forum:

- **Housing assistance and related services** is one of the top priorities for this region. Long Island's housing market is in some areas more expensive than in New York City, making the private market insufficient to meet housing needs for people living with HIV/AIDS. In addition, there is limited multi-family and rental housing stock, making rental subsidies generally not the most effective housing strategy. PLWHA on public assistance note that a major portion of their monthly income goes toward housing, which leaves very little for other subsistence needs including food, utilities and transportation. The lack of appropriate and adequate emergency housing options in most areas of Long Island leaves all homeless persons at heightened risk of HIV because of strong associations between housing status and risk for HIV transmission. Also, HIV infected homeless persons are at risk of non-adherence to prescribed treatment regimens. All of these factors highlight the need for more safe, low-income housing, and more resources to increase the public assistance housing allocation, rental subsidies, and grants for housing-related supportive services.

- **Transportation** needs continue to be a significant barrier to services for HIV-infected persons. With a limited mass transit system that is difficult for healthy people to navigate, the need for funds to provide transportation services is critical. Transportation assistance should be provided on a regional basis, i.e., there should not be a prohibition about crossing a county line to obtain a service. At times, that service may actually be the closest. While the system of care in this region is well developed and of high quality, the lack of transportation blocks entry into the system. Without these funds, it will become increasingly difficult for PLWHA to remain in care. In addition, outreach efforts for those who know their status but are not currently in care will be ineffective if services cannot be accessed.

- For those living in poverty and/or without insurance, management of care is complex and increases the importance and need for **case management**, particularly intensive case management, to assure access to medical care and entitlements that provide financial assistance for living and health care costs. Individuals without insurance may have to wait to access services, resulting in later diagnosis, greater difficulty with treatment options, and increased costs. This leads to sicker patients who are more difficult to treat and require more extensive and costly care.

- Expansion of **emergency financial assistance** is needed to assist with various expenses when income is used to pay for rent and other subsistence needs cannot be met. Assistance is often needed to help with increasing expenses for food, utilities, and childcare.

- Expansion of **substance abuse and alcohol treatment/counseling services** is needed in the region. The co-existing conditions of HIV and substance/alcohol abuse have a debilitating impact on the health of PLWHA, resulting in the need for increased medical management and a potential to reach the limit of insured substance abuse-related services. Expansion of grant-funded substance abuse counseling is needed to link patients with treatment and to help prevent relapse. In addition, there is a lack of adequate drug treatment centers and sober houses for substance and alcohol users in Nassau and Suffolk Counties.

- **Dental services** are currently offered only in limited locations. New dental programs in more locations throughout the region are necessary to provide reasonable geographic access.

- More resources are needed to expand the continuum of **mental health services**, which should be co-located with other services wherever possible. More **mental health support groups** are needed for PLWHA and their families relating to: coping with living with HIV, parenting and raising a family, diagnosed mental health conditions, and other problems relating to substance use and living in poverty. In addition, resources are needed to support psychiatrists who are skilled in providing care for PLWHA, can prescribe medications, and can support counselors working with infected and affected persons.

Service needs and barriers were also summarized for specific populations, based on source documents and comments from the SCSN/CP Community Forum:

- **Persons of Color**
  - Housing
  - Medical care
  - Dental care
  - Mental health services
  - Substance abuse treatment programs
  - Transportation
  - Cultural competency
  - Lack of employment/vocational training
  - Health insurance

- Health literacy
- Translation services

- **Mentally Ill and Chemically Addicted (MICA)**
  - Transportation
  - Housing
  - Nutrition
  - Medicaid (faster enrollment and more accessible)
  - Prevention education, both primary and secondary, including safer sex and harm reduction
  - Syringe Exchange
  - Improved medical care for the incarcerated population
  - Cultural competency of service providers; lack of multi-skilled clinicians
  - Prejudice against HIV positive individuals with addiction and mental illness – fear of disclosure
  - Smoking cessation
    Life skills, including budgeting and financial management

- **Men Who Have Sex With Men (MSM), including members of the gay community and those who do not identify with that community**
  - Primary medical care
  - Dental care
  - Mental health services
  - Substance use services
  - Housing
  - Food and nutrition
  - Cultural competency
  - Translation services
  - Outreach to the gay community and to other MSM to link to care and services
  - Education to reduce stigma and discrimination
  - Prevention education that is culturally appropriate
  - Support groups for gay men and other MSM

- **Women**
  - Gynecological care
  - Housing
  - Transportation
  - Child care
  - Medicaid providers
  - Translation services
  - Mental health support for families and activities for infected/affected family members
  - Financial assistance for health care
  - Coordination of health care and ability to access multiple services in one day
  - Nutrition counseling

- **Homeless**
  - Housing
  - Transportation
  - Financial assistance for health care, food, etc.
  - Substance abuse treatment
  - Translation services and communication barriers
  - Difficulties related to treatment adherence
  - Syringe Exchange
  - Cultural competency
  - Outreach teams; more street advocates

- **Adolescents and Youth, including those who were perintally infected**
  - Comprehensive health care, coordination of care and ability to access multiple services in one day, services that support transition to adult medical care, and financial assistance to ensure access
  - Education regarding medications and treatment adherence
  - Low income and transitional housing
  - Residential placements for youth with multiple diagnoses
  - Dental care
  - Mental health services for youth and for family members
  - Family planning services
  - Case management based on level of service needs; e.g., intensive case management may be needed for young people who were perinatally infected and are becoming adolescents
  - Transportation
  - Stigma and discrimination
  - Life skills training and social support activities for infected/affected youth
  - Vocational training
  - Legal assistance
  - Permanency planning

- **Immigrants**
  - More accessible HIV-related services for undocumented persons, particularly immigrants from Central and South America.
  - Housing
  - Transportation
  - Legal assistance
  - Mental health services, and extended coverage of these services under ADAP Plus (Note: ADAP Plus currently covers 24 mental health visits per person per treatment year with an enrolled Article 28 licensed mental health provider or an enrolled Enhanced Fees for Physicians (EFP) psychiatrist.)
  - Cultural taboos associated with HIV represent a formidable barrier to care and services for immigrants

- **Inmates and Releasees**
  - Placement options for releasees who are former users and do not wish to return to their home environment, and those who have complex medical needs and/or mental illness
  - Perinatally infected youth in the criminal justice system need help with disclosing HIV status, obtaining appropriate treatment, and managing their disease.
  - High quality medical care while incarcerated, particularly in county jails
  - Housing

The following were identified as additional service needs and overall barriers to care and services in this region through source documents and comments received at the SCSN/CP Community Forum:

- Many communities in this region are affected by high rates of poverty, which contribute to chronic housing and food shortages.

- Housing continues to be a major problem due to the rising emphasis on single-family home ownership and the lack of low-income housing and available rental units.

- Public transportation in both Nassau and Suffolk counties continues to be an obstacle for many consumers in their attempt to access adequate health care and supportive services, as well as employment opportunities, on Long Island.

- The many side effects of medication may pose barriers to seeking care and treatment adherence. Therefore, it is essential that consumers be well educated and work with their medical providers to reduce, and if necessary, treat the side effects to improve quality of life.

- Intravenous drug use is one of the most common modes of transmission for HIV/AIDS. Due to the high correlation between HIV/AIDS and addiction, a comprehensive approach should address the medical, physical, psychological, socioeconomic, sociocultural, and political factors relating to both addiction and HIV.

- Grandparents and other extended family members often become the primary caretakers of infected children and youth. They need education and support to meet the full range of needs of these young people.

- Concerns were expressed regarding foster parents having information regarding the HIV status of children placed with them, and the need for training of staff involved with these placements. Complete information regarding the child's health status is needed to ensure appropriate medical care and treatment.

- There is a lack of services addressing the needs of persons who are deaf and hard of hearing.

- More providers are needed on Long Island that conduct outreach directly to the gay community.

- Service needs for all subpopulations on Long Island include: prevention with positive individuals, expanded testing opportunities, and better coordination among service providers to eliminate duplication and make the most of scarce resources.

- Denial is present regarding the impact of HIV/AIDS in the region. In general, residents do not recognize the connection between HIV, homelessness and substance abuse. This may be due to the fact that Long Island is adjacent to New York City, which leads Long Island residents to mistakenly believe that HIV/AIDS is a problem of the city and not of their own suburban community.

- Concerns were expressed regarding how Medicare Part D will affect medication coverage for PLWHA who are dually eligible for Medicare and Medicaid, and on spenddown. At a minimum, consumers must be educated about this process so that there is no disruption in medication regimens.

- Medicaid prohibition of billing for different services provided on the same day (e.g., mental health services and primary health care) is a barrier to provision of comprehensive care and not cost-effective relating to transportation and childcare. (Note: Medicaid does allow same day billing for certain limited services, such as HIV counseling and testing and non-HIV clinic visits. Specific guidance on same day billing can be obtained from AIDS Institute staff in the Bureau of HIV Ambulatory Care.)

In terms of policy and broad program issues, the following comments were received at the Community Forum:

- Importance of continuing the mandate for consumer representation and participation as the Ryan White CARE Act is reauthorized.

- Need to emphasize in reauthorization discussions New York State's disproportionate burden of the national epidemic: 7% of US population and 17% of all PLWHA in the country.

- Official case counts often underestimate the number of persons in need of care. Providers note, for example, that the number of persons living with HIV/AIDS who were perinatally infected and are receiving treatment in Nassau and Suffolk County is higher than the official case count. This is most likely because cases are reported based on county of residence at time of diagnosis. Therefore, cases diagnosed in New York City or other surrounding counties are not reflected in official Nassau/Suffolk case counts. Providers note that many adopted children from New York City live on Long Island.

- Providers need cost of living increases (COLAs) to meet the growing demand for more services, and for services that are increasingly complex; flat grants mean services are stretched too thin.

- The importance of funding Program Coordinators was noted, to ensure that programs run smoothly and to better coordinate services with other agencies. Clinicians and other direct service providers are not able to carry out these important functions.

- Federal poverty levels need to be adjusted so that very low-income persons can receive needed benefits, especially housing and food.

- New York State's Request for Proposals (RFP) process needs to be simplified and streamlined so that small CBOs serving high risk, hard-to-reach populations can apply and be competitive.

- The need for common and simplified data collection systems was strongly emphasized. Providers noted that different data systems are required by different funders – examples include: URS, CareWare, HIVQUAL, HMIS (for HOPWA grants). These data systems do not "talk to each other" and it often means that providers have to manually produce required reports. The need for common demographic data elements was also noted.

P. Rochester (Finger Lakes) Ryan White Region

Since the beginning of the epidemic, there have been nearly 2,900 AIDS cases reported in the nine-county Rochester (or Finger Lakes) Region. Over 2,400 persons are living with HIV or AIDS in the region**.** Of newly diagnosed HIV cases (2001-03), 70 percent are among persons of color. Over 70 percent of AIDS cases in the region are from Monroe County, which has 58 percent of the region's population; however, each of the other more rural counties has reported HIV and AIDS cases. Similar to other areas of the State, this region has seen a decline in cases among MSM and IDUs and a significant increase in heterosexual transmission.

Service Needs and Barriers

The Finger Lakes Region 2005 Service Delivery Plan — Preliminary Draft (Document # 102) identified the following needs as the most pressing:

Stable Housing:

Providers in this region often cite lack of "decent affordable housing" as a barrier to stabilizing a person living with HIV/AIDS. Because of the shortage, PLWHA frequently move from place to place, consuming their energy as well as agency staff and resources. In 2004, a major provider had 126 new HIV positive clients and 100 percent had housing needs.

Emergency Financial Assistance:

High-energy costs associated with harsh, long winters deplete the financial resources of clients. For the last two years, one provider used all budgeted emergency funds by the seventh month of the year due to need for this assistance.

Substance Abuse Services:

The most frequently cited needs are: residential programs especially for women with children; more detoxification programs/beds; substance abuse counseling; transportation to services; and the lack of or inadequate insurance coverage for substance abuse treatment. The Plan also noted that harm reduction/recovery readiness services need to be expanded, and that substance abuse providers need more HIV training.

Mental Health Services:

A continuum of mental health services for HIV-infected persons needs to be developed. The Plan cites regional data indicating that 10-15 percent of those with AIDS who died in 2003 died of suicide.

Enhanced Services for Women:

Prior to 1990, 12 percent of AIDS cases in the region were women. By 2001 the percentage of cases increased to 38 percent. The Plan identifies a goal of obtaining Ryan White CARE Act Title IV funds for the Region as there are currently no Title IV grants focused on providing health care and support services for women, children and families in the region.

Transportation:

Many persons with HIV/AIDS in the region must depend on public transportation to get to appointments. Only one county in the region (Monroe) is a major urban area with public transit systems. In the other counties with inadequate or no public transportation, many clients are dependent on case managers or volunteers to take them. One major provider indicates that 75 percent of their 126 rural clients rely on case managers for transportation. Rising fuel costs adversely impact the willingness of volunteers to drive people to appointments and increase the costs for agencies to provide transportation.

At the Community Forum, participants noted specific problems with inability to access Medicaid reimbursement for transportation to mental health services provided at a satellite site that is not an OMH site. This problem poses a barrier to providing these services.

Case Management:

Because of the growing number of persons living with HIV/AIDS and the complexity of their needs due to socio-economic factors, the demand for case management services continues to escalate. Case managers assist clients in obtaining essential enabling services, such as housing, transportation, and benefits/entitlements, that assist patients in entering care and staying in care.

Other service needs and barriers identified for this Region in source documents and at the SCSN/CP Community Forum include:

- Enhanced access to HIV counseling and testing, partner notification assistance and out-patient medical care
- Treatment adherence support
- Counseling and support, such as peer support groups, parent-to-parent peer support, and bereavement counseling
- Enhanced outreach to bring high risk persons into care and substance abuse treatment and to help them stay in care
- Services to support families in transition (permanency planning)
- Legal assistance
- Dental care

- Transitional case management and support for criminal justice populations/releasees

- Consumer-directed center to enhance peer outreach, education and nutrition for PLWHA. Community Forum participants noted that 93% of PLWHA supported the need for this center is a recent survey.

- Services for HIV+ persons who are deaf, including supportive services and signing services in all care and service settings.

- The service needs of Native American communities in the Rochester Region need to be more specifically addressed. In addition, it is important to acknowledge that the reported number of infected Native Americans is likely an undercount due to persons not being tested, inability to access services, and/or not self-identifying as Native American.

- The service needs of persons who use crack/cocaine and marijuana must not be ignored as resources are directed to crystal meth users. Persons using any of these substances are at increased risk for acquiring and transmitting HIV.

- The needs of transgender persons should be addressed more specifically in the Special Populations section, including issues relating to Medicaid coverage of hormone therapy, needle sharing, self-identification and resulting stigma and discrimination.

- Need to track trends relating to HIV+ persons aged 50 and over, and develop strategies to reach and serve this age group.

- Expanding and improving human resources by enhancing support for recruiting and training experienced, diverse and culturally competent health and human service providers to meet the complex needs of increasing numbers of people living with HIV/AIDS, many with co-morbidities.

- More peer education is needed to empower consumers in addressing such topics as nutrition, harm reduction, phone and other general life skills.

- Consideration should be given to creating streamlined "Single Point of Access" (SPOA) procedures for HIV+ persons who need multiple services, such as housing, intensive case management, mental health and supportive services. Forum participants noted SPOA in Rochester is a very good concept.

- Science-based HIV Prevention service models need to target communities of color. Those models need to be adapted and tailored to address diverse subpopulations within communities of color.

Additional comments received at the SCSN/CP Community Forum:

- Forward-looking, broad policy and program issues were addressed in a written document prepared by the Coordinator of the Rochester Area Task Force on AIDS, Inc. which is included in full in Section IX of this document. Highlights include:

  - Needs that are unmet or under met in the region:
    - Funding for Hepatitis C screening and treatment.
    - Funding for skyrocketing utility bills.
    - Funding for rapid testing by primary care providers
    - Training for primary care providers to help assess who should be tested for HIV, STDs, hepatitis, etc.
    - Additional dialysis capacity for PLWHA who need End Stage Renal Disease Services
    - Increased access to dentists, especially in rural areas
    - Medical homes and program models that address holistic needs of transgender people
    - Continuum of housing services including supported and supervised housing for: youth who are AIDS orphans, developmentally disabled HIV+ persons, those in need of long-term recovery from substance abuse, and those who are physically and mentally impaired due to AIDS-related illnesses; and
    - Providing qualified translators for immigrants to protect their confidentiality.

  - Considering a different taxonomy to describe special populations, including the following categories and associated needs:
    - *Alcohol and substance users*, noting that Monroe County research indicates that over 50% of persons in the No Identified Risk (NIR) category use alcohol and cocaine and have multiple sex partners. There is a growing concern about the numbers of crystal meth labs in rural areas, and how meth increases high risk sexual activity among all who use this drug.
    - *People with disabilities*, noting the following as examples: 1) Persons who are deaf; Rochester has the highest rate of deaf people per capita in the U.S.; 2) Blind and visually impaired; 3) Developmentally disabled persons; and 4) Persons who are seriously and persistently mentally ill. Each of these populations has unique needs that pose challenges for providers in relation to access, care, treatment and prevention.
    - *Transient populations*, including: the homeless, migrants, evacuees, people who temporarily reside at VA facilities, people in jails, prison releasees, and people receiving inpatient rehabilitation. These populations require case management that addresses the challenges of transition and resettlement. Other transient populations, such as college students, truck drivers, business people who engage in high risk behavior away from their home community, and young people between the ages of 19 and 29, pose unique challenges relating to HIV prevention.
    - *Poor people who engage in high risk behavior for economic survival*, including drug dealers, low income women and youth, people who engage in sex to support a substance abuse habit, and transsexuals. In addition to being poor, these people share other environmental risks associated with living in low income

neighborhoods. Intensive case management is often indicated because they are at high risk of being multiply diagnosed and their lives are impacted by the syndrome of poverty.

- Data Needs that would enhance planning and evaluation processes: 1) develop the URS database so that aggregate profiles of the populations receiving services by region can be used in future needs assessments and planning documents; 2) more regional data relating to delayed diagnosis and entry into care, unmet housing needs, and estimated unmet need; and 3) better and more accessible data relating to mortality of persons with HIV and AIDS.

- Suggestions for inter-agency cooperation and regulatory relief, including: 1) allowing school clinics to provide condoms; 2) State oversight to ensure enhanced shelter allowances are provided to all eligible in all counties; 3) State process for counting cases of presumed heterosexual transmission; 4) improved care for the multiply disabled facilitated by consistent regulations and policies from interagency effort involving OASAS, Mental Health and the AIDS Institute; and 5) monitoring nursing home admission practices to identify cases of AIDS-related discrimination.

- Additional considerations for the environmental assessment which have been enumerated in Section V of this document.

Highlights of the impact on and unique characteristics and needs of infected subpopulations in the Region can be summarized as follows:

Racial/Ethnic Trends and Disproportionate Impact on Persons of Color:

The regional epidemic is dynamic in that it has affected racial and ethnic groups differently over time. The percentage of AIDS cases among White/Non-Hispanics declined from 67 percent in the l980s to 36 percent in 1999-2001. During the same time period, the percentage of cases diagnosed among Blacks increased from 25 percent to 54 percent; cases among Latinos increased from 8 percent to 12 percent; cases among Asian/Pacific Islander and Native American increased from 0.3 percent to 0.7 percent.

In the Finger Lakes Region, Blacks account for 9 percent of the population but nearly 43 percent of HIV/AIDS cases; Latinos account for 4 percent of the population and 13 percent of HIV/AIDS cases; Native Americans account for 0.2 percent of the population and 0.4 percent of HIV/AIDS cases.

Blacks have HIV/AIDS rates nine times greater than those of Whites in the region. Rates for Latinos are more than six times higher than White/Non-Hispanics. Native Americans have AIDS rates more than twice the rates for Whites and HIV rates fives times those of Whites. The lowest reported rates are among Asian/Pacific Islanders; however, this may reflect low testing rates in this subpopulation.

Substance Users:

Regional data indicates that injection drug use accounts for approximately 28 percent of people living with HIV/AIDS. Injection drug users are not the only substance using population affected by HIV; alcohol, marijuana and cocaine use probably affects more people's lives than injection drug use. Among heterosexual women with HIV, 52 percent of those in a recent local study (RARE report) were found to use cocaine, and 32 percent used alcohol. Many of these women are sex workers supporting themselves and their families and use substances to dull the pain.

Men Who Have Sex with Men (MSM):

Two-thirds of those living with HIV/AIDS in this region are men. The highest prevalence of people living with AIDS in this region is men between 30-59 years of age. Monroe County data for new HIV diagnoses suggests that at least 44 percent are MSM cases.

Prisoners/Releasees:

There are 12 State prisons in this region, one youth detention facility, and 9 county jails. There were 206 reported cases of persons living with AIDS in State prisons in this region.

Migrant Workers:

New York State ranks tenth in the nation in the use of migrant farm workers, and Wayne County from this region ranks first in NYS. The Wayne County Health Department has found that there are 3,000-5,000 true migrants annually in Wayne County and up to 10,000 seasonal and agricultural workers. There are an estimated 350-400 licensed migrant camps in the Finger Lakes Region. These farm workers work from sun up to sun down, seven days a week for less than 85 percent of the minimum wage, with no vacation or sick leave and usually no benefits. Accurate reporting for this population is difficult because of barriers to seeking care and many cultural issues, including infected males not allowing their female partners to be tested.

Immigrants:

Census data from 2000 indicate that between 1990 and 2000, 22,633 people from other nations moved into the Finger Lakes Region. Four regions accounted for 85 percent of the counted immigrants: Asia 38 percent; Europe 32 percent; the Caribbean 10 percent and Africa 5 percent. More than 19,500 of the immigrants are located in Monroe County.

Marginally Housed:

People without stable housing have problem keeping track of medications and keeping them properly refrigerated. They usually lack nutrition and rest, and they have many stressors in their lives. Those who are marginally housed need greater than average case management services to assist with multiple survival needs.

People in Denial:

Service providers in this region, especially in urban areas, have been doing aggressive work to encourage at risk populations to get tested and into care. Anecdotal evidence suggests that there are an increasing number of persons engaged in high-risk behavior who are afraid to take the test and get the result.

Aging of the Infected Population:

Prior to 1990, one-third of those diagnosed with AIDS were over age 40. During 1999-2001, over half of AIDS cases were over age 40.

Domestic Violence:

The Plan notes that while the extent of domestic violence is not known, it was so prevalent among HIV positive persons in care that case managers requested and were provided intensive training in 2004 to enhance their skills for serving those in abusive relationships. Getting this population in care and keeping them there is a major challenge for service providers.

Q. Syracuse Ryan White Region

There have been over 3,200 AIDS cases reported in this 11-county region, and nearly 2,900 persons are living with HIV or AIDS**.** The presence of 16 State prisons in the region accounts for more than 40 percent of cumulative AIDS cases. Nearly 55 percent of newly diagnosed HIV cases (2001-03) are among persons of color. Two counties, Onondaga and Oneida, have 62 percent of the region's AIDS cases, but every county in the region has reported AIDS cases. MSM is the primary risk factor for White, Asian/Pacific Islander and Native American males living with HIV/AIDS in the region. Among Black and Hispanic males, IDU is the primary risk factor closely followed by MSM. Among females living with HIV/AIDS, heterosexual transmission is the primary risk factor across racial/ethnic groups.

Service Needs and Barriers

The Network Service Delivery Plan (Document #59) and other source documents for the Syracuse Region identified the following service needs and barriers:

- **Primary Medical Care and Dental Services:** The need to strengthen and expand primary care resources for communities of color and in smaller cities was noted. Specific needs include:
  - Ambulatory Medical Care relating to a shortage of specialty care in outlying areas.
  - Dental Care accessibility due to providers not accepting Medicaid payment.
  - Building patient/provider partnerships to improve care effectiveness, especially in outlying areas.

- **Lack of Health Insurance** is often a barrier causing delays in seeking services or disruptions in therapy.
  - Providers note there are some serious gaps in medical care coverage that become evident as people live longer and have more medical complications. HIV+ persons who do not have full coverage usually cannot afford to pay out-of-pocket costs. ADAP Plus does not cover all needed services, such as CT scans and biopsies. Many low income persons do not qualify for Family Health Plus, another plan which provides "gap coverage." Onondaga County has a Catastrophic Health Insurance Fund (CHIF), but it is limited and often exhausted.
  - There are also serious gaps in dental care coverage. Many local dentists do not provide services under Medicaid, ADAP Plus or Family Health Plus.

- **Mental Health Therapy/Counseling:**
  - Expanded mental health service accessibility for PLWHA
  - HIV/AIDS-specific training for mental health professionals
  - Increased mental health counseling staff in the North Country

- **Housing Assistance:** Transitional housing, assisted living, emergency rental assistance, more affordable and larger family units are needed in the region.

- **Transportation Services** for Medical Care and Supportive Services need to be expanded and program participants should be better educated on how to access Medicaid-supported transport.

- **Coordinated Care for Substance Users**: PLWHA who are dually diagnosed with a chemical addiction are often denied services because of unresolved substance abuse problems. There is a need to coordinate care and provide counseling for this population in order to retain them in health care and drug and/or alcohol treatment.

- **Support Services**:
  - Direct emergency financial assistance, particularly for HIV/AIDS medications while coverage is pending.
  - Supportive services for HIV positive parents and their children, including Permanency Planning and expanded child care services to enable HIV infected women and families to consistently seek care and participate in treatment.
  - Vocational training and access to employment resources for PLWHA able to return to work.
  - Drop-in centers in rural communities to promote PWA peer support, prevention, and access to care.
  - PWA empowerment, advocacy and participation in consumer advisory boards.

Additional service needs and barriers identified in the source documents for this region include:

- Cultural competency training for clinical staff throughout the region.
- Training for rural pharmacists.
- Language resources for non-English speaking individuals, and specifically, additional well-trained Spanish-speaking interpreters are needed to facilitate services to Latino populations in the region in a culturally sensitive manner.
- Early application for Medicaid and ADAP benefits would assist pre-releasees from criminal justice settings in accessing services offered by these programs before they are released into the community.
- The availability of Ombudsman resources would make Medicaid services more user friendly for those accessing local social services districts or managed care entities.
- Nutrition services are not consistently provided to PWAs in some neighborhoods in the region due to drivers not being willing to go into certain areas.
- Additional harm reduction services need to be provided to engage high-risk individuals.
- A regional PWA Ombudsman program is needed to strengthen client advocacy in obtaining entitlements, housing, supportive services, etc.

Special Populations:

The following special populations were identified in need of targeted services in the region:

- Men of Color who have sex with men
- Homeless persons

- Mentally ill and chemically addicted persons
- Immigrants and refugees
- Migrants and seasonal farm workers
- Inmates and Releasees
- HIV-positive babies, children and youth
- Persons 50 and over

Comments Received at SCSN/CP Community Forum:

- Written comments were received regarding the section describing Native American populations within New York State and their service needs. These comments have been reflected in the Statewide Service Needs and Barriers Section of this document.

- Providers working with inmates and releasees identified the following issues:

  - It is a challenge to get inmates the services they need: they are not always given appropriate space for rapid testing and for prevention education; inmates not allotted enough time to spend with providers, and at times not allowed to participate in peer education programs; and prison policies limit access to inmates in isolation. (Note: Provider advised to contact AIDS Institute staff who communicate frequently with DOCS Central Office Medical staff who are often able to address some of these issues with the correctional facility.)

  - Concern expressed regarding the DOCS policy that prohibits condom distribution within correctional facilities.

  - Pre-release planning is a challenge since county of residence is not yet established. In addition, at times provider staff devote much time to effect linkages to care for potential parolees but communication from the Parole Board regarding their decision is not good and limited staff time is often not used most efficiently.

  - County jail inmates who are hospitalized with serious medical problems are sometimes released from custody early so the county does not incur high costs as county jail budgets for health care are minimal.

  - Providers indicated additional subpopulations that require targeted services:
    - Perinatally infected children aging into adolescence – these young people have unique needs and require special support in transitioning from pediatric care to adult care settings in large health care facilities. There are also challenges associated with disclosure to the child as some, maybe many, are not told about their status until 12-13 years of age.
    - Babies born to HIV+ mothers – Providers are seeing an increase in the number of HIV+ women delivering; most are on anti-retroviral therapy which means that most babies will be exposed to the virus but not infected. Exposed babies are followed closely until 15 months to two years of age.
    - Sexually assaulted children, ages 2-21, who are potentially exposed to HIV.

- One participant recommended that enhancing case management should be a goal of the Comprehensive Plan. He further recommended that Centers for Independent Living should be considered as potential case management providers for PLWHA since they have experience providing services for persons with multiple disabilities and cover regional areas upstate, including rural areas. This alternative would give PLWHA a choice of providers for case management services.

- One provider noted the need for a PLWHA Ombudsman to work on provider/consumer relations, and empowering consumers.

- Concern was expressed about the need for targeted prevention and support services for persons aged 50 and over. Discussion occurred regarding innovative ways to reach this subpopulation by integrating with other programs that serve Seniors.

SECTION VIII: COMPREHENSIVE PLAN

The organization of this Comprehensive Plan is based on the guidance provided by HRSA. The required topics are addressed in the narrative below, included as Appendices to this report, or referenced in other documents too voluminous to be part of this Plan. All such documents will be included in the transmittal of this report to HRSA and are available to all readers. To eliminate repetition, other sections of this report are referenced when they address topics required by HRSA to be part of the Comprehensive Plan.

A. New York's Current System of Care

1. Brief History and Description of New York's HIV Epidemic and the Response

New York State is the epicenter of the HIV epidemic in the United States. While the overwhelming majority of cases (~80 percent) are from New York City, all of the other 57 counties within the State have reported cases. New York State has both rural and urban epidemics. This is illustrated by the fact that even if New York City cases are excluded, New York State ranks 5th among all states in cumulative AIDS cases and 7th in terms of living AIDS cases nationally.

As of December 2004, the New York State surveillance system has documented a cumulative total of over 164,000 AIDS cases. Statewide data shows that the number of AIDS cases peaked in 1993 with just over 15,000 AIDS cases reported that year. Effective June 1, 2000, HIV became a reportable disease in New York State. As of December 2004, more than 35,000 HIV cases have been reported to CDC. The addition of HIV reporting more than doubled the number of cases that would have been reported under the previous AIDS case reporting system.

Deaths due to AIDS reached its peak in 1994, with more than 8,000 deaths attributable to AIDS. Since then, with the advent of more effective antiretroviral therapies, there has been a dramatic decline in AIDS-related deaths; in 2002 there were 1,998. As a result, there are many more persons living with AIDS and HIV – this number is estimated to be nearly 170,000 in New York State. In addition, an estimated 6,000 new infections occur annually.

In 1981, the number of AIDS cases among persons of color was higher than among whites and this has been true every year since. Among newly diagnosed HIV and AIDS cases in 2003, approximately 80 percent are persons of color, primarily Black and Hispanic. Many believe that cases among Native Americans and Asians/Pacific Islanders are likely to be undercounted. Most cases in New York State are attributable to injection drug use, either directly or indirectly (through sexual contact with an injection drug user or infants infected perinatally). Male to male sexual contact is the next highest risk, followed by heterosexual transmission.

More detailed information describing state and regional epidemiological data, maps depicting the five boroughs of New York City and the regional Ryan White CARE Networks in all areas outside of New York City, and special populations are contained in Sections IV, VI and VII of this document.

In 1983, the New York State Legislature enacted a law creating the AIDS Institute as part of the NYS Department of Health, with a mandate to coordinate the State's policies and response to the AIDS epidemic. Its mission, drawn from the legislative mandate, is to "promote, protect and advocate for health through science, HIV prevention and assurance of access to a coordinated system of quality health care and support services for persons with HIV/AIDS." The AIDS Institute vision is to "prevent HIV infection and improve the quality of life of those infected and affected by HIV through a collaborative, coordinated approach focusing on individuals, families and diverse communities."

The AIDS Institute established a comprehensive continuum of HIV care and services through numerous partnerships and close collaborations with: Persons Living with HIV and AIDS, partners and affected family members, the New York City Department of Health and other local health units throughout the State, Title I Planning Councils, Title II CARE Networks, health and human service providers and agencies, community-based organizations, leaders of diverse communities, and advocates. Direct services are most often delivered through contractual agreements with health agencies and community-based organizations on the front lines of the epidemic**.** Medicaid reimbursement is available for HIV counseling and testing and for a wide range of clinical services and pharmaceuticals provided to HIV positive Medicaid enrollees. By leveraging existing public sector programs and available resources from federal, state and local government agencies, NYS created the most comprehensive continuum in the nation, described below, and designed it to meet the needs of diverse populations.

Landmark legislation, the HIV Confidentiality Law, was enacted in New York State in 1987, protecting the privacy rights of all persons infected with HIV and of those who take an HIV antibody test, addressing a major barrier to ensuring appropriate care and services. Many other key events in the history of the AIDS epidemic are displayed on the Milestones graphics attached as Appendix C to this report. These events have shaped the course of the epidemic and New York's response.

2. Assessment of Needs and Barriers

Detailed summaries of medical and supportive service needs and barriers by geographic area are presented in Section VII of this document. Environmental considerations, relevant policies and emerging trends that affect service access are covered primarily in Section V. Prevention needs are addressed in Regional Gaps Analyses submitted as source documents, as well as in other comprehensive needs assessments that were submitted and reviewed in the SCSN process.

3. Unmet Need Estimate

The Unmet Need Calculation updated for the 2006 Title II application and attached as Appendix D to this report indicates the following, based on the methodology and definitions described in the calculation: 125,473 Estimated Persons Living with HIV/AIDS (PLWHA) in New York State through 2004, which includes cases that are not reported for various reasons (undetectable viral loads, CD4 >500, and persons participating in research studies or clinical trials). Based on the Unmet Need Calculation, of the estimated 125,473 PLWHA, 66 percent, or 82,382, are "in care," and 34 percent, or 43,091, are not "in care**."**

To place these numbers in context, CDC recently estimated that there are 1 million persons living with HIV/AIDS in the United States. Of that 1 million, CDC estimates further that 25 percent of those persons, or about 250,000, are unaware of their status. Of the estimated 750,000 persons who know their status, New York has about 16.7 percent based on the above PLWHA estimate from the Unmet Need Calculation (125,473/750,000). New York's share of total persons unaware of their status is about 37,500, or 15 percent of the national total (250,000).

CDC also estimates 40,000 new infections annually in the nation. Assuming New York accounts for at least 15 percent of those, an additional 6,000 infected persons each year are in need of services, 1,500, or 25 percent, of whom may require intensive outreach and HIV testing and other services in nontraditional settings to make them aware of their HIV positive status.

These estimates can be summarized as follows in terms of the total number of HIV infected persons in need of services in New York State:

125,473	Estimated PLWHA through 2004 (aware of HIV+ status)
+ 37,500	New Yorkers unaware of HIV+ status through 2004
162,973	Estimated Total New Yorkers with HIV/AIDS as of 2004

Add to the above each year:

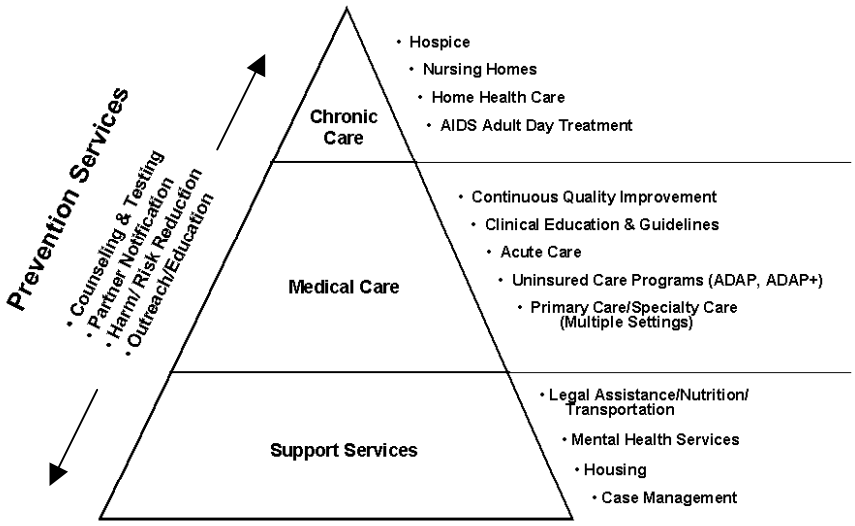
4,500	New diagnosed infections each year
+ 1,500	New undiagnosed infections each year
6,000	Total new infections each year in NYS

As death rates continue at about the same level and people with HIV live longer, the cumulative number of infected persons in need of care and preventive services climbs dramatically. Based on the above estimates, New York has nearly 170,000 persons with HIV in need of services as of 2005.

4. New York's Continuum of HIV/AIDS Services

The AIDS Institute's overall goal is to ensure the availability and accessibility of quality care and services that are culturally appropriate for all populations affected by HIV through the development, implementation and maintenance of a comprehensive continuum of care and services, including prevention, client support, medical and chronic care, depicted in the graphic below. The continuum is supported by funding from all sources — federal, state and local grants as well as revenue from Medicaid rates.

New York's Continuum of HIV Care and Services



It is important to note that consistent with the epidemiology of New York's HIV epidemic, the service continuum primarily targets communities of color – 80 percent of the total served by agencies under contract with the AIDS Institute are persons of color.

HIV prevention services span the continuum and include outreach and risk reduction education; peer education and support; counseling, testing, linkage to care, and partner notification assistance; and a range of harm reduction services. These services are provided in a variety of settings such as: community-based organizations, health care settings, substance abuse treatment programs, mobile vans and storefront locations in high risk neighborhoods. Prevention initiatives target specific populations, including communities of color; substance users; men who have sex with men; women; youth; and incarcerated persons. Prevention services are supported by State and CDC funds.

For infected persons, the continuum includes services that address the needs of individuals from asymptomatic infection through the acute and chronic stages of HIV disease. Due to improvements in medical management and the availability of combination therapies, HIV disease has evolved to a chronic manageable disease. The established importance of early treatment in delaying the progression of HIV disease, improvements in ambulatory care management and diagnostic testing, and the resulting improved quality of life and increased longevity of persons diagnosed with AIDS have resulted in a shift in the locus of HIV care from the hospital inpatient unit to ambulatory and long term care settings.

The HIV care and service continuum is ongoing but not static — it evolves to meet new and emerging service needs. New York's HIV continuum represents a strong collaboration and significant work of many partners, including health providers, community-based organizations, persons living with HIV/AIDS and government agencies at the local, state and federal levels. Productive partnerships with the Ryan White Title I EMAs further strengthen the continuum.

Descriptions of organizations providing the full spectrum of HIV services by service category are contained in the Resource Directories published by the New York State Department of Health AIDS Institute (Document #142) and the Title I EMAs (Document Nos. 151, 152, 155). A resource listing of New York State agencies funded under other RWCA Titles has also been compiled (Document #159). These documents are available to the public and will accompany transmittal of this report to HRSA.

The publication *About the AIDS Institute, 2004* (Document #141) contains a detailed description of programs and initiatives managed by the AIDS Institute, and is also available to the public and will accompany transmittal of this document to HRSA. Key elements are described below by highlighting selected initiatives that focus on care and services for HIV infected persons and on services that engage high risk persons in testing, care and enabling supportive services.

MEDICAL CARE AND RELATED SERVICES

The AIDS Institute's HIV ambulatory care strategy consists of combining funds from a variety of sources to achieve the following goals: 1) to increase early identification of HIV infection by promoting HIV prevention education, counseling and testing in a variety of health care settings; 2) to ensure that care is provided by an HIV specialist or in consultation with an HIV specialist; 3) to ensure the provision of services to underserved populations, including persons of color, substance users, women, children, adolescents and young people, men of color who have sex with men, prison releasees, MICAs, immigrants and migrants; and 4) to empower uninsured individuals to access health services. This strategy has been implemented through grants, HIV-specific Medicaid rates, reimbursement pools for therapeutic drugs and for primary care services for uninsured and underinsured persons with HIV. Descriptions of specific Primary Care Initiatives follow.

Community-Based HIV Prevention and Primary Care:

The goals of this Initiative are to educate those at increased risk of HIV infection, promote the availability of HIV counseling and testing and develop the capacity to deliver on-site HIV primary care services. Forty (40) providers, including community health centers, county health departments and hospitals, are funded to provide: primary health care, outreach and prevention education, HIV counseling and testing, partner notification assistance, peer support, patient and staff education regarding HIV disease and treatment options, case management and referral to services unavailable on site. Many providers also offer specialty medical care, substance abuse counseling, medical, dental, and nutrition services. Special emphasis has been placed on integrating strategies to strengthen treatment adherence and on health behavior counseling, including prevention with positives, as critical components of the service package.

HIV Primary Care and Prevention Services for Substance Users:

This initiative is designed to develop a co-located continuum of comprehensive HIV prevention and primary care services on-site in substance abuse treatment settings throughout New York State, based on current standards and best practices in the treatment of HIV/AIDS. Outreach, HIV education, risk/harm reduction services, capacity building for smaller drug treatment programs and transitional case management for active substance users not in treatment, are also featured in this model. Twenty-four (24) drug treatment agencies of

varied modalities, including methadone maintenance, methadone-to-abstinence, drug-free residential, outpatient and detoxification, participate in this initiative through grant funding. In addition, ten community-based programs that serve substance users are funded, including two that focus on co-occurring mental health issues and two syringe exchange programs. Recent advances have been incorporated into the service delivery package, such as screening and treatment for Hepatitis C, behavioral-based prevention interventions, and new testing technologies. This initiative has been instrumental in broadening the mission of the substance abuse treatment community from a singular focus on rehabilitation to the provision of public health services.

Women, Children, Youth and Family Services:
In New York State, many families affected by HIV have histories of poverty, substance use, domestic violence, mental illness and family disruptions. HIV often affects several generations and extended family members. In addition to addressing the immediate health care concerns and emotional needs of their children and adolescents, infected and affected parents often face issues such as custody arrangements, daily child care, elder care and discrimination. The following briefly describes some of the initiatives in place to reach and serve the needs of these subpopulations:

***Maternal-Pediatric HIV Prevention and Care Program*:**
This program is designed to reduce perinatal HIV transmission through education, technical assistance, monitoring and regulatory action. The goal of the program is to ensure that pregnant women have access to HIV counseling and testing and that those who test positive have access to antiretroviral therapy (ARV) for their own health and to prevent HIV transmission to their babies. A three-part regimen, with ARV administered to the mother during pregnancy, labor and delivery and to the newborn immediately after birth, is optimal. However, studies conducted by the New York State Department of Health (NYSDOH) have shown that partial ARV regimens, initiated during the intrapartum and newborn periods, can significantly reduce the risk of perinatal transmission. With the collective efforts of facilities across the state and by providing program oversight, NYSDOH has documented dramatic improvement in perinatal HIV testing rates and a marked decrease in the mother-to-child transmission rate. The percent of babies born to HIV positive mothers has dropped sharply – from 10.9 percent in 1997 to 2.4 percent in 2002. (In 1997, there were 97 HIV-positive births; in 2002, there were 17.) In addition, the prenatal HIV testing rate has greatly improved – from 64 percent in August 1999 to 94 percent in January 2003.

Family-Centered Health Care Services:
This Initiative promotes a holistic approach to family health linking medical, psychosocial and other concrete services to meet the needs of families. Multi-disciplinary teams integrate medical care, including HIV specialty care, with mental health, substance use, case management and other HIV-related services to manage the complex medical and social issues faced by HIV affected families. Eleven (11) programs are funded statewide to foster strong working relationships between adult medicine, obstetric/gynecological and pediatric programs to co-locate care for family members wherever possible, and to coordinate care and services in all cases.

***Youth-Oriented Health Care Initiative*:**
This initiative is intended to develop models of care for youth that promote collaborations among providers, integrate prevention and care services, and offer services in safe, confidential environments. There are eleven funded programs in two components of this initiative:

***a. Youth Access Programs*:**
Funded health care facilities provide low-threshold clinical services in accessible community-based settings to meet the immediate health care and social service needs of at-risk youth. Methods for implementing low-threshold clinical services include mobile multi-disciplinary teams, part-time clinics in community-based settings and on medically equipped mobile vans. Youth access programs have community partners who can reach the highest risk youth, such as young men of color who have sex with men. Programs are funded to provide client recruitment, HIV prevention and risk reduction services, HIV counseling and testing, immediate primary health care for acute illness, access to pharmaceuticals, pregnancy testing and family planning services, screening and treatment for sexually transmitted disease, psychosocial assessments and transitional case management.

b. Specialized Care Centers for Youth:
These Centers provide comprehensive health care and support services as an integrated model to address the needs of adolescents and young adults who have, or are at high risk for HIV. Services include: client recruitment, HIV prevention education, individualized risk assessment and health promotion, HIV counseling and testing, comprehensive medical services, case management and advocacy, supportive counseling, concrete supportive services (e.g., transportation, child care, language interpretation), and peer support. In addition, these programs provide mental health and substance use assessments with referral to or provision of treatment services, if indicated.

***Pediatric Centers of Excellence*:**
Perinatally acquired HIV infection is, for most infected children, a chronic disease that requires complex medical and psychosocial management. These Centers offer comprehensive care by multi-disciplinary teams of experienced providers that include one or more pediatric HIV specialists. In addition to primary and sub-specialty medical care, nutritional, neurological and developmental assessments by qualified staff are integrated into the service package. Other services include: family-centered case management, treatment and prevention education, and adherence support, as well as strong linkages with a variety of community-based organization to support the child and his/her family with psychosocial and advocacy services. Because of the dramatic success in significantly reducing new cases of perinatally transmitted HIV, these centers primarily treat children infected several years ago as they age.

HIV Uninsured Care Programs, encompassing the AIDS Drug Assistance Program (ADAP), ADAP Plus, ADAP Plus Insurance Continuation, and the HIV Home Care Program:
The mission of these programs is to provide access to medical services and medications for all uninsured and underinsured New York State residents with HIV/AIDS. The programs' goals are to empower individuals to seek, access and receive medical care and prescription drugs, and to provide a stable and timely funding stream to health care providers, enabling them to use the revenues to develop program capacity to meet the needs of the uninsured HIV populations. All four programs are integrated, centrally administered, use a unified application form and coordinate outreach activities. The HIV Uninsured Care Programs are funded through a partnership among New York State and the HIV Planning Councils of New York City, Long Island, the Lower Hudson and Dutchess County Regions, using funds from Titles I and II of the Ryan White CARE Act and State funds. The service package for each program is as follows:

> ***ADAP:*** The formulary consists of more than 450 drugs, including: antiretrovirals, antineoplastics, prophylaxis and treatments for opportunistic infections; and medications for related conditions.
>
> ***ADAP Plus*****:** covers a full range of HIV primary care services, provided on an outpatient ambulatory basis, including annual comprehensive medical evaluation; clinical HIV disease monitoring; drug and immunotherapy administration; treatment of both HIV-related and non-HIV related illness; mental health; dental services; ambulatory surgery; laboratory services; and nutritional counseling and supplements.
>
> ***ADAP Plus Insurance Continuation*****:** will pay the premiums of individuals who lose their employment and are eligible to continue their insurance, or working individuals who cannot afford their insurance premiums.
>
> ***HIV Home Care Program*****:** Covered services include: skilled nursing; personal care; homemaker and home health aid services; adult day health care; intravenous administration and supplies; and durable medical equipment. The need for these services has significantly declined with antiretroviral medications that help infected persons stay healthy.

Designated AIDS Centers (DACs):
DACs are State-certified, hospital-based programs that serve as the hubs for a continuum of hospital and community-based care for persons with HIV infection and AIDS. The Centers provide state-of-the-art, multi-disciplinary inpatient and outpatient care coordinated through hospital-based case management. DACs usually have a dedicated team and are required to provide or arrange for: specialized inpatient units and/or scatter beds; coordinated outpatient services; 24-hour emergency room coverage; access to clinical trials; home care and long term care as needed; counseling, testing and education in the community; and inpatient and outpatient case management. There are 44 DACs statewide, each of which has an active quality program including a broadly inclusive quality improvement committee to implement targeted strategies to improve patient care.

HIV Special Needs Plans (SNPs)/Managed Care:
SNPs are specialized managed care plans to address the health and medical needs of persons with HIV/AIDS, providing an alternative source of managed care to Medicaid enrolled persons with HIV/AIDS who choose this option. HIV SNP networks are required to be broadly composed, encompassing the full continuum of HIV services currently available in New York State. Inclusion of health and human service providers with experience in the provision of HIV services will enable SNPs to meet the complex medical and psychosocial needs of enrollees, either through direct service provision or by referral. Currently, three SNPs are operational in New York City. Voluntary enrollment to date totals approximately 1,300.

HIV-Specific Medicaid Rates:
Licensed health care facilities and physicians are eligible to enroll in programs that provide HIV-specific Medicaid rates for HIV primary care, including HIV test counseling, annual comprehensive exams, and clinical monitoring visits. These programs are intended to ensure fair reimbursement for the provision of HIV care services to Medicaid recipients.

CLIENT SERVICES

Since 1984 the AIDS Institute has supported a broad network of community-based organizations to deliver a comprehensive array of HIV prevention and supportive services. Approximately 512 contractors, including AIDS services organizations and health and human service providers across the state, are funded to provide one or more of the following prevention and supportive services: outreach, HIV prevention and risk/reduction education, case management, individual and group counseling, peer education and support groups, buddy/companion services, caregiver support and bereavement services. Specific initiatives are also in place to provide essential concrete services, through grant funding, that enable clients to enter into and remain in care, such as supportive housing services, food and nutrition counseling, transportation, legal assistance, vocational training and job placement. In addition, several initiatives focus on serving specific high risk subpopulations in settings where they can be easily reached; examples include: the Criminal Justice Initiative, the Gay, Lesbian, Bisexual and Transgender HIV Initiative, and the Adolescent and Young Adult Prevention Program.

Several community-based initiatives are highlighted below as an illustration of client services included in New York's HIV service continuum.

Multiple Service Agency Initiative:
MSAs were established in response to the disproportionate impact of HIV in New York's communities of color and its devastating effect on those communities. MSA funding allows existing minority community-based organizations to develop their infrastructure and expand their service capacity to provide HIV-related services, including outreach; individual and group level interventions that use evidence-based risk reduction strategies; health communication and public information strategies to build HIV awareness; community level interventions that influence community norms, attitudes and practices; and program development and capacity building activities for the delivery of HIV prevention and supportive services that meet the needs of their clients. Thirty-four (34) MSAs are funded to provide services to African Americans, Hispanics, Asians and Pacific Islanders, Native

Americans, Caribbean women, high risk youth, homeless men and women living on the street or in shelters, men who have sex with men, people who identify as transgender and other subpopulations that might not readily access the traditional service delivery systems.

Community Service Programs:
CSPs, organizations with HIV-specific missions, provide a broad range of prevention and client-based services in a defined geographic area. The model was established in 1984 as the first community-based response to the growing AIDS epidemic. CSPs have a regional approach to service delivery through satellite sites, collaborations with local health units, businesses, and other community-based organizations. CSPs often provide leadership in developing comprehensive regional programs that identify changing and emerging needs and address service gaps. Services include: outreach; evidence-based individual and group level interventions; case management; health communication and public information strategies to build HIV awareness; community level interventions that influence community norms, attitudes and practices; support services, such as treatment adherence education, transportation, peer support groups, counseling, legal assistance, emergency financial assistance and provision of food/meals; bereavement counseling; and referrals to other services not provided on-site.

Nutrition Initiative:
Good nutrition is essential to the management of HIV infection. Nutritious food profoundly affects the immune system, may delay disease progression, increases tolerance of medical treatments and can have a major impact on the quality of life. The Nutrition Initiative supports 14 contractors statewide and includes four components. Congregate meals are served in community locations, fostering sociability, access to health care, prevention and supportive services, and nutrition services. Many PLWHA using the congregate meal programs are indigent, homeless, or in marginal housing which lacks kitchen facilities. Pantry bags of groceries and food vouchers allow PLWHA with limited financial resources access to nutritious food. Home-delivered meals help to maintain or improve the health and well-being of home restricted individuals with HIV/AIDS by providing high calorie, high protein, therapeutically tailored meals and snacks. Nutritional services, conducted by registered dietitians, include screenings, assessments and reassessments, counseling and workshops on HIV/AIDS nutrition-related topics.

Supportive and Legal Services for Families in Transition:
This initiative funds 18 providers statewide to provide legal, social support and transitional services to assist families affected by HIV/AIDS. Social support services include: assistance to parents in disclosing their HIV infection to their children, counseling for family members to improve coping skills, education about the placement and custody plan options available to families, assistance in identifying an appropriate new caregiver and activities to promote stabilization and build relationships between children and new caregivers. Non-profit legal service agencies are funded to provide legal assistance to families to help them develop and execute care and custody plans. Experience with this initiative has shown that supportive and legal services must be linked together and integrated with health care and other services in order to effectively support families in transition and enhance permanency.

General Legal Services:
Six legal service agencies are funded to enable low income, HIV infected persons and their families to gain access to legal professionals for assistance in receiving health care services and entitlements, developing advance directives, maintaining or acquiring housing, combating discrimination, and writing wills. Funded agencies are successful in enlisting the services of attorneys to do pro bono work for individuals and families affected by HIV, greatly expanding access to legal services for those in need. Legal service agencies are also active in providing training and technical assistance about HIV-related legal matters to staff and clients of health and human service agencies.

Transportation Assistance:
Many HIV infected persons living in both urban and rural areas do not have the financial means to cover the cost of transportation to access critically needed services. The Transportation Initiative provides resources to support transportation assistance for individuals living with HIV/AIDS in accessing health and supportive services, and for persons whose behavior places them at high risk of HIV infection, to receive HIV counseling and testing. Transportation assistance includes car, taxi, or bus service; subway token disbursement; ticket reimbursement; van or ambulette transport; and car mileage reimbursement. In addition to this specific initiative, many AIDS Institute-funded community-based agencies include a transportation component in their overall service delivery plan to provide access to services. All transportation services maintain client confidentiality and enable clients to be transported safely, in comfort and with reasonable waiting and travel times.

CHRONIC CARE

As HIV disease progresses, various levels of chronic care are required to help keep individuals as healthy as possible and to improve their quality of life. Fortunately, advances in care have resulted in far fewer persons progressing to the point where they require nursing home care. The two chronic care models described below have contributed to helping individuals maintain their health and independence for as long as possible.

AIDS Adult Day Health Care Programs:
Fourteen licensed programs provide a comprehensive range of services to persons with HIV and AIDS in community-based, non-institutional settings: general medical care, treatment adherence support, nursing care, rehabilitative services, nutritional services, case management, HIV risk reduction, substance abuse and mental health services. The intent is to complement existing medical services through close coordination with primary care providers and to minimize the need for patients to obtain additional off-site services. ADHCPs serve individuals with HIV and AIDS with multiple and complex needs — poor, homeless, mentally impaired, chemically dependent, formerly incarcerated or otherwise disenfranchised and unable to easily access the health care system.

AIDS Home Care Programs:
There are 33 AIDS Home Care Programs providing, either directly or through contractual agreements, one or more of the following: nursing services, home health aides, medical supplies and equipment, and other therapeutic services which may include physical and occupational therapy, speech pathology, nutritional services, personal care services, homemaker services, and housekeeping services. AHCP staff also help patients obtain other needed services, such as primary and specialty medical care, dental care, pastoral care, and mental health services. These services help to maintain persons in their own homes, improving quality of life and reducing costs.

COORDINATION/COMMUNITY PLANNING

Care Networks
Through Title II of the CARE Act, the AIDS Institute has developed 16 regional, borough-wide, or community-level HIV Care Networks throughout New York State. The Networks are local associations of health care providers, community-based organization, PLWHA and affected persons, all of whom have a shared concern for achieving a comprehensive continuum of health and supportive services in a specific geographic area. The Networks are responsible for defining the local epidemic; planning and coordinating services, identifying service gaps and developing strategies to address those gaps; and raising public awareness about HIV/AIDS services, treatment and policies. The 16 Networks consist of eight regional networks: Albany (Northeastern), Binghamton Tri-County, Buffalo (Western), Lower Hudson, Mid-Hudson, Nassau/Suffolk, Rochester (Finger Lakes), and Syracuse, and eight borough-wide or community-level in New York City: Central Harlem, East Harlem, Bedford-Stuyvesant/Crown Heights, East New York/Brownsville, Williamsburg/Greenpoint/Bushwick, the Bronx, Staten Island, and Queens. The Networks routinely work on updating and implementing their Service Delivery Plans, which are the blueprints for Network activity.

Statewide AIDS Services Delivery Consortium (SASDC)
The Statewide AIDS Service Delivery Consortium (SASDC) was also established under Title II of the CARE Act. SASDC focuses on HIV services for six special populations who are unserved or underserved and have unique needs that require collaborative interventions: 1) men of color who have sex with men; 2) mentally ill chemical abusers; 3) the homeless; 4) prison releasees, parolees and probationers; 5) immigrants and refugees; and 6) migrants and seasonal farmworkers. SASDC's Advisory Group has a diverse membership, and its mission includes advising on development of the comprehensive continuum of care and support services for these six special populations whose unique needs and circumstances cannot be adequately met through the regional networks, and on RyanWhite-related matters and other issues concerning policy, planning and program development.

PUBLICATIONS

The HIV/AIDS Materials Initiative coordinates an HIV educational materials development and distribution program through which new materials are produced and existing materials are updated. Health and human service providers and the general public may request HIV/AIDS publications free of charge. There is currently an inventory of over 90 consumer

educational materials covering a wide range of topics related to HIV prevention, care and services. Materials are provided in a variety of languages and formats, including brochures, posters, bookmarks, videos, computer software, wallet cards, magnets, scratch-off cards and booklets.

The materials are designed to appeal to a number of specific target audiences including: adults, women, children, adolescents and people living with HIV/AIDS, and they are developed with considerable input from members of the intended target audiences. As part of a new focus on health and literacy, the AIDS Institute has implemented standards for the development of materials targeting persons with low literacy and has begun to add these new materials to the inventory.

The Materials Initiative publishes and periodically updates an HIV/AIDS Consumer Educational Materials Order Form that contains descriptions and ordering information. New and revised materials are disseminated through mass mailings and local, state and other public health-related conferences and exhibits. The Initiative also produces and distributes a Publications Order Form for Providers that lists all clinical guidelines and other educational materials that are available to providers.

RESOURCES

HRSA guidance issued in April 2005 indicates that the SCSN process should consider total CARE Act resources in the State and the services supported by these resources, emphasizing the six core services defined by HRSA: Primary Medical Care; HIV-Related Medications; Mental Health Treatment; Substance Abuse Treatment; Oral Health; and Case Management. The guidance, in addition, recommends addressing non-CARE Act resources in determining need, as well as consideration of the number of persons not in care as determined by the State's Unmet Need calculation. These factors are addressed below as part of New York State's Comprehensive Plan.

The chart on the following page summarizes a portion of the resources available to New York State under the various Titles of the CARE Act, HOPWA, from CDC and the State Budget directed to supporting selected services: health and supportive services for persons living with HIV and outreach to persons at high risk of infection to engage them in care and services. The chart includes the six HRSA-defined core services and other health-related and enabling services that are essential to engaging and retaining persons in care, as well as selected key management functions, such as capacity building, planning, coordination, data systems, quality improvement and evaluation activities. It is important to note that detailed information is not available for those programs not administered through New York State (i.e., Title III- and Title IV-funded programs, AETC and SPNS). The information presented is not intended to present a comprehensive picture of HIV/AIDS funding in New York State, but to highlight the services and activities identified by HRSA as relevant to the Ryan White Comprehensive Plan.

RESOURCES SUPPORTING SELECTED COMPONENTS OF NEW YORK STATE'S HIV CARE AND SERVICE CONTINUUM

	Ryan White Title I*	Ryan White Title II *	Ryan White Title III	Ryan White Title IV	Ryan White Part F	HOPWA	CDC	New York State Funds	Totals***
Medications	$ 11,810,000**	$ 128,100,000						$ 56,600,000	$ 303,510,000
Primary Care	$ 27,730,000	$ 10,190,300					$ 417,000	$ 7,253,700	$ 45,591,000
Mental Health	$ 8,947,000	$ 3,000,000					$ 123,400	$ 1,100,000	$ 13,170,400
Substance Abuse Services	$ 13,154,600	$ 454,200					$ 333,200	$ 409,000	$ 14,351,000
Oral Health	$ 1,024,500				$ 5,500,000				$ 6,524,500
Case Management	$ 6,819,100	$ 4,788,000					$ 1,507,700	$ 14,884,000	$ 27,998,800
HIV Counseling, Testing & Partner Notification Assistance	$ 826,000	$ 863,800					$ 3,489,000	$ 7,023,000	$ 12,201,800
Outreach/Case Finding	$ 4,737,000	$ 1,775,000					$ 3,361,500	$ 8,200,000	$ 18,073,500
Treatment Adherence	$ 5,640,700	$ 840,400						$ 1,100,000	$ 7,581,100
Home Health Care	$ 1,700,000	$ 100,000							$ 1,800,000
Housing & Related Services	$ 10,739,700	$ 1,700,000				$ 52,400,000		$ 1,800,000	$ 66,639,700
Food/Nutrition	$ 6,336,800	$ 1,100,000						$ 2,100,000	$ 9,536,800
Transportation	$ 1,937,900	$ 785,000					$ 26,600	$ 200,000	$ 2,949,500
Legal Assistance	$ 4,813,600	$ 93,800						$ 2,700,000	$ 7,607,400
Other Supportive Services	$ 3,502,000	$ 1,550,000					$ 1,008,800	$ 8,321,900	$ 14,382,700
Clinical Education/Training		$ 739,500					$ 677,400	$ 6,000,000	$ 7,416,900
AETC					$ 4,100,000				$ 4,100,000
SPNS					$ 6,000,000				$ 6,000,000
Quality Management	$ 2,167,400	$ 1,239,700					$ 61,900	$ 2,300,000	$ 5,769,000
Data Systems/Planning/Evaluation	$ 3,700,000	$ 1,094,400						$ 1,960,000	$ 6,754,400
Capacity Building — PWDs & CBDs	$ 4,394,600	$ 721,500					$ 62,500		$ 5,178,600
Planning Councils/CARE Networks/PWA Advisory Groups	$ 1,825,500	$ 1,900,000					$ 125,000	$ 564,000	$ 4,414,500
Functional Breakout Not Available			$ 25,400,000	$ 14,000,000					$ 39,400,000
***Totals:	$ 121,806,400	$ 161,035,600	$ 25,400,000	$ 14,000,000	$ 15,600,000	$ 52,400,000	$ 11,194,000	$ 122,515,600	$ 523,951,600

* Carry over not included unless otherwise noted.
** Includes $4 million in carry forward from NYCEMA.
*** Totals are not necessarily reflective of all funds in a particular category and do not include Medicaid reimbursement.

HIV resources available in New York State must be viewed in the context of the overwhelming HIV/AIDS need in the State which is quantified by considering the total number of Persons Living with HIV/AIDS in New York State (~170,000), the estimated number in need of continuing care and services (~82,400), the estimated number of diagnosed persons not in care (~44,000), the estimated number of undiagnosed persons (~37,500) and the estimated number of new infections each year (~6,000).

These significant numbers, coupled with the multiple complex needs and low socioeconomic status of those most heavily impacted by HIV in New York State, demand continuing dedicated resources commensurate with the burden of the epidemic. Over the last several years, only ADAP (medication assistance) has seen increases at the State and federal levels, and the outlook for the foreseeable future is for flat funding. Grant-funded providers are struggling to provide care as caseloads are growing and resources are shrinking. New York's Ryan White Title II funds covering core services have decreased about 10 percent over the last several years due to across-the-board recissions to the federal budget. In addition, set-asides and carve-outs have limited the State's ability to allocate Title II funds according to locally identified need. Further, State grant funding has remained about level. Moreover, flat grant funding to agencies over an extended period has the effect of a cut since the agency must absorb increases in fixed costs (rent, utilities, etc.) and salaries to retain essential personnel.

It is critically important to note that the comprehensive continuum in New York State is premised on the continuation of dedicated federal, State and local resources that are commensurate with the level of need across the State. If drastic changes in resource availability occur, extremely difficult choices will need to be made to the overall plan, goals and objectives, which will result in reductions to specific allocations that support direct services.

Also, comparing New York to other states is enlightening in terms of assessing the burden it bears and resources needed. As previously noted, New York has approximately 17 percent of all persons living with AIDS in the United States, but only 7 percent of the nation's population. According to CDC estimates of Persons Living with AIDS at the end of 2003, New York State had 66,660 PLWAs. This number exceeded the next four highest incidence states by significant numbers: California by 11,000, Florida by 23,000, Texas by 33,000, and New Jersey by 49,000. Analysis of CDC data indicates, in fact, that New York has more PLWAs than the 31 lowest incidence states combined.

B. New York's Evolving HIV Care and Service Continuum -- Where We Need to Go and How We Will Get There

The AIDS Institute proactively manages the HIV Care and Service Continuum, making refinements to ensure its responsiveness to changes in the epidemic and to scientific advances that prolong and improve the quality of life for infected persons. To address unmet need, program models are being refined to emphasize creative outreach strategies, targeted particularly to the high-risk subpopulations identified in this document, for the purpose of casefinding and engagement in care.

Based on needs identified across New York State through the SCSN process and numerous factors described in this document related to epidemiological trends, environmental considerations and characteristics of subpopulations most affected by the HIV epidemic in New York State, the following five **broad long-term goals** have been established to guide priority setting:

1. Ensure HIV+ persons learn their HIV status and enter care early by promoting strategies to reach high risk persons, communities of color, and other special populations identified in this document, broadening access to counseling and testing, and arranging connections to care and enabling services.

2. Improve health outcomes by ensuring access to comprehensive, high quality, culturally competent health and dental care for all persons living with HIV/AIDS, emphasizing the importance of engagement and retention in care, treatment adherence support and prevention with HIV+ persons.

3. Ensure timely and on-going access to life-saving medications for all uninsured and underinsured persons living with HIV/AIDS.

4. Improve access to mental health services and substance/alcohol abuse counseling and treatment for persons living with HIV/AIDS and co-morbidities.

5. Provide appropriate levels of case management and improve access to essential supportive services that enable persons living with HIV/AIDS to seek treatment, remain in care, and support adherence to medication regimens. Such services include but are not limited to: housing and related supportive services, food/nutrition counseling, transportation, legal assistance, family support services, peer education and support, and emergency financial assistance.

It is important to reiterate that these goals and the resulting program initiatives are premised on the continuation of dedicated federal, State and local resources that are commensurate with the level of need across the State. If drastic changes in resources occur, extremely difficult choices will need to be made to the overall plan, goals and objectives, resulting in program reductions and service disruption.

The following **principles** guide the development and implementation of program models to achieve the above goals:

- All HIV risk reduction and treatment programs and policies must be based on science and have as their foundation the latest scientific knowledge about HIV epidemiology, transmission and clinical care.

- The care and service continuum must be accessible to individuals and families in urban and rural areas regardless of their ability to pay. Funding mechanisms should be creative and focus particularly on the needs of poor communities..

- Methods for routine assessment of the outcome of care and services must be in place for all HIV service providers. Continuous quality improvement facilitates measurement of service outcomes, while fostering on-going self-assessment and improvement.

- Policy and program design must reflect input from a broad range of people affected by HIV/AIDS, including persons living with HIV and health and human service providers engaged in direct care. Communities of color must be central to this collaboration, given the disproportionate impact of HIV on persons of color in New York State. Peer education and support is a key component of service delivery and leadership development.

- Confidentiality protections must be in place, providing the basis for assuring personal privacy and anti-discrimination safeguards.

All AIDS Institute and Title I EMA programs serving persons living with HIV/AIDS are designed to meet the above goals and are based on the stated principles. These programs will be continued. The HIV programs funded by other Titles of the CARE Act also provide essential services to targeted subpopulations. Specific short-term goals and measurable objectives are outlined in the annual Title I and II Implementation Plans, included as Appendix E to this report.

The following **selected program initiatives highlight key strategies and activities for achieving the above goals.** These initiatives have recently been designed and implemented in response to changes in the epidemic, analyses of HIV/AIDS data, clinical advances, and new testing technologies.

The program initiatives are grouped in four key areas: 1) Enhancing access to and availability of HIV testing; 2) Outreach, casefinding and engagement in care and services; 3) Enhancing direct services; and 4) Promoting consumer/provider communication and prevention with HIV positive persons.

1. Enhancing Access to and Availability of HIV Testing

Streamlining HIV Test Counseling In All Settings:
The NYS Commissioner of Health announced in 2005 revised Guidance for HIV Counseling and Testing, designed to streamline counseling to encourage HIV testing and make it more routine. This revision is based on the fact that many people with HIV do not know their HIV status and many people are receiving their HIV diagnosis when they have advanced HIV disease. The NYS Public Health Law already provides the latitude for tailoring HIV test counseling to individuals' needs. NYSDOH has provided a new simplified written Informed Consent form which covers all of the required counseling elements under the law in more simplified language and in an easy-to-read format that maintains important confidentiality protections. For those who test positive, the revised Informed Consent form now also includes authorization for resistance and viral load testing. Implementation of the new guidance and consent form is underway in both clinical and non-clinical settings.

Integrating Routine HIV Testing In Medical Care Settings:
In addition to maintaining targeted HIV testing programs, the NYS Commissioner of Health is promoting the routine offering of HIV testing in medical settings to reach those who might otherwise be missed by targeted approaches. Recent publications in the *New England Journal of Medicine* suggest that HIV testing may be cost-effective even in populations with an HIV prevalence rate of less than the 1 percent that CDC currently recommends as the cutoff for routine testing. Making HIV testing a normal part of medical care in NYS is crucial to assure individuals have access to early care and treatment. As a pilot project, the AIDS Institute recently contracted with eight community-based health providers to integrate HIV counseling and testing, including new rapid tests, into routine medical care. Full implementation is underway at all sites, and preliminary results from a special study of four of these providers indicate that: 1) after training, provider staff demonstrated a marked increase in knowledge and confidence in providing rapid HIV testing; 2) almost all clients (98.6 percent) tested during a four-month period chose the rapid test, citing "same day results" as the reason for this choice; and 3) with proper training and preparation, ambulatory care sites are excellent venues for providing rapid testing.

Encouraging Use of Rapid HIV Testing Technology:
The recent approval of rapid HIV tests has the potential to revolutionize HIV testing and make it more accessible and acceptable to clients. The AIDS Institute initiated two pilot projects to encourage the use of rapid tests and to determine the essential elements for successful implementation. The first pilot took place in five emergency rooms of Designated AIDS Center Hospitals in New York City and Buffalo. Emergency rooms, provided they

meet the standards for confidential HIV counseling and testing, offer an ideal opportunity to counsel and test hard-to-reach persons who access health care only in the emergency room. The pilot successfully concluded with 2,916 tests identifying 29 HIV+ patients who were linked with care in the DAC clinics. Most participating facilities elected to continue the project in the absence of dedicated funding due to its success in casefinding.

The second pilot took place in three substance abuse detoxification programs. Conventional testing methodologies in the detox setting are problematic since the results are generally not available until after the patient has been discharged, and the return rate for post-test counseling is low. Almost all persons (96 percent) testing during the pilot chose rapid testing over conventional blood draws, and all three programs are continuing to offer rapid testing as a result of the pilot.

Rapid Testing Training:
The AIDS Institute developed rapid testing training for community-based organizations serving communities of color. Three types of training were offered. One training was designed to assist executive and program directors at CBOs with information on program and laboratory policy and procedures that need to be considered when making decisions about offering rapid testing. A second training prepared frontline workers who do not have experience offering counseling and testing to conduct rapid testing. A third training was designed to assist coordinators and supervisors with new responsibilities associated with rapid testing.

Training on Rapid Testing and Risk Reduction Services for Private Physicians:
The AIDS Institute contracted with Callen Lorde Community Health Center and the New York Academy of Medicine to develop and pilot a curriculum for training physicians in private practice to offer rapid HIV testing and to provide risk reduction interventions in the course of medical practice. Training sessions on testing and risk reduction protocols are tailed to the information needs and time constraints of the private practice setting. A curriculum was developed and pilot training sessions for HIV experienced and HIV inexperienced providers were held in early 2005. The sessions were well attended and participating providers received CMEs.

Other activities that enhance the availability of HIV counseling and testing include statewide counseling and testing sites that offer rapid testing and the incorporation of HIV counseling and testing into a range of grant funded programs.

2. Outreach, Casefinding and Engagement in Care and Services

ADAP Outreach and Enrollment Initiative:
Nine minority-operated community-based organizations across New York State receive Minority AIDS Initiative funding to serve hard to reach and underserved persons of color. Each agency is charged with increasing enrollment in health care services and ADAP, Medicaid, or other health care coverage, as appropriate. The scope of service under this initiative includes: 1) targeted outreach to populations known through local epidemiological data to be at disproportionate risk of HIV infection, to be conducted at times and in places where there is high probability of reaching persons at high risk; 2) education regarding the importance of early HIV care and treatment to build knowledge base and change community

norms leading to early entry into care; 3) linkage to health care and referrals to supportive services if necessary for individuals to enter into care; and 4) activities related to enrollment in health care, including engaging and building trust, assisting with applications for ADAP and other health care coverage, and making the connection with a health care provider. Each agency targets specific high-risk subpopulations, such as: correctional releasees, immigrants, transgender persons, homeless persons, migrant workers, etc.

Community Action for Prenatal Care:
This initiative (CAPC) supports the development of community coalitions dedicated to the reduction of perinatal HIV transmission through the recruitment of high risk pregnant women into prenatal care in targeted zip codes of four high newborn seroprevalence areas of NYS. Lead agencies are responsible for coordinating the activities of their local community coalitions, including implementation of a comprehensive model to reach high-risk pregnant women who are not in prenatal care. The basic elements of the comprehensive model are: local planning; recruitment of high risk women including a social marketing campaign geared to this population, a 24/7 confidential free hotline, and direct outreach by specially trained peer outreach workers; intake and transitional case management; user-friendly prenatal care systems, including clinical consultations for providers; and the integration of HIV education, counseling and testing.

In a recent expansion of this program, grant funding was provided to Prison Health Services at Rikers Island in New York City to create the position of Prenatal Care Linkage Specialist. The incumbent is responsible for linking pregnant inmates to CAPC programs or to other prenatal care providers and for comprehensive discharge planning for pregnant inmates when released back to the community.

CAPC development and activities are guided by the New York Task Force for the Prevention of Perinatal HIV Transmission, a partnership that includes staff from the New York State Department of Health (the AIDS Institute and the Bureau of Women's Health), the New York City Department of Health and Mental Hygiene, and the New York State Office of Alcohol and Substance Abuse Services.

Project WAVE:
Project WAVE (War Against the Virus Escalating) is a nonprofit organization working in partnership with public and private sectors across the nation to fight the HIV/AIDS epidemic in communities of color. In June 2001 Project WAVE New York was founded as a partnership between local minority radio stations, HIV/AIDS service providers, the New York State Department of Health and local departments of health. Project WAVE NY coordinates collaborative efforts among the partners to reach people in communities of color, particularly young people, to raise awareness about the importance of knowing one's HIV status and about the availability of HIV counseling, testing and partner notification assistance. Minority radio station partners directly promote HIV education and awareness and offer incentives for HIV testing at community events staffed by counselors from clinics and AIDS service organizations.

Project WAVE NY also developed a series of five public service announcements (PSAs) promoting the importance of knowing one's HIV status by getting tested. The PSAs, widely aired on television and radio, target communities of color including the African American and Hispanic communities, women and youth.

Other activities that support outreach and casefinding to identify people with HIV and link them to care include: incorporation of outreach into a wide range of grant-funded programs that target the special populations identified in this document, peer education and support, and low-threshold services that facilitate casefinding and outreach to care.

3. Enhancing Direct Services

Case Management:
Case Management is a multi-step process to ensure timely access to and coordination of medical and psychosocial services for a persons living with HIV/AIDS. The steps include: intake; assessment of needs; service plan development and implementation; service coordination, monitoring and follow-up; reassessment; case conferencing; crisis intervention; and case closure. A recently published article in *AIDS* (2005, Vol. 19 No 4.) (Document #143) concluded that a brief intervention by a case manager was associated with a significantly higher rate of successful linkage to HIV care.

Through contracts with health care agencies and community-based organizations, the AIDS Institute supports varying levels of case management services based on the complexity of the client's needs, and in a variety of settings. Family-centered, intensive case management is provided to Medicaid enrolled HIV positive persons utilizing teams of case managers and paraprofessionals through the Medicaid-reimbursed Community Follow-Up Program (CFP). This program is designed for persons who have multiple complex service needs, require frequent contact with care providers and have had difficulty accessing medical care and supportive services either due to issues with follow-up or because of barriers to service. Program goals are to provide access to services that foster independence and self-sufficiency, prevent or delay institutionalization, increase universal access to HIV-related services and promote early intervention. There are currently 49 approved CFPs across New York State.

Two important initiatives were recently initiated regarding Case Management.
The AI Case Management Standards Committee was convened to review overall case management service guidelines and expectations across all AI programs. Provider focus groups representing both community-based case management providers and medical-based case managers gave feedback on existing models and problem areas to be considered in redefining case management models and standards. Also, statewide case management training assists agencies to ensure proper training of staff. Centers of expertise in case management develop and deliver advanced curricula statewide based on provider input. Examples of training topics are: Psychosocial Issues for Women Living with HIV; Case Management with Active Substance Users; Managing HIV as a Chronic Illness; and Case Management with Clients Involved in the Criminal Justice System.

Treatment Adherence Initiative:
Clinical therapeutic advances provide opportunities to delay HIV disease progression and improve the quality of life. However, achieving this potential remains challenging. It requires the patient and health care provider, in collaboration with the patient's support network, to address multiple issues surrounding adherence to the treatment plan. These issues involve patient characteristics and circumstances, the treatment regimen, the health care delivery system and the patient-provider relationship. The consequences of non-adherence to HAART can seriously affect an individual's personal health and that of the community. Seventeen (17) treatment adherence programs are funded, with a combination of Titles I and II and State funding, to integrate treatment adherence services into the continuum of HIV primary care. The fundamental objective of this initiative is to foster a comprehensive approach to assess and assist consumers at risk for non-adherence, focusing on consumer and provider collaboration to develop consumer-specific strategies that lead to sustained treatment adherence. An individualized treatment plan is designed with the patient and modified based on his/her changing needs and circumstances. In addition, programs provide access to a variety of tools intended to further assist clients in taking their medications, including pill boxes, beepers, written instructions, visual aids, and watches equipped with timers.

Mental Health Initiative:
Studies indicate that at least 30 percent of people with HIV may suffer from some form of mental illness. A continuum of mental health services is necessary to address the full range of conditions among people living with HIV/AIDS, including: evaluation, a comprehensive care plan addressing individual needs and co-existing disorders, treatment, and support services, as well as specialized services for women, children and adolescents. Since 2000, the AIDS Institute has funded 13 agencies as part of this Initiative to provide mental health services, emphasizing the integration and co-location of these services with primary care and substance use treatment services. A network of HIV/mental health providers (30 agencies) has been established that includes providers funded through this Initiative as well as other grant-funded providers that include mental health services as part of their programs. The range of supported services includes psychiatric assessment/evaluation, treatment planning, psychotherapy and care coordination; psychiatric consultation and medication management; and case management.

In 2005, the AIDS Institute held a series of one-day educational forums for PLWHA focusing on mental health. Thirteen workshops were held across the State to increase consumer awareness of mental health issues and to offer support with seeking treatment. The goals of these sessions included: 1) creating a safe environment for PLWHA to talk about mental health leading to a new norm in the community – to normalize supportive discussions around mental health problems; 2) creating a coaching environment where a peer-to-peer model of connection and sharing around mental health would take place; 3) reducing fear and stigma relating to seeking services through education and sharing information about services; 4) emphasizing the importance of good mental health for the physical well-being of HIV positive individuals; and 5) empowering PLWHA to help other PLWHA to improve and maintain their mental and emotional well-being. A significant number of participants indicated they would share what they learn with friends, co-workers and family.

Housing and Supportive Housing Services for Persons with HIV/AIDS:
HOPWA is the primary source of funding for housing for PLWHA; in recent years, HOPWA funding has either decreased or at best remained level from previous year's allocation. The AIDS Institute supplements available HOPWA funding to fill some housing-related needs. Based on findings from the recent comprehensive needs assessments on housing needs of PLWHA, the AIDS Institute resolicited funding for this purpose and announced new awards in 2005. The assessments found that the majority of HIV+ persons serviced by housing providers had co-morbidities, including mental illness and substance abuse, and almost half had a history of incarceration. The reports identified substantial needs in the areas of supportive services, referral and placement services, and emergency financial assistance.

As a result, the AIDS Institute resolicitation focused on these services and awarded 34 grants to 24 different agencies statewide. Eighteen agencies statewide received grants to provide enhanced supportive housing services which address the housing needs of special and underserved populations including those who are at risk of losing housing or who are significantly challenged to remain in housing. Seven agencies were funded to serve as centralized points of contact to provide housing placement and referral services in multi-county regions of upstate New York. Finally, nine agencies were funded to provide financial assistance (one-time only assistance/short-term rental and utility assistance) to PLWHA. Financial assistance promotes housing retention and stability by helping consumers obtain and maintain safe, appropriate and affordable housing, and preventing evictions and utility shutoff.

Please also see the initiative descriptions in Section A of the Comprehensive Plan for More information on components of the continuum that enhance direct services. Continuing support for essential services including food/nutrition, transportation assistance and legal services will help to ensure that HIV infected persons meet basic subsistence needs and stay connected to care.

4. Promoting Consumer/Provider Communication and Prevention with HIV Positive Persons

Health Behavior Change Training for Health Care Teams:
The AIDS Institute has completed a series of pilot trainings on Health Behavior Change for multi-disciplinary HIV care teams at nine facilities. The purpose of this pilot is to determine whether this training increases the effectiveness of care teams in addressing a wide range of behavioral issues, including adherence to medications and reduction of transmission risk behavior. A comprehensive training curriculum was developed and delivered. Numerous evaluation tools were also developed and completed by training participants and clients to track the impact of their training. Evaluation data are being examined closely to assess the outcomes of the training and whether it should be replicated for other facilities in the region.

Prevention with HIV+ Persons and Crystal Methamphetamine Pilot Projects:
A promising intervention for integrating prevention into routine HIV care is "Options," a clinician-initiated model developed by the University of Connecticut Center for Health/HIV Interventions (CHIP). The Options intervention was shown to be effective in reducing transmission risk behavior among HIV patients when implemented as a research protocol at Nathan Smith Clinic of Yale University. In 2004, the New York State Department of Health

AIDS Institute launched a demonstration project (Options New York) to determine the feasibility and effectiveness of the Options intervention when implemented as a routine component of the HIV medical visit. HIV programs at three facilities are participating in this pilot that will be completed in March 2006. If the Options intervention is shown to be effective in practice, the AIDS Institute plans wide dissemination of the program elements to grant-funded HIV health care providers.

The AIDS Institute is working with the same two organizations on the development, implementation and evaluation of a two-part pilot program to address crystal methamphetamine (CMA) use among gay and bisexual men. One component involves evaluation of a detox protocol that includes psychopharmacologic treatment to control the symptoms associated with reducing CMA use. The other component will evaluate the short and medium term effects of participation in a ten-week group intervention on the drug use and sexual behaviors of participants. This pilot is in the early stages of implementation.

Other activities that promote better communication between providers and consumers include the Leadership Training Institute for PLWHA and the integration, in a wide range of grant funded programs, of multiple strategies for treatment adherence support, for community-based consumer education to improve health literacy regarding treatment and health care, and for reducing high-risk behaviors.

C. Enhancing Quality of Care and Monitoring Progress

Numerous strategies are employed in New York State to improve quality of care and monitor progress in meeting long- and short-term goals and objectives. These include the following initiatives which are described below: 1) the HIV Quality Management and Improvement Initiative, including Education, Training and Technical Assistance; 2) Special Evaluation Studies; 3) Contract Management Monitoring Process; and 4) Expanded Laboratory Reporting Requirements.

1. Quality Management and Improvement Initiative

This initiative is critical to maintaining high quality HIV care and services by providing education, training and technical assistance, promoting adherence to standards of clinical care, and implementing quality improvement approaches for clinical care and other HIV-related services. Components of this initiative are described below.

HIV Clinical Guidelines Program:
The AIDS Institute's Office of the Medical Director oversee the updating and refining, publication, dissemination and implementation of state-of-the art clinical practice guidelines. These guidelines address medical management of adults, adolescents and children with HIV infection; primary and secondary prevention in medical settings; and include informational brochures for care providers and the public. AIDS Institute clinical guidelines are developed by committees of clinicians and others with extensive experience providing care to people with HIV infection. External peer review of all new and revised criteria ensures that guidelines incorporate opinions from outside the committees. All current guidelines, quality of care documents, best practice booklets and Power Point presentations are published on the Program's website: HIV Clinical Resource located at www.hivguidelines.org.

Guidelines are most likely to be effectively implemented when they are actively disseminated through a coordinated plan to reach their appropriate target audiences, which include clinicians, support service providers and consumers. Often, separate versions of guidelines are prepared for different audiences. For example, the AIDS Institute recently developed a manual for consumers that explains antiretroviral therapy guidelines in non-clinical terms. A similar booklet was developed on mental health guidelines targeted to case managers and other non-clinical staff. Best practice booklets will continue to be developed; these contain practical solutions to common problems related to access, delivery or coordination of care, in order to ensure that updated HIV guidelines are implemented and that patients receive the highest level of care possible.

HIV Quality of Care Program:
The Office of the Medical Director promotes, monitors and supports the highest quality of HIV clinical care for people with HIV in New York State. The activities of this program include: development of clinical performance measures derived from practice guidelines, on-site quality of care reviews, promotion of continuous quality improvement (QI) activities, peer learning opportunities for HIV providers, and consultations to support on-site quality improvement efforts. Quality of care consultants provide professional assistance to build quality improvement programs in HIV clinical facilities throughout New York State. They work with clinicians and administrative staff to set priorities for improvement initiatives and develop plans for QI and on-going internal quality monitoring. Consultants provide education in QI tools and techniques, assist with the interpretation of data and promote creative thinking by facility personnel to improve performance.

Facility-based results of quality of care reviews are presented as aggregate data so that providers can evaluate overall performance rather than focus on individual cases. Results from similar facilities in New York State are provided as well, in a format that permits comparative evaluation while maintaining confidentiality. The results are used to target providers for assistance and consultation, rather than to penalize. The Consumer HIV Quality Committee provides the opportunity for members of the HIV community to discuss quality of care issues that empower consumers in their relationships with providers, and solicits their input and recommendations relating to the overall Quality of Care Program.

At no cost to agencies, the AIDS Institute provides HIVQUAL software, designed to capture data and generate reports to measure clinical performance based on clinical practice guidelines. To respond to changes in clinical practice, the software is continually revised to ensure its consistency with current standards of care.

In addition, the AIDS Institute expects to continue its contractual relationship with the New York City HIV Health and Human Services Planning Council to measure the quality of health and supportive services provided under Ryan White Title I. To date, performance measures for ambulatory health care, dental care, mental health, case management, and food/nutrition services have been developed. Performance indicators are in process for drug treatment services, housing and other social services. This new quality of care initiative offers a comprehensive portfolio of clinical and non-clinical indicators and serves as an incentive for providers of support services to monitor and improve the quality of services offered.

HIV Clinical Education Initiative:
This initiative is designed to encourage and expand HIV clinical expertise among community clinical providers, managed care plans, substance use treatment programs, long-term care facilities and adult day health programs. Thirteen Clinical Education Centers will continue statewide. These Centers provide progressive education through preceptorships, case conferences, regional conferences and lecture series. Programs are primarily conducted on-site at community-based settings to maximize clinical staff attendance, involve all members of the clinical care team and minimize disruption of clinical services. Through its CEI-Line, this initiative provides free access to HIV Clinical Specialists for practitioners who provide care to people with HIV/AIDS in community-based, primary care settings. It gives the clinician the opportunity to discuss clinical management issues and current practice guidelines with an experienced HIV clinician.

The Nicholas A. Rango HIV Clinical Scholars Program:
This is a special post-graduate training program designed to train clinicians in the management of HIV disease and the public health aspects of the HIV epidemic. This program develops highly qualified, broadly trained physicians, nurse practitioners, physician assistants and dentists who have the commitment and skills needed for leadership in the rapidly changing field of HIV. The Scholars Program is a collaboration between the AIDS Institute and selected academic medical centers, offering several training options. While focused on HIV ambulatory care, the program also offers concentrations in urban health or substance use and may be coupled with a fellowship or the pursuit of a relevant advanced degree. Scholars are selected through a competitive process and receive a stipend, full benefits and depending upon the option chosen, tuition support.

AIDS Education Training Center Partnership:
AIDS Education Training Center (AETC) Partnership: The New York/New Jersey AETC, managed by Columbia University, is one of 11 regional AETCs funded by the federal government to improve clinical care and treatment of persons living with HIV. The AIDS Institute is a full partner in the New York/New Jersey AETC, which covers the region most heavily impacted by HIV in the nation. While only 9.6 percent of the country's population resides here, 21% of the nation's AIDS cases are found in this region. Each year the AETC has conducted more than 2,000 trainings reaching over 20,000 health care providers -- more than any other region in the country. However, in the most recent competitive grant process, the AETC received a significant cut in funding. Unless funding is restored, this cut will have a serious impact on the number of health care providers trained, compromise the care of the nation's most underserved and vulnerable populations -- people of color, women and immigrants. This funding inequity and regional bias furthers already significant health disparities -- specifically, those that the Department of Health and Human Services' Healthy People 2010 goals attempt to eliminate.

2. Special Evaluation Studies

Special studies are undertaken periodically to evaluate processes and outcomes associated with specific initiatives that provide services directly impacting the health and quality of life for PLWHA, and initiatives that have public health significance. The findings of these studies are used to inform program management decisions regarding the models of service

delivery, funding allocations, and relative priority. Examples of special evaluation studies in the areas of case management and treatment adherence support are highlighted here.

Case Management Evaluation Studies:
In the mid- to late 1990s, the AIDS Institute contracted with the Graduate Management Institute at Union College to evaluate case management services for persons living with HIV/AIDS in New York State. The intent of this evaluation was to assess case management services supported by the AIDS Institute via grant funding and Medicaid reimbursement in a variety of settings. The study examined:

- The extent to which clients receiving HIV case management gain access to services throughout the continuum of care;
- Other case management outcomes and the extent to which outcomes vary by case management model or by the geographic location of the agency providing services; and
- The extent of case management duplication and communication/coordinated efforts among multiple case managers serving the same client.

The study examined agencies representing four AIDS Institute-funded case management models. Highlights of Union College findings can be summarized as follows. Agencies appear to be focusing on the acquisition of concrete services, versus the provision of supportive counseling, and are doing a good job acquiring those services, at least in comparison with previous studies. Case managers also appear to be doing a good job advocating for clients and helping them participate in ongoing services, such as substance abuse counseling. Clients, in general, are very satisfied with case management services and with their case manager. While the potential for case management duplication is strong in New York City, it is less widespread than might be imagined and, when it occurs, it occurs for rational reasons. Areas for improvement include: documentation, communication between multiple case managers, and client utilization of pre-arranged services.

In 2002, Union College published an article in *AIDS Care* (Document #145) documenting the public/private partnership used by the AIDS Institute to develop outcome indicators and measures for the Community Follow-Up Program (CFP), an intensive case management program for HIV-positive individuals and their families. Results from two years of outcomes data collection are also presented.

The article notes that in the mid-1990s, the Case Management Section of the AIDS Institute (AI) formed a CFP Quality Assurance Committee, composed of volunteer participants from CFP agencies across the state and AI staff. This committee was charged with redefining the CFP quality focus from a structure/process-oriented approach to an outcome-oriented approach. Through this Committee, a streamlined set of outcomes were eventually incorporated into an outcome assessment tool for use in record reviews, focused on the following eight areas: health care, independent living, adult education and employment, family stability, mental health, substance use, legal support and financial entitlements/benefits.

Union College found that the success of this project was partially the result of using a process specifically designed to overcome the barriers to implementation, which include: 1) active

inclusion of providers in identifying outcomes and providing training; 2) development of a clear process for generating and prioritizing potential outcomes indicators; 3) selection of reasonable, non-threatening benchmarks against which to compare provider outcomes; 4) an emphasis on using outcome data in positive versus punitive ways; for example, to facilitate quality improvement activities; 5) an experienced facilitator capable of operationalizing provider ideas and coordinating overall data collection; and 6) strong leaders within the AI willing and able to commit the time and resources to make this process happen.

In terms of the results of data collection from two initial rounds, Union College reported several trends. There was improvement in optimal status for the majority of indicators, although improvement did not always reach statistically significant levels. Significant improvement was noted in four areas: communication between primary care providers and case managers; clients following medication regimens; clients receiving needed legal services; and clients receiving job counseling and/or training. In addition, there was a significant decrease in "unclear" responses for several key indicators, and there was a substantial increase in documented case management effort to improve problematic client indicators. The authors note that due to documentation problems, the results from initial rounds must be viewed somewhat tentatively. Future rounds of data collection should enable more definitive conclusions as documentation improves and trends are noted.

Treatment Adherence Evaluation Study:
The consequences of non-adherence to HAART can seriously affect an individual's personal health and that of the community. Less than perfect adherence allows viral replication and mutation to continue, leading to the development of drug-resistant strains of virus which can, in turn, compromise an individual's health and future treatment, and may lead to transmission of drug-resistant strains to other individuals. Adherence to antiretroviral therapy may be the single most critical determinant of the success of clinical therapeutics for HIV infection today. In 1999, the Treatment Adherence Demonstration Project was created, through a collaborative effort between the AIDS Institute and the NYC Title I EMA, to provide and assess innovative models of adherence support to HIV-infected individuals on HAART. Seventeen programs are funded to support networks of clinical and non-clinical providers who work collaboratively to reduce barriers to adherence and provide on-going support for maintenance of positive adherence behaviors. Members of the care team work in concert with clients to develop, implement and evaluate tools and skills-building activities to increase and sustain adherence to therapy.

To document results of this Demonstration Project, a specific evaluation strategy was designed in the conception phase. Through February 2005, data were collected by client interview and chart abstraction upon enrollment (baseline) and approximately every three months thereafter. In addition, programs completed encounter forms for each adherence-related visit that contained information related to the specific service being provided. As of March 2005, adherence programs are required to submit monthly reports and a Treatment Adherence module is being developed for the AI computerized contractor data system (URS) that contains data elements needed for ongoing evaluation and monitoring.

During the last three years, three articles have been published relating to findings from this demonstration project and resulting studies (Document Nos. 148, 149 and 150). Staff from the funded programs contributed data and staff from the AI Office of Program Evaluation and Research in collaboration with other researchers conducted systematic analyses and prepared reports leading to these publications. Key findings from these published studies include:

- Overall, adherence rates among clients attending these adherence support programs targeted to high-risk individuals increased at each interview period, demonstrating that program clients effectively maintained, and even increased, their adherence to HAART over time. Although the study did not attempt to establish a causal relationship between program attendance and the observed increases in client adherence, these encouraging findings deserve mention and point to the need for future research.

- The periodic assessment of potential barriers to adherence (e.g., housing status, stress, drug and alcohol use) appears important. For at least some clients, it may be the instability in these factors, rather than simply their presence or absence, that contributes to nonadherence.

- Programs that identify and address adherence and the clinical, psychosocial and behavioral impediments to adherence should be closely aligned with health care professionals who provide HIV clinical care for individuals on HAART. Regular communication between providers from a variety of disciplines will help ensure that the multiple and complex needs of HIV-infected individuals on HAART are thoroughly addressed.

- When looking at the association between HIV-related knowledge and adherence, knowledge was significantly associated with self-reported adherence. This finding suggests that providers should be diligent with respect to patient education, providing the information needed to support reasoned decision-making relating to adherence.

- The most recent study explores the relationship between the "Perceived Stress Scale" and nonadherence to antiretroviral therapy, attempting to present a validated scale that could practically be applied in treatment settings to identify individuals at higher risk of nonadherence. Findings indicated that clients who scored in the highest quartile of perceived stress using this scale were twice as likely to be nonadherent at baseline and first follow-up and more than five times as likely to be nonadherent at second follow-up than clients in the lowest quartile of perceived stress scores.

3. Contract Management Monitoring Process

In 2003 the AIDS Institute developed a detailed *Resource Guide for Site Visit Monitoring* to guide AI staff in managing funded contracts (Document #153). Each year the AI distributes millions of dollars in state and federal funding for HIV/AIDS services to community-based organizations, hospitals, health centers, addiction treatment facilities, and other agencies that directly serve the public. Every funded program works closely with an AI contract manager to ensure that it meets the terms of the contract, uses funding appropriately, and delivers

effective services. Contract managers monitor the implementation of programs, report progress, and assist in finding solutions to problems. They have a responsibility for a continuum of tasks, many quite complex, that help determine how programs achieve their goals. They are key players in the chain of events that leads from understanding a service need to meeting it. To help contract managers in one of their most critical tasks, the AI developed the Resource Guide, with the input of many experienced staff. This Guide focuses on the process of planning and conducting site visits and following up on the results.

The Guide defines eight distinct types of site visits, scheduling frequency, required documentation, and the follow-up process to assure corrective action when necessary. The Guide defines AI policy in some areas; in others, it provides guidance and tools that can be adapted based on the specific program and judgment of AI staff. The intent is to: share useful methods and tools gathered from various AI units; offer support to new and seasoned contract managers; define the monitoring process; expedite the process for conducting monitoring and issuing timely reports; and facilitate optimal follow-up on recommendations and corrective actions.

The Guide has been well received by AI Staff, is used frequently, and will continue to evolve as AI staff further define best practices for contract management with the ultimate goal of facilitating the most effective, efficient HIV/AIDS programs possible.

4. Expanded Laboratory Reporting Requirements

New test technologies now provide information that can help better monitor the epidemic. Laboratory reporting of the results of resistance testing, viral load and CD 4 tests is essential for improved monitoring of the quality of HIV care. In addition, HIV incidence testing, recommended by CDC and conducted by the NYSDOH Wadsworth Laboratory, will provide a more comprehensive HIV public health surveillance system. Improved laboratory surveillance is being required by regulations that took effect on June 1, 2005.

SECTION IX: COMMUNITY RESPONSE

Introduction

This section describes the results of Steps Five and Six of the 2006 SCSN/ Comprehensive Plan process, which involved conducting regional forums and incorporating community input into the final document. The draft document was mailed to more than 1,400 agencies and individuals. In addition, the draft was available via the Internet and upon request. Seven community forums were held in the locations listed below; more details regarding attendees at the forums are included in Appendix B. It is important to note that although the regional meetings focused on specific regions/boroughs, all were invited and welcome to attend any of the sessions.

- Rochester – focusing on two regions: Rochester (Finger Lakes) and Buffalo (Western)
- Syracuse – focusing on two regions: Syracuse and Binghamton Tri-County
- Poughkeepsie – focusing on three regions: Mid- and Lower Hudson and Albany (Northeastern)
- Deer Park, Long Island – focusing on Nassau/Suffolk
- Bronx – focusing on the five boroughs of New York City
- Brooklyn – focusing on the five boroughs of New York City
- Manhattan – focusing on the five boroughs of New York City

Each forum began with an overview of the draft document, covering the following areas:

- Legislative Requirements and Methodology
- Epidemiological Data
- Key Environmental Considerations, Emerging Trends and Special Populations
- Service Needs and Barriers – Statewide and Region/Borough-Specific
- Comprehensive Plan

The second part of each forum was devoted to public comments on the draft document. All community members were given the opportunity to provide comments at the forums and to offer written comments following the forums. All of the meetings were well attended — a total of 171 community participants at all seven forums; 39 participants identified as PLWHA. Ample time was available for participants to speak if they chose to do so. In addition, a total of 14 written comments were received.

Overview of Community Response

In general, the draft was well received. Participants commented that it reflected input provided through the source documents so that it accurately captured regional and borough-specific needs and barriers. It was also noted that the document was comprehensive and well organized.

Comments reflected the need to emphasize some key services and barriers, such as housing; ensuring comprehensive health care, prescription drug coverage, dental care, mental health services, case management and supportive services, particularly transportation, food/nutrition, and legal assistance; barriers to access faced by the uninsured, underinsured and rural residents; and enhanced use of rapid testing to ensure early diagnosis, linkage to and retention in care. Comments addressed the need to support community-based consumer education to improve health literacy regarding treatment and health care. Others addressed specific service needs and special populations in their respective services areas. These are summarized below and included in detail in the geographic-specific sections of the document so that those sections completely capture the input received from source documents, community forums, and subsequent written comments.

Comments were received about the need to more clearly describe the unique needs of transgender persons, to emphasize the needs of recent immigrants, rural residents, persons who are deaf, and persons aged 50 and over. Forum participants emphasized the value of programs that train consumers to provide peer education and support, take leadership roles, and provide input on policies and programs. Comments were received in many areas of the State regarding the importance of reauthorizing the CARE Act, funding levels that allow services to keep pace with increasing demands, and scientifically proven prevention methods. The impact on communities of color, the importance of diverse community leadership and staffing, continued efforts to address stigma and discrimination, and adequate support for community-based organizations were all emphasized.

Concerns were expressed about the need to more accurately describe the data presented in Section IV regarding HIV/AIDS Epidemiology, and the time period covered. Comments were also received about variations in the data included in Section IV and in the more detailed data tables included in the Appendix of the draft document. These comments focused on differences in the data reporting variables, the time period covered, and whether or not prisoners were included in the various tables and graphs. The data in the Appendix were from a published Surveillance Report and differed somewhat from the special data run used to produce the tables and graphs in Section IV. Based on comments regarding the confusion created by these differences, the decision was made to eliminate the cross-tabulated data in the draft Appendix and give readers website addresses where they can easily access the most recent data of this nature. Section IV data tables, which provide overview and trend data, were enlarged to make them more legible, footnotes were added and changes were made in the graphics to improve clarity.

Valuable input was also received, through written comments from 14 entities which are listed in Appendix B. Three sets of written comments are included in full at the end of this Section, and referenced in the summaries below. The first, from the Rochester Area Task Force on AIDS, Inc., addresses broad statewide issues; the second, from NETWORTH/Positive Action, Inc., presents a consumer perspective on service needs and barriers, and the third, from Legal Services of the Hudson Valley, addresses the need for continued support of legal services.

Comments from Regional Forums

Comments received at each of the forums are summarized below. Detailed comments are included in the appropriate geographic area of Section VII – Service Needs and Barriers by Region.

Rochester Community Forum – September 26, 2005

Twenty-six community participants attended this forum which focused on two CARE Network Regions: Rochester (Finger Lakes) and Buffalo (Western). Numerous verbal and written comments were received, and are reflected in the sections of this document describing Service Needs and Barriers for these two regions.

Rochester (Finger Lakes) Region

Detailed comments are noted in the Rochester (Finger Lakes) Service Needs and Barriers Section of this document. Highlights of comments received include the following:

- Forward-looking, broad policy and program issues were addressed in a written document prepared by the Coordinator of the Rochester Area Task Force on AIDS, Inc., which is included in full in this Section of the document, and outlined in detail in the Rochester Region Section. Issues addressed include: needs that are unmet or under met in the region; a suggested taxonomy to describe special populations; data needs to enhance planning and evaluation processes; suggestions for inter-agency cooperation and regulatory relief; and additional considerations for the environmental assessment.

- Commenters emphasized the needs of the following subpopulations: HIV+ persons who are deaf, Native Americans, persons who use crack/cocaine and marijuana in addition to crystal meth users, transgender persons, and persons aged 50 and over.

- The following service needs/barriers were emphasized: Medicaid-reimbursed transportation to obtain mental health services; a consumer-directed center to enhance peer outreach, education and support; streamlined “Single Point of

Access" for persons with multiple service needs, science-based HIV prevention models adapted for diverse subpopulations within communities of color.

- Expanding and improving human resources by enhancing support for recruiting and training diverse, culturally competent health and human service providers.

Buffalo (Western) Region

Detailed comments are noted in the Buffalo (Western) Region Service Needs and Barriers Section of this document. Highlights of comments received include the following:

- The Coordinator of the AIDS Network of Western New York shared the recently completed 2004-05 Service Delivery Plan Update Report. This update resulted in major revisions to the Buffalo (Western) Service Needs and Barriers Section of this document, reflecting the Network's five top service needs/barriers and associated recommendations:

    - The Unconnected – HIV+ persons who have never accessed services or who have accessed services, and then dropped out of care
    - Case Management
    - Housing and Related Services
    - Discrimination and Stigma
    - Transportation

- Other major needs identified in the Update and from comments at the Forum include the need for enhanced access to primary and specialty medical care in both urban and rural areas, and the unique challenges associated with access to care and supportive services for rural residents.

- Participants emphasized the needs of the following subpopulations: persons who use crack/cocaine and marijuana in addition to crystal meth users, Native Americans, transgender persons, and persons aged 50 and over.

- The following service needs/barriers were emphasized: need for transportation assistance for residents of rural counties in the Western Region; streamlined "Single Point of Access" for persons with multiple service needs; and science-based HIV prevention models adapted for diverse subpopulations within communities of color.

- The lack of incentives to recruit and train experienced, diverse and culturally competent health and human services providers was emphasized.

- Participants also noted the need to clearly label the data tables included in both the Epidemiology Section and the Appendix to the document with reference to

inclusion of prisoners and time period covered by the data. In addition, the point was made that official case counts often underestimate the true number of persons in care in a region as individuals migrate after their initial diagnosis.

Syracuse Community Forum – September 27, 2005

Fifteen community participants attended this forum which focused on two CARE Network Regions: Syracuse and Binghamton Tri-County. Verbal comments were received, and are reflected in the sections of this document describing Service Needs and Barriers for these two regions.

Syracuse Region

Detailed comments are noted in the Syracuse Region Service Needs and Barriers Section of this document. Highlights of comments received for this region include the following:

- Serious gaps in medical and dental care coverage were noted even with the various gap coverage programs including ADAP Plus and Family Health Plus. Many dentists do not participate in these programs.

- Written comments were received regarding the section describing Native American populations within New York State and their service needs. These comments have been reflected in the Statewide Service Needs and Barriers Section of this document.

- Inmates and releasees should be added as a special population in this region. Challenges associated with serving inmates and releasees were enumerated.

- Providers indicated additional subpopulations that require targeted services: perinatally infected children aging into adolescence, exposed babies born to HIV+ mothers, and sexually assaulted children who are potentially exposed.

- The importance of enhancing case management services was noted. One participant recommended that the Centers for Independent Living be considered as an option for provision of HIV case management based on their experience serving persons with multiple disabilities and their regional coverage of upstate New York.

- Need for PLWHA Ombudsman to empower consumers was noted.

- Need was noted for targeted HIV prevention and support services for persons aged 50 and over.

Binghamton Tri-County Region

Detailed comments are noted in the Binghamton Tri-County Region Service Needs and Barriers Section of this document. Highlights of comments received for this region include the following:

- The shortage of covered dental services, including care provided by oral specialists, was emphasized as a serious problem, as well as the inability of private dentists to provide services under ADAP Plus.

- The shortage of psychiatrists to provide services for HIV+ persons was noted.

- The potential of rapid testing to enable more people to learn their HIV status was noted, and recommendations made to make it more available through private medical providers.

- The need to educate consumers about different levels of intensity associated with case management services was noted, particularly with the availability of COBRA case management in the region.

- The need for a syringe exchange program in the region was reiterated.

Poughkeepsie Community Forum – October 7, 2005

Twenty-seven community participants attended this forum which focused on three CARE Network Regions: Mid-Hudson, Lower Hudson, and Albany (Northeastern). Numerous verbal and written comments were received, and are reflected in the sections of this document describing Service Needs and Barriers for these three regions.

Mid-Hudson Region

Detailed comments are noted in the Mid-Hudson Service Needs and Barriers Section of this document. Highlights of comments received for this region include the following:

- Needs from the consumer perspective include three broad areas: housing, medical care and transportation. Consumer needs were elaborated upon in a written document, "Living with AIDS – A Hudson Valley Consumer-Based Observance," which is included in full in this Section of the document and highlights the emerging and complex needs of PLWHA whose illness is progressing, and those who have become homebound, semi-homebound or temporarily incapacitated.

- Compelling facts regarding the need for expanded resources to support legal assistance for low income PLWHA in this region were received at the Community Forum; written comments on this topic are included in full in this Section of the

document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans.

- Clarification regarding current HOPWA-funded housing services in the region, and the critical need for more housing resources.

- Need to expand availability and geographic accessibility of comprehensive health care, dental care, mental health services, co-located services and case management throughout the region.

- Additional service needs of injecting drug users and adolescents.

- Additional subpopulations in need of focused attention: communities of color, particularly Blacks and Hispanics; immigrants; rural and transient populations; deaf and hard of hearing; homebound; elderly and long-term survivors.

Lower Hudson Region

Detailed comments are noted in the Lower Hudson Service Needs and Barriers Section of this document. Highlights of comments received for this region including the following:

- Need for outreach to immigrants and for access to the full continuum of health and social services. The need to reach and serve undocumented persons was noted, emphasizing in particular the need to expand ADAP Plus coverage.

- Lack of medical and dental providers in the region who accept Medicaid and ADAP Plus.

- Compelling facts regarding the need for expanded resources to support legal assistance for low income PLWHA in this region were received at the Community Forum; written comments on this topic are included in full in this Section of the document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans.

- More resources required to support emergency financial assistance for basic subsistence needs including housing, gas and utilities.

- Regarding data presented in the SCSN/CP document, helpful comments were received regarding the need to clarify differences in data in the Epidemiology section of the report and in the Appendix tables, and suggestions for more accurate descriptions of the data presented for all regions.

Albany (Northeastern) Region:

Detailed comments are noted in the Albany (Northeastern) Service Needs and Barriers Section of this document. Highlights of comments received for this region include the following:

- Extensive written comments were received regarding updated needs for this region determined through the process of completing the 2005 Care Network Service Delivery Plan, which was recently approved. These comments resulted in major revisions to the Albany (Northeastern) Service Needs and Barriers Section of this document reflecting the following updated top service needs and associated recommendations:

    - Case Management
    - Dental Care
    - Outpatient and Specialty Care
    - Housing
    - Mental Health and Psychosocial Support
    - Transportation
    - Nutrition
    - Substance Abuse Services

- Legal Services were added to the above list based on compelling facts regarding the need for expanded resources to support legal assistance for low income PLWHA in this region which were received at the Community Forum; written comments on this topic are included in full in this Section of the document. These comments reference a recent national report documenting "the Justice Gap," which is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low income Americans.

Long Island Community Forum – October 11, 2005

Twenty-six community participants attended this forum which focused on the Nassau/Suffolk Ryan White Region. Numerous comments were received and have been incorporated in the section of this document describing Service Needs and Barriers for Nassau and Suffolk Counties. Highlights include:

- Housing and transportation needs for all subpopulations were emphasized and elaborated upon at the community forum, as well as the need to expand the continuum of mental health services, particularly as it relates to the availability of psychiatric care.

- In terms of targeted subpopulations, additional service needs were noted for almost all of the specified subpopulations. Two additional subpopulations were included along with service needs for each: Immigrants and Inmates/Releasees.

- Additional service needs and barriers were noted, such as outreach to the gay community; expanded testing opportunities; prevention with positive persons; education and support for extended families and foster parents caring for children; concern regarding the impact of Medicare Part D prescription drug coverage; and Medicaid prohibition of billing for different services provided on the same day.

- Various policy and program issues were addressed, some of which are broad concerns that relate to the funding and provision of HIV services in general. All are listed in the Nassau/Suffolk section of this document. These issues touch upon:

    - Continued CARE Act mandate for consumer participation.
    - Limitations of official case counts relating to demand for services.
    - Cost of living increases to meet the growing demand for more complex services.
    - Importance of funding Program Coordinators.
    - Need to adjust Federal poverty levels.
    - Need to simplify the State's competitive funding process.
    - Need for common and simplified data collection systems.

Bronx Community Forum – October 5, 2005
Brooklyn Community Forum – October 14, 2005
Manhattan Community Forum – October 14, 2005

Seventy-seven community participants attended these three forums which focused on the five boroughs of New York City: Bronx, Brooklyn, Manhattan, Queens and Staten Island. Numerous verbal and written comments were received, and are reflected in the sections of this document describing Service Needs and Barriers for each of the five boroughs.

Bronx

Detailed comments are noted in the Bronx Service Needs and Barriers Section of this document. Highlights of comments received for this borough include the following:

- Service needs emphasized: housing; increased access to rapid testing for casefinding and early intervention; treatment education; dental care; peer education and support as a component of all service delivery; continuum of mental health services and enhanced coordination for all age groups, and for adolescents under age 18 in particular; transportation assistance; family services for infected and affected children/youth orphaned by the epidemic and their

caretakers; financial assistance for funeral/burial expenses; and HIV prevention with positive persons.

- Subpopulations addressed: distinction between the needs of perinatally infected youth and young people infected as adolescents; addressing individual and family needs resulting from the increasing number of infected female youth and adult women; targeted outreach and services for persons aged 50 and over; transgender persons; and Spanish-speaking immigrants.

- Gaps in insurance coverage were noted, particularly for the working poor who are HIV+ and uninsured or underinsured but whose income is just above eligibility levels.

- Education/training needs: regarding mental illness to alleviate stigma and discrimination; provider training regarding gender sensitivity, and the need to address risk factors with the 50 and over age group; consumer education regarding coverage options; and job readiness education.

- Ensuring on-going consumer input and advocacy through such programs as the PLWHA Leadership Training Institute (LTI), and reiterating the important role played by CARE Networks.

- Concerns expressed regarding potential service disruption resulting from funding cuts, the need for education and advocacy regarding CARE Act reauthorization issues, and the need for more HASA services for HIV+ persons who are asymptomatic.

Brooklyn

Detailed comments are noted in the Brooklyn Service Needs and Barriers Section of this document. Highlights of comments received for this borough include the following:

- Concern expressed regarding the number of HIV positive people in Brooklyn who are not in care – either because they do not know their status, or are aware and not accessing care. Greater emphasis is needed on providing the following in multiple settings: broad-based HIV awareness-raising, counseling, testing and linkage to care.

- Service needs emphasized: supportive services, such as transportation, are essential to link persons to care and maintain them in care; better release planning from prisons; the importance of ADAP and ADAP Plus for immigrants and related training for providers; better agency coordination; expanded syringe exchange.

- Subpopulations addressed: the need for outreach and services targeted to the increasing number of Asian/Pacific Islander immigrants was noted; the distinct needs of transgender persons and lesbians need to be better articulated; and targeted services are needed for transgender persons.

- Education/training needs: for substance users regarding safe injection and maintenance of wellness; adult education and health literacy; and training of law enforcement re syringe exchange.

- Participants expressed concern that Brooklyn is underfunded given their share of the epidemic, and emphasized that limited available funding should support direct services.

- The importance of the CARE Networks as a vehicle for community input was emphasized, as well as the critical role of the PLWHA Leadership Training Institute (LTI) in empowering consumers.

- "One-stop shopping" service models are important but clients should be allowed to choose among service options to ensure confidentiality will be safeguarded.

Manhattan

Detailed comments are noted in the Manhattan Service Needs and Barriers Section of this document. Highlights of comments received for this borough include the following:

- Concerns expressed about potential funding cuts causing service disruptions and possible elimination of essential services not deemed to be the highest priority.

- The disproportionate impact on communities of color in general, and on Black men and women in particular, was emphasized. The need for outreach and services targeted to the increasing number of Asian/Pacific Islanders was also noted.

- The need for food and nutrition services was emphasized, noting that adequate nutrition is fundamental and is needed by PLWHA to stay healthy and to help prevent opportunistic infections. Nutrition education is very important, especially relating to what and when to eat while taking medications.

- Subpopulations addressed: perinatally exposed youth aging into young adulthood need targeted services, and the distinct needs of transgender persons and lesbians need to be better articulated.

- The need to enhance PLWHA and diverse community leadership as a way to combat stigma and discrimination was noted. The Leadership Training Institute

(LTI) was cited as an excellent model to build capacity, ensure consumer input, and help PLWHA with disclosure issues.

- The training and technical assistance needs of small Community-Based Organizations (CBOs) providing HIV prevention and support services were emphasized, especially: grant writing and financial management, program planning, logic models and implementing scientifically proven interventions such as Diffusion of Effective Behavioral Interventions (DEBI), and process and outcome evaluation.

- The need to educate decision makers about key facts from this document that describe the burden of New York's epidemic was noted, particularly as it relates to reauthorization of the CARE Act.

Queens

Detailed comments are noted in the Queens Service Needs and Barriers Section of this document. Highlights of comments received for this borough include the following:

- The need for more scatter site housing was emphasized, noting that many homeless residents of Queens have to leave the borough to find available housing.

- Other service needs emphasized: services targeted to mentally ill/chemically addicted (MICA) persons; and transportation assistance and mass transit available during later hours so clients can access services during the evening.

- A Queens-based site is needed for provision of HIV-related training for clinical providers to improve access and participation. The need for health and human service provider training, particularly related to cultural competency, was also noted.

Staten Island

Detailed comments are noted in the Staten Island Service Needs and Barriers Section of this document. Highlights of comments received for this borough include the following:

- The CARE Network is currently updating the Staten Island Service Delivery Plan for release in 2006. Findings from consumer focus groups held to date validate major service needs in the following areas: housing, transportation, continuum of mental health services, food and nutrition, and a needle exchange program based on Staten Island.

- While a continuum of housing services has begun to be developed, affordable and appropriate housing remains the most critical need noted by consumers and

providers. Specific needs include more scatter site supportive apartments, long-term congregate HIV housing for people with multiple needs and emergency housing.

- Other service needs emphasized: aggressive outreach to high risk communities and broader access to HIV counseling, testing and early intervention; food and nutrition services that are able to meet the increasing demand; access to dental care; transportation and legal assistance; and a day care program serving active drug using and mentally ill homeless PLWHA.

- Subpopulations addressed: Immigrants, including undocumented persons; targeted, culturally competent Lesbian, Gay, Bi-Sexual and Transgender (LGBT) prevention and service programs; access to care for the uninsured since the major provider of uninsured care and only AIDS Designated Center on Staten Island is in bankruptcy and for sale.

- Comprehensive strategies are needed for access to clean syringes, including syringe exchange and ESAP. Harm reduction services must include safe injection information, HIV testing, treatment options and referrals, hepatitis screening and vaccination, and overdose prevention.

- Major concerns were expressed about threats to the Ryan White CARE Act and to Medicaid, accompanied by the perception that the epidemic is "controlled." Education and advocacy are needed to prevent "dismantling" the systems built over the last 20 years with the goal of providing comprehensive, accessible, and respectful services for all.

Written Comments

Written comments from the Rochester Task Force on AIDS, Inc., NETWORTH/Positive Action, Inc., and Legal Services of the Hudson Valley, referenced above, are included in full on the following pages. The complete listing of written comments received is included in Appendix B.

Rochester Area Task Force on AIDS, Inc.

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Coordinator's Comments on the 2006 Statewide Coordinated Statement of Need

September 26, 2005

I would like to begin by commending the author of the document on doing a fine piece of work distilling an incredible amount of information into a manageable format. Most of the material in the document I found to be a thoughtful presentation of the data, programming, needs and issues confronting the HIV/AIDS community in New York State. What follows are notes that I made as I reviewed the document and hope that they will be received as constructive input on the document.

Special Populations:
Finding a coherent and consistent taxonomy to describe special populations is a major challenge for all of us who develop Service Delivery Plans. Since populations do not self -identify by their risk behavior, and since none of us are defined by a single characteristic, developing a taxonomy is problematic. I would like to suggest several categories that you may wish to consider for reasons that I hope will become clear.

Alcohol and Substance Users: This is a category you already have. I commend your use of this category because substances are responsible for more high risk behavior resulting in HIV than injection drug use. Monroe County research demonstrates that over 50% of persons in the NIR category use alcohol and cocaine and have multiple partners.

I would suggest that the discussion in this section also include a growing concern about the numbers of crystal meth labs in rural areas, and how meth increases high risk sexual activity among <u>all</u> who use the drug. Its use is not limited to men who have sex with men. From information gathered as I spoke with people throughout this region, meth is being used by truck drivers, others who need to work long hours including suburban housewives.

People with Disabilities: Rochester has the highest rate of deaf people per capita in the United States. The University of Rochester has a CDC grant that will be studying health status and unmet needs of the deaf as the basis of national work on the subject of deaf health status. We are aware of at least 6 people who are deaf and living with HIV/AIDS in this region. In addition to the deaf, it is reasonable to suggest that the *blind and visually impaired* may be another population where AIDS programs should be doing more. Because so much f what we learn about HIV we learn about HIV we learn through

auditory and visual messages. Outreach, education and testing, and service delivery to these populations raise special challenges which we are working on.

In this region we have begun to notice that a number of those with HIV/AIDS are *developmentally disabled*. I requested and received a run of those known to the state DD system who were also known to be living with HIV/AIDS. Statewide there are over 600 that could be quickly identified. These individuals pose special challenges to prevention, testing, harm reduction counseling, treatment adherence etc. At our last case management meeting we invited a supervisor from the Finger Lakes DDSO to come to begin discussions about how we can better collaborate across systems to serve this population.

Another population that we are seeing more frequently is people who are seriously and persistently mentally ill. While some are MICA, there are others with Bi-Polar disorders, personality disorders, and other mental illnesses who present special challenges for care providers.

These populations are examples of people with disabilities who are also living with HIV/AIDS. Because each group presents special challenges, I would suggest that your taxonomy include "people with disabilities" and the various groups be identified. There will be population specific as well as cross cutting strategies for addressing their needs.

Transient Populations: There are several populations that are identified in the SCSN that might be included under a category of "transients." The homeless, migrants, immigrants, evacuees, people who temporarily reside at VA facilities, people in jails, prison releasees, and people receiving inpatient rehabilitation are people who have a number of characteristics in common. The type of case management they receive while in transition will have common elements as well as aspects unique to the various populations. We need more case managers that specialize in assisting people during the challenges of transitions and resettlement.

Another type of "transient" population creates issues for prevention. These are college students, truck drivers, business people who may engage in high risk behavior away from their home community.

Finally, there are those between the ages of 19-29 who may be transient in the world of work, and housing. They often lack health insurance and a usual source of health care. Given their age, they are presumed to be sexually active and likely to have multiple partners.

Poor people who engage in high risk behavior for economic survival: This category includes drug dealers who cannot make a living wage in the current economy; low income women who are trying to support their children; low income youth who have been told by their parents that they need to get money so the rent can be paid; youth who desire high cost/trendy clothing; people who engage in sex to support a substance abuse habit; and transsexuals who work for steroids that Medicaid won't pay for.

Besides being poor, these people often share other environmental risks associated with living in low income neighborhoods. These include more single parent households; higher rates of poverty, lower rates of home ownership, excess exposure to lead paint; higher rates of teen pregnancy, STDs and premature birth; excess rates of morbidity from other chronic illnesses (diabetes, hypertension, heart disease, mental illness, addiction); and excess exposure to violence. Intensive case management services for these populations is often indicated because they have excess risk of being multiply diagnosed and their lives are impacted by the "syndrome of poverty."

Unmet Needs:
I would now like to itemize some under met and unmet services needs that I believe deserve additional consideration. These include:

- Funding for Hepatitis C screening and treatment;
- Funding for utility bills that are expected to skyrocket this winter; especially in poorly insulated homes of the urban and rural poor;
- Funding to pay for rapid testing by primary care providers of Medicaid patients;
- Training for primary care providers that would provide them with trigger questions to help them asses who should be tested for HIV, STDs, hepatitis, ect.
- Additional dialysis capacity to address the increasing needs that people with AIDS have for ESRD services;
- Increased access to specialists in nephrology, cardiology, gastroenterology, endocrinology who are willing to accept ADAP;
- Increased access to dentists, especially in rural areas and for people who have used crystal meth;
- Medical homes and models of programming that address the holistic needs of transgender people;
- A continuum of housing services including: supported and supervised housing for: youth who are AIDS orphans; those with HIV/AIDS who are developmentally disabled; those in need of long term recovery from substance abuse; those who are physically mentally impaired due to AIDS related illnesses;
- A system to provide qualified translators for people who come to upstate NY from countries in Africa, Asia and other areas, where there are a few to no local people who can speak the languages. Often the only people who know the language are part of the person's small local community; to use them violates the person's need/right to confidentiality.

Data Needed for Planning*:*
I would like to recommend that this be the last plan that is written without the benefit of information from the URS system. That data base should be able to provide aggregate profiles of the populations receiving the various types of Ryan White Services by region. By comparing utilization profiles to profiles of those who are believed to be living with

HIV/AIDS, we would have additional ways to assess accessibility to services, and determine which populations may have unmet needs.

In at least two place, the SCSN discusses an unmet need in New York City or statewide when regional data would enhance the document and assist local planners. Regional data that would enhance the analyses are:

- Data on delayed diagnosis and entry into care;
- Unmet housing needs;
- Estimated unmet need.

Environmental Assessment:

I would propose some additional considerations for the environmental assessment. These include:

- The growth in the federal debt due to the wars in Iraq and Afghanistan; the costs of Homeland Security; and the costs of Hurricane Relief and Reconstruction. These may be expected to contribute to a reticence to increase if not slash domestic spending;
- Gaps in public health messages targeted to high risk groups of people who are not currently infected or partners of those infected;
- Expected federal and state cuts in Medicaid and Medicare benefits;
- The public health resources that are being diverted to other health threats including: STDs, Avian Flu, West Nile Virus, Hepatitis, diseases borne by people fleeing hurricane flooding, cryptosporidium from water parks, etc.;
- Programmatic and agency consolidations to reduce administrative and overhead costs in an era of flat funding and governmental cuts.

Regulatory Relief Needed:

Before ending there are some ways in which inter-agency cooperation and regulatory relief might enhance service delivery. These include:

- Allowing school health clinics to provide condoms;
- Providing state DSS oversight to ensure that enhanced shelter allowances are provided to all who are eligible in all counties;
- Having the state Bureau of HIV/AIDS epidemiology develop a way for all counties to count and account for cases of presumed heterosexual transmission when the HIV status of the partner is unknown so that additional funding can follow that at risk population;
- Having the OASAS, Mental Health, and the AIDS Institute review regulations to determine those regulations which are inconsistent across agencies and determine how these might be modified to make it easier to provide care for people who are multiply diagnosed;
- Having the office of civil rights monitor nursing home admission practices to identify cases of discrimination that affect access for people with AIDS.

Measuring Quality:
Finally, I would like to recommend a way to enhance evaluation. The Finger Lakes region has spent approximately two years trying to assess mortality of those living with HIV/AIDS. Our study indicates that current state data do not facilitate evaluation of this important marker of access to care and quality of care. Our draft report has been made available to Dr. Agins, and you might wish to review it to understand some of the problems we encountered as we undertook our study.

I would suggest that the AIDS Institute make it a priority to develop ways of assessing quality of care by monitoring mortality of those with AIDS who die. It is important to have aggregate profiles of who dies; and what they are dying from. Our preliminary work suggests that there are populations with excess mortality, and populations who may be dying prematurely for lack of adequate access to health and mental health services. This region has developed an assessment tool to track and study mortality. We will be piloting it in this area and then recommending that the data elements be added to the URS system. A statewide data system would allow bench marking and more rapid identification of issues that affect premature/unnecessary mortality. Clearly excess mortality rates of subpopulations and premature mortality are fundamental elements in assessing the quality of AIDS service delivery.

Thank you for this opportunity to address you today.

NETWORTH/Positive Action, Inc.
c/o P.O. Box 1374
Pleasant Valley, New York 12569

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518-339-AIDS (2437)

LIVING WITH AIDS -A HUDSON VALLEY CONSUMER BASED OBSERVANCE by NETWORTH /Positive Action - October 2005

Since 1989 our collective efforts as persons living with AIDS and HIV have built the opportunity to respond creatively and participate supportively in directly addressing community Care and Prevention needs from our HIV positive perspective. Our first-hand experiences have been demonstrated across the entire spectrum of living with the virus and its effects as AIDS Care and HIV Prevention initiatives have progressed and changed .

In addition to the realities and the truths found in New York State's 2006 SCSN and Comprehensive Plan, we wish to add our voice and perspective to bring focus to some of the needs we are encountering, and highlight some concerns we anticipate for the near future. In our working principally across the urban to rural setting of the Hudson Valley of New York State we do now note some crosscutting and emerging needs requiring additional attention for persons and families living with AIDS -to be considered and addressed newly at varied levels of services -distinct and beyond the standards implemented and in use for those living with HIV.

>AIDS SURVIVOR STATISTICS SUPPORT ADVANCING and EXPANDING SERVICES:

the newly documented figures that show such a high percentage of those living with AIDS locally in the Hudson Valley compared to HIV, now varying upwards more than 1/3 to ½ by geographic area of all those living cases -clearly support the broad need for Ryan White funds in each area of the lower,mid and upper Hudson Valley and beyond -and shows an expanded Care need for persons with AIDS that can go beyond current funded case management aptly applied, but geared primarily around the norm of the physically able, often asymptomatic, HIV positive person.

ASO's,CBO's, etc. should be financially empowered to be able to better address the downward Care spirals of AIDS clients and respond in timely consideration to provide and deliver essential case-driven extended Care services -e.g. Ranging from reevaluating specific daily needs and helping to combat new limitations, to providing for new legal dilemmas, or any service area previously not considered relevant by the healthy HIV client and their projected needs, but newly requiring an emergency teamwork response of in-depth efforts, as needed, for maintaining the welfare of the AIDS patient and their family.

Systemic Case management adjustment and a renewed evaluation prioritizing matching of services to address needs should occur in a partnership effort put into play not annually, but when the client attains AIDS status -whether newly presenting in the

Care system or changed from a previous HIV diagnosis. Scheduling adding Caregiver time and enhancements which allow the provider the essentials of focus, flexibility and response are important to address the shifting and limiting situations potentially encountered by the AIDS diagnosed individual, whether homebound,semi-homebound, or temporarily incapacitated. Paramount is the ability of the provider to have the time and resources to reconsider all factors, including the challenges for others caught in,or directly impacted by, the crossfire of addressing new needs(e.g. dependents, children).

Individual barriers to services emerge as the hallmark of newly diagnosed illnesses which accompany AIDS health complications -relevant today as persons live longer but move from HIV to AIDS-and suddenly in that transition may encounter diverse health assaults that they sometimes learn are not currently funded or structured or even linked into the HIV Care safety net of contacts, referrals or services.

e.g. One Primary Care reality/observation of the current system is found in the Doctor / patient visit-which currently expects Physicians to manage and address a patient's care needs during an office visit of 15 to 20 minutes.

In our experiences, for the quickest caring Physician to adequately address an Aids patient's multiple complications often absorbs time that can go far beyond double to even triple the expected 15-20 minutes per patient allotment. Escalating complications including funding pressure, can range across the board from future office scheduling difficulties, to patients minimizing warning signs of impending complications, jeopardizing for all involved the ability to accomplish optimum health solutions.

> **RUMOR & EFFECT & PREVENTION:**

We note the lack of funded services appropriate to those long term and new AIDS cases are met with confusion by consumers who at street level completely mistake funding going to needed HIV 'Early intervention' services-as a 'not caring' prioritizing of Prevention at a cost to local direct Care resources. We have found efforts prove beneficial to providers who can serve an educated client base who do not feel minimized when they understand the purposes of the distinct funding streams that separate Prevention and Care. The CDC,TitleI, TitleII,HOPLA,etc are needing to be clarified for many at the community level to avoid the ongoing, time-consuming misunderstandings and confusions by many in Care as to what AIDS/HIV funds can specifically meet which outstanding needs (e.g. Housing). **(Also of note: Actualities and assurances conveyed as they evolve to those at the ground level may prove beneficial to counter those consumers that in depressions, or a sense of future despair, or acting on dire forecasts for the future of Care funds might act out new risk behavior patterns, or give in to non-adherence issues, or in fear might begin hoarding costly medications for future use, etc.)** A related consideration: the cry for a cut in National federal health program spending-where the conversation has potentially turned to include the funds of Medicare's Senior prescription plan,which focuses on 35 million Seniors-yet in the media the un-mentioned 6 Million disabled below aged 65 -which includes those with AIDS within that funding-also need proper information delivery to avoid sparking the same potential for individual risk responses or behaviors referenced earlier.

> ISOLATION AND COMMUNITY:

Sadly we note both communication efforts and Care services can be too easily lacking for persons especially in rural or solo circumstances living with symptomatic Aids and severe multiple-related conditions,esp. when managing bouts of temporary health-imposed limitations. We note when homebound, whether medication or illness based , some are left seemingly to their own devices when they need communication the most, isolated unless well enough and able to access and travel to participate in area group services. A further current complication is that most home/buddy/volunteer programs and community -driven interventions have now fragmented away, seemingly due to the demands of the times we now live in, but reinforced by a broadly held misconception in the community at large that AIDS (rather than HIV) is now a manageable illness. This community response is further exacerbated by the evaporation of most front-line small grassroots organizations and their tailored Prevention and Care messages that worked to prioritize and ingrain HIV and AIDS respective concerns in the local public mindset.

The far too common Care solution employed now seems to be to call in Hospice and hand aspects of Care and daily life sometimes prematurely over -yet we note in some regions Hospice may not be connected in Care planning, or aware of local updates and trainings, and some home workers have no specific Aids sensitive knowledge beyond Universal precautions, as the use of a dedicated but not specifically trained volunteer base for supplemental services increases.

There are a growing number of persons, living in the wake of the now absent AIDS community groups and services due to funding cuts, who are psycho-socially and service isolated, unless ambulatory and able to participate.

Many can still manage, deserve and prefer a life with a quality of spirit to thrive at home despite multiple daily limitations, if only provided some appropriate partial assistance or specific scheduled home help to counter being constantly sick and needing access to specialized care for ongoing complications. For these individuals it would surely be cost effective and life-affirming to help manage their independence, even for those being semi-homebound across rural areas, rather than abandon the client into placement of end stage levels of palliative /terminal care before its time.

There is a need to plan better for persons in this growing service gap with targeted funds, programs and services. With the knowledge in any future form Ryan White is still to be the gold standard for inclusive care needs and serve as a emergency safety net for persons across the spectrum with AIDS/HIV, we restate the need for implementing new and improved Care and heightened ancillary services as needed for those persons living with the limitations imposed by AIDS.

>**GOING FORWARD:**

We ask that some discussion and directives be considered and established in NYS for service providers to be enabled to address and manage these evolving changes and current to future needs.

We anticipate new service delivery complications and ask for planning to consider now the needs for those with AIDS and their caregivers in Nursing home, rehabilitation and recovery settings, as our populations living with the virus ‘full-blown’

continue to age, undergo transplants, etc.

Based on current events, we are also hopeful of contingency plans being developed now in place for future successful assistance for those living with AIDS, in the event of a future natural or man-made disaster of catastrophic incidence or proportion affecting the community at large.

Those of us living with AIDS and experiencing multiple complications, who are increasingly becoming the most physically limited and disabled, and struggle on a day to day basis across all communities, seem to be doing so today in more isolation than ever before. It is frustrating to see how our working grassroots efforts for persons with AIDS, identified in-depth beyond the emphasis of the last few years, have been so currently minimized across whole communities at large.

Programs are needed which are more AIDS specific in design and delivery application. There needs to be a stronger plan and conceptualization for meeting the increased demands on those growing weaker and challenged by the effects of cumulative illness,etc. We believe this reality and need is being often repeated in other regions, perhaps unnoted in the absence of what was just a few years past, an AIDS/HIV "community". As Mary Fisher in her keynote address at the New York State Seventh Annual AIDS Policy Conference in Albany in 1997 prophetically remarked:

... ***"The consequence of all -the prematurely announced end of the epidemic,the loss of visibility, the appeal that we are not responsible for each other - is an AIDS community that is in danger of no longer being a community... But of all the enemies to the AIDS community perhaps the greatest is tiredness. It's the weariness that will finally keep us from each other***

...It will have us all wondering what ever happened to community."....

Today in the United States, some of us left are now fading from the cumulative effects of AIDS -not as before in this pandemic's history -within very public and apparent eyesight -but in newly isolating circumstances that can erase our efforts, our needs, and ourselves away with imposed physical and Spirit-numbing limitations.

It is clear that without some new and dedicated focus, concerted formal effort, and renewed public funding, we will all be left lingering, hoping, and at cross-purposes - unable to adequately bridge our shared goals in Prevention and Care as the ranks of those newly struggling with AIDS swell; this in what should be an opportunity for change and resolve -a future-defining moment -but one that can still be realized now -in and for this 21st century.

-Michael Reynolds ***executive director***

NETWORTH/Positive Action is a nonprofit 501(c)(3) membership organization founded to promote AIDS care and HIV prevention awareness and education to the public, provide safe resources and user-friendly support referrals to meet members needs and create community-based interventions, projects and outreach efforts based on the perspective of persons living with AIDS and HIV and their families and loved ones, with the goal of helping people with AIDS/HIV to help themselves and to benefit infected/affected and at-risk community at large.

Legal Services of the Hudson Valley
Protecting Rights Promoting Justice

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October 19, 2005

Rhea Temblador
NYS Department of Health
AIDS Institute
Corning Tower, Room 478
ESP
Albany, NY 12237

Dear Ms. Temblador:

I write this letter on behalf of Jacqueline Frost and myself of Legal Services of the Hudson Valley, Maura Hayes-Chaffe and Lillian M. Moy of the Legal Aid Society of Northeastern New York, and Howard Sherwin of the Legal Aid Society of Rockland County. Collectively we represent the three primary providers of civil legal services to people living with AIDS and HIV in the Northeastern, Mid-Hudson and Lower Hudson regions. In response to your request for comments on the draft 2006 New York State Ryan White Statewide Coordinated Statement of Need (SCSN) and Comprehensive Plan, we submit the following comments.

Thank you for giving us the opportunity to review and comment on the draft SCSN and Comprehensive Plan. It is an extremely impressive document. Additionally, we appreciate the support our programs have each received from the AIDS Institute in funding our legal services programs as well as giving us the opportunity to participate in various community networks and committees. Our comments and suggestions flow from our experience as general providers of civil legal assistance, and our knowledge of how life with HIV and AIDS raises issues best addressed or only addressed through legal advocacy.

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Documenting The Justice Gap in America

The Legal Services Corporation (LSC) in Washington DC has just issued a national report documenting "the Justice Gap" (accessible at www.lsc.gov/pressr/releases/101705pr.htm). The Justice Gap is defined as the difference between the current level of legal assistance and the level which is necessary to meet the needs of low-income Americans. The Justice Gap Report confirms that the unmet need for civil legal services is tremendous.

The Report reviews the American Bar Association's 1994 Legal Needs Study as well as the statewide legal needs studies that have been done since 2000. The Report concludes that the ABA finding that the legal needs of only one in five low income people can be met by current resources is the lowest possible expression of continuing legal need. Indeed, more recent studies demonstrate that the current level of need is actually substantially higher than the level found in the ABA Study. Findings also show that as many as 16 million legal problems experienced by low income people - and probably more - are addressed without any legal help whatsoever. Many people do not even seek help or call local legal services offices because they do not understand that the problem has a legal dimension and a potential legal solution, or because they are unaware of available legal aid.

Recently the LSC grantees in New York participated in an LSC-required effort to record the number of financially eligible clients with eligible legal problems who LSC grantees were unable to serve or unable to serve fully. Nationally, the data shows that at least one client is turned away from a local legal aid office for every client whose case could be accepted. New York statewide data demonstrates that approximately 88,440 low income New Yorkers with eligible legal problems cannot be served by LSC grantees each year.

Taking northeastern New York as an example, the data showed that LASNNY would be unable to serve or unable to serve fully about 5,932 low income people. This is close to the number of cases that program closed last year and is thus right in line with the national data showing that of those low income people who actually call a legal aid office, one applicant is rejected for every applicant who can be served.

Finally, the Justice Gap Report compares the number of lawyers available for the general population as a whole, to the number of lawyers available in any civil legal aid program for a low income person. Currently there is about one lawyer for every 525 people in the general population; however, there is only one poverty law lawyer for every 6,861 low income individuals. In northeastern New York, based on the services available at LASNNY, there is one lawyer for every 5,658 low income individuals in poverty. Comparing available resources at our program to the Health Department statistics on people living with AIDS and HIV in each of our regions, the Legal Aid Society of Northeastern New York has one lawyer to serve 3,400 people living with AIDS or HIV; for the entire Lower Hudson and Mid-Hudson Regions, to serve over 7,100 people living with HIV and AIDS, Legal Services for the Hudson Valley has two lawyers and the Legal Aid Society of Rockland County one. It is clear that the Justice Gap is substantial for all low income people, and in particular, the disproportionately low income group of people living with AIDS and HIV.

The Justice Gap for PLWA Means Basic Survival Needs Cannot Be Met

Our experience is that the legal needs of low income people in general mirror the legal needs of people living with HIV and AIDS. In 2004, 79% of all cases closed by LASNNY fell in the areas of family, income, housing and health - basic survival needs. Similarly, an informal review

of year to date 2005 statistics for clients served under the HIV & AIDS Law Consortium grant involved protecting basic survival needs. For Legal Services of the HudsonValley, 84% of all cases closed in 2004 addressed the same basic survival needs as do 82% of those cases opened to date in calendar 2005.

We write to suggest that legal services be given greater priority so that there will be more lawyers available to respond to the emerging trends that this Department has identified, i.e., the differing legal needs of people who are living longer, Medicaid reform, stigma and discrimination and the disproportionate impact on communities of color who statistically remain poorer than white communities. As legal services providers, we are well aware of the multiple and simultaneous legal needs experienced by emerging high risk and under-served sub-populations living with HIV and AIDS, such as children and families, the homeless, immigrants and migrant workers. Certainly legal services are among their most pressing needs.

The Specifics of Our Experience as Providers to People Living with HIV and AIDS

For years, New York State, the consumers and the providers of direct services to those living with HIV or AIDS have worked to build and to maintain a continuum of care, in keeping with the need and the mandates of the Ryan White Care Act. The providers of legal assistance to people living with HIV/AIDS remain a vital part of that continuum. When a challenge, even one that has been the subject of case management or other supportive service, becomes a legal crisis - loss of housing, loss of custody of children, lack of a will while hospitalized and the end approaches, denial of SSI or SSD benefits, the need to appeal in a Medicaid or other public benefit case - the only recourse with the potential to correct an injustice is legal advocacy. We provide that backstop.

We have provided this recourse for clients through many years. Among the three regional legal service providers we have handled thousands of the very types of crises noted above through persuasion, through litigation, and through thorough advice to our clients of the legal options that let them take control of their lives through planning and to assert their right to respect from persons and agencies who affect them and their families.

In anchoring our end of the spectrum of the continuum of care we appreciate the opportunity both to clarify the unique role that we serve and to note that this role has the explicit support of the consumers and providers in the Northeast, Mid-Hudson and Lower Hudson regions. While their understanding and support of the need for legal services is gratifying, all of us recognize that the justice gap cruelly affects people living with HIV/AIDS. Ultimately, the only way the profound legal needs of this population can be addressed is through the preservation and expansion of funding allocated to that purpose. The need has been identified and, we believe, demonstrated. Beyond that, the threat of profound losses and disruptions faced by all of our clients underscores the urgency of addressing the need.

Restrictions that Limit Our Ability to Serve People Living with HIV/AIDS

The justice gap for people living with HIV or AIDS is threatening to grow wider due to recent restrictions, promulgated by HRSA, concerning permissible use of Ryan White Title I funding for legal assistance. Under a strict interpretation of the policy that legal services funded under Title I can only be those which are directly necessitated by a person's HIV status, Title I funds may no longer be used to represent persons living with HIV or AIDS who are facing eviction (other than those cases directly involving discrimination). Safe and affordable housing has consistently been identified as one of the most important service needs/barriers facing people living with HIV or

AIDS in the Northeastern, Mid-Hudson and Lower Hudson regions. Access to high quality legal representation is clearly one of the most important and effective tools in ensuring retention of housing for people living with HIV/AIDS. In recognition of the extreme importance of, and high demand for, legal representation in housing matters, legal services providers have been forced to rely on funding sources outside the Ryan White Care Act to fill in the gap caused by the HRSA restrictions. It is therefore urged that additional non-restricted funding be authorized to fund those crucial legal services, such as eviction defense, which are no longer funded by Ryan White Title I.

Specific Suggestions for the SCSN/CP

We applaud inclusion of legal assistance among the essential supportive services in New York State's broad long term goals to guide priority-setting. A few specific suggestions as to the documents in question follow:

On page 72, where the SCSN identifies statewide barriers and service needs, we suggest that increased legal assistance be separated out from the laundry list of supportive services and highlighted, as with Case Management and Food/Nutrition.

On pages 140 and 149, amongst the AIDS Institute current successful initiatives, you might consider adding a description of the general legal services initiative as well as the Families in Transition initiative. Together these two initiatives permit at least minimal funding for both individuals and families living with or affected by HIV and AIDS. A further strategy to continue to expand the provision of legal services to begin to close the Justice Gap for low income people living with AIDS and HIV would be a wonderful addition to the Plan.

Thank you again for the opportunity to review and comment on the Plan and for your fine work in serving persons living with HIV and AIDS. If I can provide you with additional information, please do not hesitate to contact me.

Sincerely yours,

/s/

Paul Callagy, Esq.

cc: Lillian M. Moy
Maura Hayes-Chaffe
Jacqueline Frost
Howard Sherwin

APPENDICES

Appendix A-1

2006 Statewide Coordinated Statement of Need
Source Documents By Number Including Brief Descriptions

1. **Service Delivery Plan: AIDS Network of Western New York; 2003.**
   This report is the 2003 update of the Service Delivery Plan of the Western New York HIV Care Network. It provides data from both published and unpublished state and local sources on recent trends in the HIV epidemic and includes limited new data collected from surveys and focus groups involving providers and consumers. This report includes the results of epidemiological analysis and data generated from surveys, focus groups and community forums, which led to the identification of a number of significant issues.

2. **Regional Gaps Analysis Final Report: AIDS Network of Western New York; 2001-03.**
   Conducted by the AIDS Network of Western New York, in collaboration with the AIDS Institute and the New York State HIV Prevention Planning Group, this Regional Gap Analysis provides a systematic approach for identifying gaps between the needs of at-risk populations and the availability of existing services within a specific geographical area. This document obtains an overview of HIV prevention needs, the HIV delivery system, and HIV prevention resources within a specific geographical area in order to improve HIV prevention efforts and services.

3. **Needs Assessment and Workplan for the Ryan White Title III Program: Hudson Headwaters Health Network; January 2005.**
   This document serves as Hudson Headwaters Health Network's application for Ryan White Title III funding to support ongoing HIV primary care available at eleven health centers and three affiliating offices. The document includes a program narrative that provides background information on HIV seroprevalence and surrogate markers, target populations, the social context of HIV/AIDS in the region, and the local HIV service delivery system. The needs assessment and workplan include gaps in local services and barriers to care, and corresponding objectives/responses and evaluation methods for each.

4. **New York EMA Consumer Focus Group Report: New York City Department of Health and Mental Hygiene, Office of AIDS Policy Coordination; August 2004.**
   This report summarizes the findings of four focus groups of People Living with HIV/AIDS conducted in the New York EMA on July 28 and 29, 2004. The 38 participants, diverse and broadly representative in terms of race/ethnicity and sexual orientation, responded to questions relating to Ryan White CARE Act Reauthorization issues, which included service needs, barriers and gaps.

5. **New York City Ryan White Care Act Title I Consumer Advisory Group Survey Report; March-April 2004.**
This report documents the results of the recent survey conducted by the PLWA/HIV Advisory Group of the HIV Health and Human Services Planning Council of New York in March and April 2004. This survey gave consumers an opportunity to set priorities and identify needs for the 2005 priority setting process for Ryan White Title I services. A total of 72 responses were received from 62 agencies, double the return rate of previous years.

6. **New York EMA HIV/AIDS Needs Assessment Update: New York City Department of Health and Mental Hygiene, Office of AIDS Policy Coordination; 2004.**
Commissioned by the HIV Health and Human Services Planning Council of New York, this document updates the Initial Needs Assessment for New York City, 2002. The purpose of the needs assessment is to define and describe services needs and gaps in services for people living with HIV disease, which in turn enables planning, priority setting, and allocation of resources in local communities.

7. **Monitoring and Evaluation Update of the New York EMA Comprehensive Strategic Plan for HIV/AIDS Services, 2002-2005: New York City Department of Mental Health and Hygiene, Office of AIDS Policy Coordination; 2004.**
The purpose of this update is to examine the EMA's progress in achieving its goals and objectives between publication of the New York EMA Comprehensive Strategic Plan for HIV/AIDS Services, 2002-2005 in the summer of 2002 and the summer of 2004.

8. **Community Forum Report: New York City Department of Health and Mental Hygiene, Office of AIDS Policy Coordination; Spring 2004.**
This document is the final report from a series of five community forums sponsored by the HIV Health and Human Services Planning Council of New York held in Spring 2004. The purpose of these forums was to allow the Planning Council to gather testimony from individuals infected and affected by HIV, providers of services to people living with HIV/AIDS, community members and advocates regarding the unique service needs of their communities, and gaps in services in communities throughout the City.

9. **Service Delivery Plan Update: Bedford Stuyvesant/Crown Heights HIV Care Network; 2001.**
This document outlines activities, expected outcomes, responsible parties and time frames associated with development of the Service Delivery Plan. Input from health and social service providers delivering care and services to PLWHA in Bedford Stuyvesant/Crown Heights, consumers receiving services in that area, and local community planning boards.

10. **Stability of Adherence to Highly Active Antiretroviral Therapy Over Time Among Clients Enrolled in the Treatment Adherence Demonstration Project: Journal of Acquired Immune Deficiency Syndromes; 2003.**
This article, published in a peer-reviewed journal, investigates the stability of adherence to antiretroviral medications over time among HIV-infected individuals attending adherence support programs in New York State.

11. **HIV-related Knowledge and Adherence to HAART: AIDS Care; October 2003.**
This abstract examines the association between HIV-related knowledge and adherence to determine whether or not a better understanding of HIV and its treatment is associated with better treatment adherence.

12. **Offender Re-entry - Establishing Public Benefits for Eligible Offenders; January 2004.**
This report states the issues that offenders released from prison face when they re-enter the community. The report discusses the benefit programs, current practices and recommendations for strengthening access to offender benefits.

13. **Interagency Offender Re-Entry Task Force Interim Report: New York State Division of Criminal Justice Services; December 15, 2003.**
This report discusses the two-part strategy that New York State has implemented in order to maximize public safety through the optimal use of correctional resources, including the work of the task force, the status of the current system, the development of a strategic plan by the Task Force and the current status of plan implementation.

14. **Request for Applications for HIV Primary Care Models for Treatment Adherence to Combination Antiretroviral Therapy: NYS Department of Health AIDS Institute; July 2002.**
This RFA outlines goals, objectives and criteria for awarding funding to HIV organizations for the purpose of developing and providing comprehensive strategies that lead to successful treatment adherence and demonstrate the ability to measure adherence to combination antiretroviral therapy.

15. **Queens HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; 2005.**
This document provides current statistics and epidemiological data for the borough of Queens. Some of the data is reported by zip code and some of the data is reported by United Hospital Fund neighborhoods.

16. **Bronx HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; 2004.**
This document provides statistics and epidemiological data for the Bronx for 2004.

17. **2004 Brooklyn AIDS Fact Sheet: Brooklyn AIDS Task Force; April 2004.**
This document provides statistics and epidemiological data for the entire borough of Brooklyn for the years 2002-03.

18. **2004 Borough Park Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Borough Park for the years 2002-2003.

19. **2004 Canarsie/Flatlands/Starrett City Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Canarsie/Flatlands/Starrett City for the years 2002-2003.

20. **2004 Central Brooklyn Profile including Bedford-Stuyvesant, Brownsville and North Crown Heights: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Central Brooklyn for the years 2002-2003.

21. **2004 East New York, New Lots & Cypress Hills Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for East New York, New Lots & Cypress Hills for the years 2002-2003.

22. **Flatbush Profile: Crown Heights, East Flatbush, Lefferts Garden, Midwood, Prospect: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Flatbush for the years 2002-2003.

23. **2004 Greenpoint Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Greenpoint for the years 2002-2003.

24. **2004 Northwest Brooklyn Profile: Brooklyn Heights, Carroll Gardens, Clinton Hill, Downtown Brooklyn, Fort Green, Park Slope & Red Hook: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Northwest Brooklyn for the years 2002-2003.

25. **2004 Southern Brooklyn Profile: Coney Island, Brighton Beach, Gravesend, Sheepshead Bay: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Southern Brooklyn for the years 2002-2003.

26. **2004 Southwest Brooklyn Profile: Bensonhurst, Bay Ridge, Dyker Heights: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Southwest Brooklyn for the years 2002-2003.

27. **2004 Sunset Park Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Sunset Park for the years 2002-2003.

28. **2004 Williamsburg/Bushwick Profile: Brooklyn AIDS Task Force; July 2004.**
This document provides statistics and epidemiological data for Williamsburg/Bushwick for the years 2002-2003.

29. **Staten Island HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; 2004.**
This document provides current statistics and epidemiological data for the borough of Staten Island. Data is reported by zip code and by United Hospital Fund neighborhoods.

30. **2003 Central Harlem/Morningside Heights HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; December 2002.**
This fact sheet provides a summary of incidence and prevalence in the region, compared and contrasted with NYS and national figures.

31. **2003 Central Harlem/Morningside Heights HIV/AIDS Profile: Brooklyn AIDS Task Force; December 2002.**
This document summarizes the history, incidence, prevalence and epidemiological data for Community Districts 9 and 10.

32. **2003 Lower Manhattan HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; December 2002.**
This fact sheet provides a succinct summary of important statistics related to HIV/AIDS in Lower Manhattan.

33. **2003 Washington Heights/Inwood HIV/AIDS Profile: Brooklyn AIDS Task Force; December 2002.**
This document presents a historical overview of the neighborhood, a description of the neighborhood today and epidemiological information describing the extent of the HIV/AIDS epidemic in this neighborhood.

34. **Service Delivery Plan: Bronx HIV Care Network; December 2001.**
This document presents regional priorities for the Bronx HIV Care Network, including the service prioritization process, the service priorities, and the Network Action Plan.

35. **Request for Applications (RFA) for Food and Nutrition Services for People Living with HIV/AIDS: New York State Department of Health AIDS Institute; April 2001.**
This RFA outlines a variety of food, meal and nutrition services that respond to the changing health and economic conditions of persons living with HIV/AIDS.

36. **Assessment of the Housing Needs of Persons with HIV/AIDS, New York City EMA, Final Report: HIV/AIDS Housing Needs Assessment Team; 2004.**
This study of the housing and support service needs of persons with HIV/AIDS in the New York City EMA is among the first attempts to assess current and future housing needs of New Yorkers living with HIV/AIDS. The ESA consists of the five boroughs of New York City and the Tri-County Lower Hudson Region (Westchester, Putnam and Rockland Counties).

37. **Request for Applications (RFA) for Project WAVE, New York: New York State Department of Health AIDS Institute; January 2005.**
This RFA, issued in January 2005, solicits organizations to oversee and carry out the statewide operations related to the continuation of Project Wave New York. This initiative is a collaborative effort to raise awareness about risks for HIV/AIDS in communities of color and to encourage individuals to know their HIV status by getting tested and into care.

38. **Report on Syringe Access in New York State: New York State AIDS Advisory Council; January 2005.**
The AIDS Advisory Council convened a Subcommittee in November 2004 to re-examine syringe access and related issues and present to the full Council an updated set of recommendations. This report summarizes the findings of this Subcommittee and subsequent recommendations of the Council.

39. **Report and Recommendations for the New York State FY 2005-06 Budget: New York State AIDS Advisory Council.**
This document serves as the New York State AIDS Advisory Council's budget recommendations for the 2005-06 State Fiscal Year. These funding recommendations are submitted to the Commissioner of Health, the commissioners of other agencies involved in funding HIV-related programs through the Governor's Interagency Task Force on HIV/AIDS, and the New York State Legislature.

40. **Report on HIV/AIDS Services in New York State Correctional Facilities: New York State AIDS Advisory Council; February 1999.**
This report, developed by a subcommittee of the AIDS Advisory Council, highlights problems in the provision of HIV services in New York State correctional facilities and offers a series of recommendations to address these deficiencies.

41. **Women in Peril - HIV & AIDS: The Rising Toll on Women of Color: New York State AIDS Advisory Council; September 14, 2005.**
In response to the ever-growing impact of HIV/AIDS on women in New York State, nationally and globally, the AIDS Advisory Council dedicated multiple meetings to presentation and discussion of the impact of HIV/AIDS on women in New York State. This report offers a series of recommendations gained from these discussions.

42. **Communities at Risk: HIV/AIDS in Communities of Color: New York State AIDS Advisory Council; Winter 2000/2001.**
This report, submitted by the AIDS Advisory Council, offers an overview of the epidemic among persons of color nationally and in New York State.

43. **Needs Assessment Tools and Final Report: People Living with HIV/AIDS (PLWHA) Leadership Training Institute (LTI).**
This report is the result of the PWHA Needs Assessment, which was initiated by the PLWHA LTI in order to gain insight into ways of enhancing PLWHA involvement in various types of community HIV-related decision-making. The PLWHA Needs Assessment involved statewide data collection in New York City and the eight other New York State Ryan White Regions. Combinations of quantitative and qualitative data methods were used.

44. **Demonstration of Service Need - Service Justification for Treatment Support: Bellevue Hospital Center; December 17, 2004.**
This document is an excerpt from a grant proposal submitted in response to a Ryan White Title I RFP, describing treatment adherence support needs of Bellevue Hospital patients.

45. **Position Paper addressing the lack of residential placements for HIV+ children and adolescents with serious mental health needs: Suffolk Project for AIDS Resource Coordination; 2003.**
This position paper address an identified gap in services for HIV+ children and adolescents with serious mental health needs. Specifically, the paper pinpoints the lack of residential placement options and facilities for children and adolescents of Suffolk County with complex HIV disease and mental illness or marked behavioral problems. Additionally, the document reports needs in this population to include: HIV treatment adherence, HIV transmission and risk reduction educational and vocational training and independent living skills training.

46. **Service Delivery Plan: Mid-Hudson HIV Care Network; 2002.**
This document addresses the full range of the Network's activities in meeting the needs of the HIV/AIDS epidemic. It provides current epidemiological information about the Mid-Hudson geographic area, lists and classifies various health care and social service providers that make up the comprehensive continuum of care in this region, identifies emerging trends in the epidemic and service inefficiencies that might arise from them, and outlines a series of strategies for addressing existing and anticipated service gaps.

47. **Regional Gaps Analysis: Mid-Hudson HIV Care Network; 2003.**
This document was developed based on a regional assessment of prevention needs and available resources related to HIV/AIDS. Data for these regional gaps analyses were collected through a series of discussion groups conducted between May 2002 and March 2003. These groups were designed to: 1) Answer questions provided by the AIDS Institute about prevention strategies and interventions in the Network's region; 2) Assess regional provider needs; and 3) Identify regional community resources.

48. **HIV/AIDS Profile: AIDS Related Community Services; December 31, 2001.**
This document, produced by AIDS-Related Community Services, provides an HIV/AIDS data profile for Dutchess, Orange, Sullivan, and Ulster counties as of December 31, 2001.

49. **Updated Epidemiological Data and Special Needs Populations: Lower Hudson Region HIV Care Network; March 21, 2004.**
The purpose of this document is to assist in community planning and needs assessment by providing up-to-date data to the Network and other interested providers and consumers. It includes an update on populations with special needs as defined by both the Statewide AIDS Service Delivery Consortium (SASC) and regionally defined special needs populations.

50. **Sister Link Community Action for Prenatal Care (CAPC) Initiative Community Planning Tool: Northern Manhattan Perinatal Partnership; 2004-05.**
This tool provides an overview of the Sister Link Coalition, which serves as the coordinating body for the statewide initiative known as the Community Action for Prenatal Care (CAPC). The CAPC initiative supports the development of community coalitions dedicated to reducing the vertical transmission of HIV by recruiting high-risk pregnant women into prenatal care and critical social support services.

51. **Regional Service Plan: Binghamton Tri-County HIV Care Network; 2002, Updated September 2004**.
This document documents the local HIV/AIDS epidemic in the Binghamton Tri-County area, describes services available in the region; identifies needs and gaps in available services; identifies priorities in addressing those needs; and develops a realistic action plan to meet those needs. It was developed with input from providers, persons living with HIV/AIDS and community representatives.

52. **Regional Gaps Analysis Final Report: Binghamton Tri-County HIV Care Network; September 2003.**
This report details an assessment conducted of HIV prevention services and includes recommendations for addressing HIV prevention needs in Broome, Chenango and Tioga counties. The scope of work for this project covered the period October 2001 thru November 2003. The AIDS Institute provided technical assistance and guidance throughout the process.

53. **HIV/AIDS Facts: Binghamton Tri-County HIV Care Network; December 29, 2004.**
This fact sheet was prepared by the Southern Tier AIDS Program (STAP) and provides statistics relating to clients served by the program such as disease classification, gender, age, ethnicity, risk factor, county of residence within the region, and number of participants in various prevention services programs.

54. **Community Health Needs Assessment: Bedford Stuyvesant/Crown Heights Community Coalition on Research & Planning; 2001.**
This Comprehensive Needs Assessment document was prepared as a foundation for the development of a plan to create a linked network of services. Its purpose is to increase community awareness and access to care, prevention, treatment for HIV/AIDS, TB, STDs and substance abuse in Bedford/Stuyvesant and Crown Heights.

55. **Community Health Needs Assessment: Bedford Stuyvesant/Crown Heights Community Coalition on Research & Planning; Updated September 2002.**
This document is an update to the 2001 Comprehensive Needs Assessment.

56. **Key Findings from Community Forums conducted by the New York State Department of Health AIDS Institute regarding HIV Prevention and Health Care for Women, Children and Young People; November 2000.**
In November 2000, the AIDS Institute held information-gathering forums related to the needs of and services for women, children and young people infected/affected by HIV or at risk for HIV infection. Providers were invited to give oral and written comments and consumers were invited to give oral comments at these forms. This report outlines key findings drawn from these forums, summarized according to common themes, emerging priorities, region-specific issues and topic area.

57. **Request for Applications for HIV Prevention and Care Services for Women, Children, Families and Young People: New York State Department of Health AIDS Institute; December 2001.**
This Request for Applications (RFA) awards State and Federal funds for HIV Prevention and Care Services for Women, Children, Families and Young People.

58. **Regional Gaps Analysis Final Report: Central New York HIV Care Network; 2004.**
This report details an assessment conducted of HIV prevention services and includes recommendations for addressing HIV prevention needs in Central New York (Syracuse, Utica, Watertown).

59. **Service Delivery Plan: Central New York HIV Care Network; 2002.**
This document presents regional priorities for the Central New York Ryan White HIV CARE Network, including the service prioritization process, the service priorities, and the Network Action Plan. The service delivery plan looks at HIV/AIDS service needs for the entire 11-county region served by the Network.

60. **Request for Applications (RFA) for Supportive and Legal Services for Families in Transition: New York State Department of Health AIDS Institute; July 2002.**
This RFA awards funds to ensure that a full continuum of permanency planning supportive and legal services is available to families affected by HIV in geographic areas of demonstrated needs. Such services provide support to children, adolescents and parents as they cope with the impact of HIV on the family, help families plan for the future care and custody of their children, assist new caregivers in adjusting to their responsibilities, and stabilize the newly blended family.

61/62. **Presentation to Bellevue Hospital Adult Virology Program: New York University Medical Center Pediatric Infectious Diseases Program.**
This presentation, given by the Bellevue Hospital Pediatric Infectious Disease Program, provides an epidemiological and clinical profile of HIV infected mothers, children and youth and a description of the Lower New York Consortium for Families with HIV. Some major service needs are also presented.

63. **Clinical Management of HIV Infection - Quality of Care Performance in New York State: New York State Department of Health AIDS Institute; 1999-2001.**
This AIDS Institute publication is the second edition of this report, providing HIV performance data collected through quality of care reviews conducted during the period 1999-2001. Clinical experts from the HIV Quality of Care Advisory Committee chose the following core indicators to be included in this report as representative measures of high quality care in HIV ambulatory care programs: 1) management of antiretroviral (ARV) therapy; 2) viral load measurement; 3) administration of intrapartum HIV prophylaxis; 4) tuberculosis screening (PPD); and 5) pelvic examination.

64. **The HIV Quality of Care Program: New York State Department of Health AIDS Institute; June 2004**.
This booklet describes the New York State Department of Health AIDS Institute's Quality of Care Program, built upon the principles of continuous quality improvement. This program is responsible for the systematic monitoring of the quality of medical care and support services provided to people with HIV infection in New York's hospitals, chronic care facilities, community health centers, drug treatment programs, and community-based organizations, as well as through HIV Special Needs Plans.

65. **A Consumer's Guide to Quality of HIV Care in New York State: New York State Department of Health AIDS Institute; September 2003.**
This booklet is designed to provide information to people living with HIV about the quality of HIV care provided in New York State, listing the results for five clinical indicators for which there is reliable information by region and facility.

66. **New York EMA Addendum to the Needs Assessment Plan Update 2004: New York City Department of Mental Health and Hygiene, Office of AIDS Policy Coordination.**
This document provides additional needs assessment information for the time period between May 1,2004 and November 15, 2004, to be used in conjunction with the July 2004 Needs Assessment Update. This addendum focuses primarily on providing updated epidemiological data and detailed community health profiles. Some updated needs information is also presented.

67. **Ryan White Care Act Title I Grant Application: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; October 2004.**
This Ryan White Title I grant application is a comprehensive account of the service gaps and service needs for Nassau and Suffolk Counties. It outlines service needs for several sub-populations; documents disease progression, insurance status and it impact on residents in the Eligible Metropolitan Area.

68. **Nassau-Suffolk Barriers to Care Forum Report: United Way of Long Island; 2004.**
This report summarizes group discussions from a "Barriers to Care Forum" conducted on Long Island by the Ryan White Title I Nassau-Suffolk HIV Health Services Planning Council and the Ryan White Title II Nassau-Suffolk HIV Care Network. The Forum addressed current needs, barriers to accessing both prevention and care services, and existing services for six specific subpopulations on Long Island (Mentally Ill Chemically Addicted; Men Who Have Sex With Men; Women; Homeless; Youth; Communities of Color).

69. **Barriers to HIV Care and Supportive Services Questionnaire Results: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; May 2004.**
This questionnaire was used to obtain input from Long Islanders living with HIV/AIDS and/or their caregivers about those issues or situations that might prevent them from seeking or getting services. Results were from 99 responses.

70. **Comprehensive Service Plan for HIV/AIDS in Nassau and Suffolk Counties: Nassau-Suffolk HIV Health Services Planning Council; October 2002.**
This Service Plan addresses HIV/AIDS on Long Island and includes information on the following: the scope of the local epidemic, the needs of infected and affected individuals, existing regional services, and barriers to care.

71. **Federal Position Paper: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; 2004.**
This document is a federal position paper that reports on policy and program issues directly impacting HIV/AIDS services in New York State.

72. **State Position Paper: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; 2004.**
This document is a statewide position paper addressing policy and programmatic gaps and barriers. Its focus is on funding in the New York State budget and restoration of funds in critical HIV/AIDS service areas.

73. **Nassau County Position Paper: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; 2004.**
This position paper documents and support five critical service needs impacting HIV+ and AIDS residents and their families living in Nassau County. The paper presents CDC data as well as demographic data with emphasis on Nassau County in general, including eight townships where the impact of the epidemic is most evident (Inwood, Hempstead, Greenport, Roosevelt, Uniondale, Westbury, Long Beach and Elmont).

74. **Long Island HIV/AIDS 2001 Survey Results: Nassau-Suffolk HIV Health Services Planning Council; June 13, 2001.**
This survey, administered by the Nassau-Suffolk HIV Health Services Planning Council, was designed to gather comprehensive information from consumers or their caregivers. This information was collected in order to assure that Ryan White priorities are responsive to the changing needs of the population in the region.

75. **Long Island HIV/AIDS 2003 Consumer Survey Results: Nassau-Suffolk HIV Health Services Planning Council; August 13, 2003.**
The Data Needs and Priorities Committee of the Nassau-Suffolk HIV Health Services Planning Council authorized distribution of a survey to identify needs of people living with HIV/AIDS in the Nassau-Suffolk EMA. This survey was a modified version of one used in the EMA in 2001, and was based on a consumer survey used in the state of Louisiana. It was designed to gather comprehensive information from consumers or their caregivers. This information was collected in order to assure that Ryan White priorities are responsive to the changing needs of the population in the region.

76. **Nassau-Suffolk Care Network Regional Gaps Analysis Final Report: Nassau-Suffolk HIV Care Network.**
This report details HIV prevention needs, available resources, and methods to improve existing HIV prevention activities on Long Island.

77. **HIV Care Network Regional Gaps Analysis: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; July 13, 2003.**
A total of 7 groups were held with 41 individuals serving as participants. The themes for the discussion groups were predetermined and included 2 groups that focused on issues related to injection rugs use, two focusing in issues related to men who have sex with men, two concentrating on issues related to heterosexual transmission and one group that concentrated on issues specific to the East End of the region.

78. **CSAP Initiative I Planning Grant Performance and Results Report: Asian and Pacific Islander Coalition on HIV/AIDS; December 24, 2002.**
This document provides the results of a planning grant with two major goals. The first was to develop a process for gathering stakeholders to assess the substance abuse and HIV prevention needs of APIs and to make recommendations on how these needs can be addressed. This goal was accomplished through a series of needs assessment and community activities. The second was to design an appropriate response to the substance abuse and HIV prevention needs of APIs and to take appropriate steps for implementing this response. This goal was accomplished through prevention intervention model development activities using the results of the needs assessment and the input of an Advisory Committee to determine the most desirable service model. The document summarizes the proposed service model focusing on high-risk A/PI youth between the ages of 14 and 24.

79. **South Asian Immigrant Women's HIV/AIDS Related Issues: An Exploratory Study of New York City: Asian and Pacific Islander Coalition on HIV/AIDS; September 1, 2004.**
This is the report of an exploratory four-month project on HIV/AIDS related issues of South Asian Immigrant Women in New York City. One of the goals of this project is to share findings with the South Asian communities and to provide recommendations to the Department of Health and Human Services (Federal Office of Minority Health). Though limited in scope due to time and budget constraints, this exploratory project provides valuable preliminary insights and the findings and recommendations provide some direction for future research. It also helps identify some key issues involved in addressing HIV/AIDS in South Asian communities, particularly for immigrant women.

80. **Asian and Pacific Islanders Living with HIV/AIDS and their Access to Primary Care Services: Asian and Pacific Islander Coalition on HIV/AIDS; May 2000.**
This is a document written for the Asian and Pacific Islander Coalition on HIV/AIDS (APICHA) as part of the Ryan White CARE Act Title III HIV Primary Care Planning process. The document consists of a literature review exploring Asian and Pacific Islanders' relationships with HIV-related primary care services. The goals of this paper are to present an overview of knowledge levels of HIV/AIDS among A/PIs, barriers to HIV-related services, and A/PI access to primary care services.

81. **The Role of Culture in HIV/AIDS Health Care - A Practical Guide for Providers Serving Asian and Pacific Islander Americans: Asian and Pacific Islander Coalition on HIV/AIDS.**
This comprehensive manual presents providers with the information and skills needed to achieve the goal of providing culturally competent services to Asians and Pacific Islanders, particularly those living with HIV/AIDS. The providers targeted by this manual include: medical service providers, social workers, case managers, health educators, outreach workers, and administrative staff such as program managers and receptionists.

82. **Service Delivery Plan Workplan: Bedford Stuyvesant/Crown Heights HIV Care Network; 2005-06**. (82)
This document, the workplan for the Bedford Stuyvesant/Crown Heights Ryan White Title II HIV Health Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

83. **Service Delivery Plan Workplan: Staten Island HIV Care Network; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in Staten Island, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

84. **Service Delivery Plan Workplan: Bronx HIV Care Network; 2005-06.**
This document, the work plan for the Bronx Ryan White HIV Care Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

85. **Service Delivery Plan Workplan: East Harlem Network; 2005-06.**
This document provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

86. **Service Delivery Plan Workplan: East New York Brownsville HIV Care Network; 2005-06.**
This document, the workplan for the East New York Brownsville Ryan White Title II HIV Health Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

87. **Service Delivery Plan Workplan: Lower Hudson HIV Care Network; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in the Lower Hudson Region, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

88. **Service Delivery Plan Workplan: Mid-Hudson HIV Care Network; 2005-06.**
This document, the workplan for the Ryan White Title II HIV Health Network in the Mid-Hudson Region, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

89. **Service Delivery Plan Workplan for Broome, Chenango & Tioga Counties: Binghamton Tri-County HIV Care Network; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in Binghamton, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

90. **Service Delivery Plan Workplan: Ryan White Care Network of Northeastern New York; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in Northeastern New York, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

91. **Service Delivery Plan Workplan: Central New York HIV Care Network; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in Central New York, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

92. **Service Delivery Plan Workplan: Finger Lakes HSA; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Care Network in the Finger Lakes region, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

93. **Service Delivery Plan Workplan: AIDS Network of Western New York; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Care Network in Western New York, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

94. **Service Delivery Plan Workplan: Central Harlem HIV Care Network; 2005-06.**
This document, the work plan for the Central Harlem Ryan White HIV Care Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

95. **Service Delivery Plan Workplan: Nassau-Suffolk HIV Care Network; 2005-06.**
This document, the work plan for the Nassau-Suffolk HIV Care Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

96. **Service Delivery Plan Workplan: Queens HIV Care Network; 2005-06.**
This document, the work plan for the Ryan White Title II HIV Health Network in Queens, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

97. **Service Delivery Plan Workplan: Williamsburg, Greenpoint, Bushwick HIV Care Network; 2005-06.**
This document, the work plan for the Williamsburg, Greenpoint, Bushwick Ryan White Title II HIV Health Network, provides objectives relating to the Service Delivery Plan's key recommendations and prioritized Network needs.

98. **Service Delivery Plan: Staten Island HIV CARE Network; 2001.**
This document presents regional priorities for the Staten Island HIV Care Network, including the service prioritization process, the service priorities, and the Network Action Plan.

99. **Same as Document #70.**

100. **Service Delivery Plan Update: Williamsburg, Greenpoint, Bushwick HIV Care Network; 2001.**
The WGB HIV CARE Network 2001 Services Delivery Plan Update, updates the SDP originally completed in 1996. Its purpose is to update that plan, provide information on trends in the HIV epidemic, highlighting significant policy changes, and identifying current and unmet service needs.

101. **Service Delivery Plan: East New York/Brownsville HIV Care Network; 1999.**
This plan is an update to the 1996 Service Delivery Plan. Its purpose is to assist community based planning and needs assessment by providing up-to-date data to the Network and other interested providers and consumers.

102. **Finger Lakes Region Service Delivery Plan, Preliminary Draft: Rochester Area Task Force on AIDS, Inc.; April 19, 2005.**
This draft report summarizes relevant HIV/AIDS and related data for the Finger Lakes Region, service priorities determined through a multi-step process, special populations, barriers to care, unmet needs, and a summary of available services in the Region.

103. **Service Delivery Plan Update: Lower Hudson HIV Care Network; 2002.**
This document is an Update of the 1997-1998 Lower Hudson Region HIV CARE Network Service Delivery Plan. The Plan's purpose is to assist community planning and needs assessment by providing up-to-date data to the Network and other interested providers and consumers. It provides data from both published unpublished State and local sources on recent trends in the HIV epidemic and includes limited new data collected from surveys and focus groups of providers and consumers. This Update adds to, but does not supplant, the many critical service needs identified in the 1997-1998 Service Delivery Plan.

104. **Service Delivery Plan for Northeastern New York: Ryan White Care Network of Northeastern New York; January 2002.**
This document presents regional priorities for the Northeastern New York Ryan White HIV CARE Network, including the service prioritization process, the service priorities, and the Network Action Plan.

105. **Service Delivery Plan: Central Harlem HIV Care Network of the New York Urban League; October 30, 1998.**
This Service Delivery Plan is the result of an annual strategic planning process for community residents, community based organizations and the Central Harlem HIV Care Network. It outlines the impact of the HIV/AIDS epidemic on the neighborhoods of Central Harlem, the needs and priorities to combat the epidemic and the activities the community needs to pursue over the next three to five years.

106. **Towards a Comprehensive Plan for Syringe Exchange in New York City: Office of Special Populations, New York Academy of Medicine.**
This report represents the first Citywide comprehensive assessment of the need for and range of existing syringe exchange program (SEPs) in New York City and includes recommendations for how SEPs might be expanded and integrated into the overall planning and provision of HIV prevention and care services in NYC.

107. **Service Delivery Plan: East Harlem HIV Care Network; 1999.**
This report describes and documents the HIV/AIDS epidemic in East Harlem, services currently availability, resources needed to improve the overall level of services in the community and to fill the service gaps identified.

108. **Queens HIV/AIDS Service Delivery Plan: Queens Ryan White Title II HIV Care Network; 1999-2000.**
This document presents regional priorities for the Queens HIV Care Network, including the service prioritization process, the service priorities, and the Network Action Plan.

109. **Request for Applications (RFA) for HIV Services for Incarcerated Individuals, Parolees/Releasees, and Juvenile Detainees in New York State.**
This RFA, issued in October 2004, awards funds to support HIV/AIDS services and interventions in correctional settings. The RFA emphasizes programs and services in facilities operated by the NYS DOCS for HIV infected persons released from DOCS facilities, as well as programs developed to address the needs of county correctional facilities outside of New York City and juvenile justice facilities operated by the NYS Office of Children and Family Services.

110. **Regional Gaps Analysis Final Report: New York State Prevention Planning Group; 2004.**
This report details an assessment conducted of HIV prevention services and includes recommendations for addressing HIV prevention needs in the Bronx.

111. **Brooklyn Regional Gaps Analysis: EQC Group, Inc.; November 2004.**
The Regional Gaps Analysis HIV Prevention Planning Group report for Brooklyn provides detailed accounts of lessons learned about HIV prevention in the Region. The report identifies the top HIV interventions including recommendations for immediate as well as long-range improvements in HIV prevention.

112. **Manhattan Regional Gaps Analysis: ECQ Group, Inc.; December 2004.**
The Regional Gaps Analysis (RGA) is a systematic approach used to identify gaps between the needs of populations at risk of HIV infection and the availability of services for them within a specific geographic area.

113. **Queens Regional Gaps Analysis: EQC Group, Inc.; October 2004.**
The Regional Gaps Analysis HIV Prevention Planning Group report for Queens provides detailed accounts of lessons learned about HIV prevention in the Region. The report identifies the top HIV interventions including recommendations for immediate as well as long-range improvements in HIV prevention.

114. **Staten Island Regional Gaps Analysis Final Draft: EQC Group, Inc.**
This report provides detailed accounts of lessons learned about HIV prevention on Staten Island. The report identifies the top HIV interventions including recommendations for immediate as well as long-range improvements in HIV prevention.

115. **Regional Gaps Analysis Final Report: Ryan White Care Network of Northeastern New York; January 2002.**
This report details prevention needs and available resources related to HIV/AIDS in Northeastern New York.

116. **Comprehensive HIV Prevention Plan Update: New York State Prevention Planning Group; September 2003.**
This document is an update to the 1998 NYS Comprehensive HIV Prevention Plan, providing information on progress related to short-term objectives for the 2002-2003 Planning Cycle.

117. **New York EMA Comprehensive Strategic Plan for HIV/AIDS Services: NYC Office of the Mayor/AIDS Policy Coordination; September 2002.**
This document addresses health and human services for people with HIV disease in the New York EMA. It is intended for use in relation to planning, funding, delivering, receiving, or measuring the effectiveness of HIV services. The plan includes goals, objectives, and a monitoring and evaluation framework, as well as a brief description of service barriers and gaps, and strategies to address them.

118. **Same as Document #49**

119. **Assessment of the Housing Needs of Persons with HIV/AIDS: Upstate and Long Island Final Report; August 2004.**
This study examines current and future housing and housing-related resources and needs of New Yorkers living with HIV/AIDS in each region of Upstate New York and on Long Island. This Assessment gives policy makers and providers on the State level and in each region of Upstate New York and Long Island the tools needed to plan for the effective use of resources to meet the housing needs of people with HIV/AIDS.

120. **Needs Assessment for Ryan White Title IV Grant: Dominican Sisters Family Health Services; March 15, 2005.**
This Needs Assessment was submitted as part of the Dominican Sisters Family Health Services' (DSFHS) competing continuation application for a Ryan White Title IV grant for Coordinated HIV Services and Access to research for Children, Youth, Women and Families. DSFHS is a certified multi-service, home-based health and social service program that serves clients from the Mott Haven and Highbridge communities of the Bronx.

121. **Statewide AIDS Service Delivery Consortium Special Populations Committees barriers and recommendations for prevention and care services; 2004.**
These grids reflect the work of the six SASDC special populations committees, based on the LCOA chapters and prior years Service Delivery Plans. Each committee compiled a list of barriers and recommendations for each of the six populations.

122. **CHAIN Report 2003-2 - Geographical Distribution of Service Gaps Among NYC CHAIN Cohort: A Geomapping Analysis: David Abramson, Columbia University Mailman School of Public Health; April 21, 2004.**
This report is a follow-up to an earlier CHAIN report, A Geographic Display of the CHAIN Cohort's Service Utilization (Update #42, May 2001). It is intended to present a graphic display of service gaps in NYC's system of HIV care, as experienced by respondents in the CHAIN cohort.

123. **Tri-County CHAIN Report 2003-1- Service Gaps and Utilization in the continuum of Care: David Abramson, Columbia University Mailman School of Public Health; May 30, 2003.**
This report provides a comprehensive analysis of service gaps and utilization within the continuum of care for respondents in the Tri-County CHAIN cohort.

124. **CHAIN Report 2004-1 - Service Gaps and Utilization In the Continuum of Care in NYC: David Abramson, Columbia University Mailman School of Public Health; July 14, 2004.**
This report provides a comprehensive look at service gaps and utilization within the continuum of care for respondents in the newly recruited NYC CHAIN cohort.

125. **CHAIN Report 2004-2 - Strategic Plan Progress Indicators: New Cohort Update: David Abramson, Columbia University Mailman School of Public Health; May 19, 2004.**
This document is a follow-up to CHAIN Report 2003-1, which presented baseline data for performance measures. In this report, performance measures for respondents in the newly recruited cohort (NYC CHAIN Cohort II) is compared with the performance measures reported at baseline from the earlier cohort (NYC CHAIN Cohort I).

126. **CHAIN Report 2004-3 - Baseline Summary of NYC II Cohort: David Abramson, Columbia University Mailman School of Public Health; July 21, 2004, January 19, 2005.**
This report compares the new NYC cohort at baseline with three similar cohorts recruited previously. The comparison focuses on socio-demographics, economic resources, family and household characteristics, HIV diagnosis and early medical care, current health status, and risks. A brief needs assessment of the new cohort is also included.

127. **Creating Successful Programs for Immigrant Youth: ACT for Youth Upstate Center of Excellence; December 2004.**
This newsletter describes assets of immigrant youth and useful strategies for three kinds of program development: with youth themselves, their parents, and their schools.

128. **Public Health and Aging: HIV/AIDS and Older Adults-New York State, 1980-2002: JAIDS, 2003.**
This journal abstract presents trends in AIDS incidence and prevalence for persons diagnosed at age $\geq$ 50 years, and describes the characteristics of persons diagnosed with AIDS and with HIV at age $\geq$ 50 years in New York State.

129. **Medicaid: Issues in Restructuring Federal Financing: The Kaiser Commission on Medicaid and the Uninsured; January 2005.**
This report discusses the implications of cuts in federal funding and fundamental changes in Medicaid at a time when there is no clear alternative to the program and the role it plays in the healthcare system.

130. **Advancing HIV Prevention: New Strategies for a Changing Epidemic-United States, 2003: Morbidity and Mortality Weekly Report; April 18, 2003.**
This journal article describes a new HIV prevention initiative launched in 2003 by the Centers for Disease Control and Prevention (CDC) in partnership with other U.S. Department of Health and Human Services agencies, other government and non-government agencies. This initiative recognizes the need for new strategies for combating the epidemic, and realizes the recent approval of a simple rapid HIV test in the U.S. creates an opportunity to overcome some of the traditional barriers to early diagnosis and treatment of infected persons.

131. **Interventions to Prevent HIV-Related Stigma and Discrimination: Findings and Recommendations for Public Health Practice: Journal of Public Health Management Practice; 2002.**
Since its emergence, the HIV epidemic has been accompanied by HIV-related stigma and discrimination, which have profound impacts on prevention policy and program development. This journal article summarizes the need for interventions, discusses practical examples from actual experience, and presents the synergy of multiple interventions in a logic model.

132. **Incorporating HIV Prevention into the Medical Care of Persons Living with HIV: Morbidity and Mortality Weekly Report; July 18, 2003.**
Medical care providers can substantially affect HIV transmission by screening their HIV-infected patients for risk behaviors, communicating prevention messages, referring patients for services such as substance abuse treatment, facilitating counseling, testing and partner notification, and identifying and treating other sexually transmitted diseases. This report discusses recommendations developed by CDC, HRSA, NIH and the HIV Medicine Association of the Infectious Disease Society of America to help incorporate HIV prevention into the medical care of HIV-infected persons.

133. **Report of the New York City Commission on HIV/AIDS -- Recommendations to Make NYC a National and Global Model for HIV/AIDS Prevention, Treatment and Care; Draft May 29, 2005.**
This draft, released for public comment, contains recommendations relating to improving prevention and treatment outcomes, and expanding voluntary testing and linkage to care.

134. **Native Americans and HIV/AIDS: Key Issues and Recommendations for Health Departments: National Alliance of State and Territorial AIDS Directors; November 2004.**
This report was prepared by the National Association of State and Territorial AIDS Directors (NASTAD) and includes key issues and health related recommendations concerning Native American communities. It is intended to serve as a resource for health departments seeking to work with Native American communities to address existing health disparities, particularly those related to HIV/AIDS.

135. **Native American Leadership Commission 2004-05 NALCHA Action Plan: American Indian Community House.**
This plan, updated annually by the American Indian Community House CDI/ALC Steering Committee, reflects current programmatic goals and shapes the agency's annual AIDS/HIV workplans. It is based on Native American community input from National AIDS Leadership Commission membership.

136. **2001-2002 Native American Community Needs and Priorities: Akwesasne, Buffalo, Syracuse: American Indian Community House.**
This document summarizes top priorities identified through the Native American Leadership Commission on HIV and AIDS, Regional Community Meetings at Akwesasne, Buffalo and Syracuse in November 2001.

137. **Regional Gaps Analysis; Discussion Group on HIV Prevention: American Indian Community Indian House; September 22, 2003.**
This document summarizes HIV/AIDS issues and needs for Native Americans in Manhattan determined through a focus group of ten Native Americans of PWAs, providers and community members.

138. **Service Access, Stigma & Advocacy: Women's HIV Collaborative of New York**
This report summarizes the major themes that emerged from seven focus groups conducted with women who live with HIV or AIDS; at least one in each borough of New York City. The focus groups explored women's experiences with the system of services designed to help them as well as the ways in which HIV related stigma might impact their access to quality services. The report also presents findings from a survey completed by participants.

139. **HIV/AIDS Prevention and Care Services and Services for the Aging: Bridging the Gap Between Service Systems to Assist Older People: Journal of Acquired Immune Deficiency Syndromes; June 1, 2003.**
This published journal article discusses the importance of the service systems for patients with or at risk for HIV infection/AIDS and for the aging to work together to address the needs of older adults who engage in HIV risk behaviors or who are HIV infected. Health and human service organizations miss opportunities for service integration in prevention, care and supportive services. The authors illustrate critical issues and offer strategies to address these missed opportunities.

140. **DHHS HIV/AIDS Fact Sheet on Transgender Persons: United States Department of Health and Human Services.**
This fact sheet presents information and statistics on HIV infection among transgender persons.

141. **About the AIDS Institute 2004: New York State Department of Health AIDS Institute; 2004.**
This publication presents an overview of the organizational structure and various initiatives within the AIDS Institute, and also includes the Institute's mission, vision and guiding principles, summary epidemiological HIV/AIDS data, and a funding matrix by program.

142. **AIDS Institute Directory of Resources and Services: New York State Department of Health AIDS Institute; June 2001.**
This resource directory, intended for use as a referral tool for providers and individuals, lists HIV/AIDS services funded by the New York State Department of Health by region and borough.

143. **Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care: AIDS 2005; Vol. 19 No. 4.**
This journal article presents the findings of an Antiretroviral Treatment Access Study (ARTAS) which assessed a case management intervention to improve linkage to care for persons recently receiving an HIV diagnosis.

144. **Development and implementation of an HIV/AIDS case management outcomes assessment programme: AIDS Care 2002; Vol. 14 No. 6.** (144)
This article focuses on a public/private outcomes assessment partnership sponsored by the New York State Department of Health Aids Institute Case Management Section, and developed in conjunction with a team of Community Follow-Up Program managers from across the state.

145. **Outcomes of HIV/AIDS case management in New York: AIDS Care 2001; Vol. 13, No. 4.**
This paper presents the findings of a study that examined HIV case management outcomes in New York State.

146. **An Evaluation of AIDS Institute HIV Case Management Services in Upstate New York and Long Island: Sue Lehrman, Ph.D., M.P.H., Graduate Management Institute, Union College; August 2000.**
In April of 1997, the New York State Department of Health AIDS Institute contracted with the Graduate Medical Institute at Union College to evaluate case management services for persons living with HIV/AIDS in Upstate New York and on Long Island. This report presents the findings of this project.

147. **An Evaluation of AIDS Institute HIV Case Management Services in New York City: Sue Lehrman, Ph.D., M.P.H., Graduate Management Institute, Union College, and Daniel Gentry, Ph.D., M.H.A., Saint Louis University School of Public Health; January 1998.**
In April of 1995, the New York State Department of Health AIDS Institute contracted with the Graduate Medical Institute at Union College to evaluate case management services for persons living with HIV/AIDS in New York City. This report presents the findings of this project.

148. **Correlation of a Brief Perceived Stress Measure with Nonadherence to Antiretroviral Therapy Over Time: Journal of Acquired Immune Deficiency Syndrome; Vol. 38, No. 5, April 15, 2005.**
This article explores the relationship between a revised version of the Perceived Stress Scale and nonadherence to antiretroviral therapy.

149. **HIV-related knowledge and adherence to HAART: AIDS Care 2003; Vol. 15, No. 5.**
In this study, based on data from the New York State Department of Health AIDS Institute Treatment Adherence Demonstration Program, the association between HIV-related knowledge and adherence is examined.

150. **Stability of Adherence to Highly Active Antiretroviral Therapy Over Time Among Clients Enrolled in the Treatment Adherence Demonstration Project: Journal of Acquired Immune Deficiency Syndromes; Vol. 33, No. 4, August 1, 2003.**
This paper investigates the stability of adherence over time among HIV-infected individuals attending adherence support programs in New York State.

151. **Tri-County HIV/AIDS Resource Directory of Service Providers: Westchester County Department of Health; Winter 2003-2004.**
This directory contains detailed information on agencies that provide HIV/AIDS-related services in Westchester, Rockland and Putnam Counties.

152. **New York City Ryan White Title I Service Directory: New York City Department of Health and Mental Hygiene; August 2002-Updated July 2005.**
This service directory includes an alphabetical list of agencies with Ryan White Title I funded services, including a brief program description, service sites and maps to show the location of services, and contact information.

153. **Resource Guide for Site Visit Monitoring: NYS Department of Health AIDS Institute; October 2003, revised November 2004.**
To assist AIDS Institute contract managers, this document focuses on the process of planning and conducting site visits and following up on the results.

154. **New York State HIV/AIDS Surveillance Semi-Annual Report for Cases Diagnosed Through June 2004: New York State Department of Health Bureau of HIV/AIDS Epidemiology; November 2005.**
This reports presents data generated from information collected and maintained by the New York State Department of Health Bureau of HIV/AIDS Epidemiology and the New York City Department of Health and Mental Hygiene HIV Surveillance and Epidemiology Unit.

155. **HIV/AIDS Resource Guide, Nassau and Suffolk Counties: United Way of Long Island; 2004.**
This guide contains a listing of service providers on Long Island; local and national hotline, helpline and online information; and general information about confidentiality, insurance, prescription information, family law and immigration.

156. **Dutchess County Resource Listing: Dutchess County Department of Health; August 2005.**
This documents lists agencies that provide HIV/AIDS services in Dutchess County.

157. **Young Men's Study Presentation to AIDS Institute, Phases I & II: Lucia Torian, Beryl Koblin and Vincent Guilin; February 16, 2001.**
This presentation summarizes findings of two phases of the New York City arm of the national Young Men's Study. Very high rates of HIV seroprevalence were found among young men of color who have sex with men, recruited through targeted peer outreach.

158. **New York City HIV/AIDS Surveillance Statistics 2003 (March 2005) and HIV/AIDS Surveillance and Epidemiology 2005 Second Quarter Report (April 2005): New York City Department of Health and Mental Hygiene HIV Epidemiology Program.**
These statistical reports provide AIDS and HIV data and trends for the time periods indicated, interpretive highlights and breakout data by borough and United Hospital Fund (UHF) neighborhood.

159. **Resource Listing - - NYS agencies funded under Ryan White Titles III and IV and Part F: United States Department of Health and Human Services; July 2005.**
This listing of Ryan White funded agencies was compiled from information available on the United States Department of Health and Human Services website as of July 2005.

160. **Regional Gaps Analysis; Finger Lakes Ryan White Care Network; April 2004.**
This report details prevention needs and available resources related to HIV/AIDS in the Finger Lakes Region.

161. **Service Delivery Plan for Northeastern New York: Ryan White Care Network of Northeastern New York; 2005.**
This document presents regional priorities for the Northeastern New York Ryan White HIV CARE Network, including the service prioritization process, the service priorities, and the Network Action Plan.

162. **Buffalo (Western) Regional Service Delivery Plan Update: AIDS Network of Western New York; 2004-2005.**
This report is the 2004-05 update of the Service Delivery Plan of the Western New York HIV Care Network. It provides data from both published and unpublished state and local sources on recent trends in the HIV epidemic and includes limited new data collected from surveys and focus groups involving providers and consumers. This report includes the results of epidemiological analysis and data generated from surveys, focus groups and community forums, which led to the identification of a number of significant issues**.**

163. **HIV Prevalence, Risk Behaviors, Health Care Use, and Mental Health Status of Transgender Persons: Implications for Public Health Intervention: American Journal of Public Health, Vol. 91, No. 6; June 2001.**
This journal article summarizes the findings of a San Francisco study describing HIV prevalence, risk behaviors, health care use, and mental health status of male-to-female and female-to-male transgender persons and determined factors associated with HIV.

164. **Transgendered People, HIV and Access to Care Course Syllabus: NYS Department of Health AIDS Institute.**
This document is the course syllabus for training sponsored by the New York State Department of Health AIDS Institute. The goal of this training is to examine specific health care and HIV prevention and treatment needs of transgendered people and to build skills for human service providers to be able to work more effectively with members of this community.

2006 Statewide Coordinated Statement of Need
Source Documents by Geographic Area

Statewide

Stability of Adherence to Highly Active Antiretroviral Therapy Over Time Among Clients Enrolled in the Treatment Adherence Demonstration Project: Journal of Acquired Immune Deficiency Syndromes; 2003. (10)

HIV-related Knowledge and Adherence to HAART: AIDS Care; October 2003. (11)

Offender Re-entry – Establishing Public Benefits for Eligible Offenders; January 2004. (12)

Interagency Offender Re-Entry Task Force Interim Report: New York State Division of Criminal Justice Services; December 15, 2003. (13)

Request for Applications (RFA) for HIV Primary Care Models for Treatment Adherence to Combination Antiretroviral Therapy: NYS Department of Health AIDS Institute; July 2002. (14)

Request for Applications for Food and Nutrition Services for People Living with HIV/AIDS: New York State Department of Health AIDS Institute; April 2001. (35)

Request for Applications (RFA) for Project WAVE, New York: New York State Department of Health AIDS Institute; January 2005. (37)

Report on Syringe Access in New York State: New York State AIDS Advisory Council; January 2005. (38)

Report and Recommendations for the New York State FY 2005-06 Budget: New York State AIDS Advisory Council. (39)

Report on HIV/AIDS Services in New York State Correctional Facilities: New York State AIDS Advisory Council; February 1999. (40)

Women in Peril – HIV & AIDS: The Rising Tool on Women of Color: New York State AIDS Advisory Council; September 14, 2005. (41)

Communities at Risk: HIV/AIDS in Communities of Color: New York State AIDS Advisory Council; Winter 2000/2001. (42)

Needs Assessment Tools and Final Report: PWHA Leadership Training Institute. (43)

Key Findings from Community Forums conducted by the New York State Department of Health AIDS Institute regarding HIV Prevention and Health Care for Women, Children and Young People; November 2000. (56)

Request for Applications for HIV Prevention and Care Services for Women, Children, Families and Young People: New York State Department of Health AIDS Institute; December 2001. (57)

Request for Applications for Supportive and Legal Services for Families in Transition: New York State Department of Health AIDS Institute; July 2002. (60)

Clinical Management of HIV Infection – Quality of Care Performance in New York State: New York State Department of Health AIDS Institute; 1999-2001. (63)

The HIV Quality of Care Program: New York State Department of Health AIDS Institute; June 2004. (64)

A Consumer's Guide to Quality of HIV Care in New York State: New York State Department of Health AIDS Institute; September 2003. (65)

Request for Applications (RFA) for HIV Services for Incarcerated Individuals, Parolees/Releasees, and Juvenile Detainees in New York State. (109)

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2004 Canarsie/Flatlands/Starrett City Profile: Brooklyn AIDS Task Force; July 2004. (19)

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Flatbush Profile: Crown Heights, East Flatbush, Lefferts Garden, Midwood, Prospect: Brooklyn AIDS Task Force; July 2004. (22)

2004 Greenpoint Profile: Brooklyn AIDS Task Force; July 2004. (23)

2004 Northwest Brooklyn Profile: Brooklyn Heights, Carroll Gardens, Clinton Hill, Downtown Brooklyn, Fort Green, Park Slope & Red Hook: Brooklyn AIDS Task Force; July 2004. (24)

2004 Southern Brooklyn Profile: Coney Island, Brighton Beach, Gravesend, Sheepshead Bay: Brooklyn AIDS Task Force; July 2004. (25)

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2004 Sunset Park Profile: Brooklyn AIDS Task Force; July 2004. (27)

2004 Williamsburg/Bushwick Profile: Brooklyn AIDS Task Force; July 2004. (28)

Staten Island HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; 2004. (29)

2003 Central Harlem/Morningside Heights HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; December 2002. (30)

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2003 Lower Manhattan HIV/AIDS Fact Sheet: Brooklyn AIDS Task Force; December 2002. (32)

2003 Washington Heights/Inwood HIV/AIDS Profile: Brooklyn AIDS Task Force; December 2002. (33)

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Service Delivery Plan Workplan: Bedford Stuyvesant/Crown Heights HIV Care Network; 2005-06. (82)

Service Delivery Plan Workplan: Staten Island HIV Care Network; 2005-06. (83)

Service Delivery Plan Workplan: Bronx HIV Care Network; 2005-06. (84)

Service Delivery Plan Workplan: East Harlem Network; 2005-06. (85)

Service Delivery Plan Workplan: East New York Brownsville HIV Care Network; 2005-06. (86)

Service Delivery Plan Workplan: Central Harlem HIV Care Network; 2005-06. (94)

Service Delivery Plan Workplan: Queens HIV Care Network; 2005-06. (96)

Service Delivery Plan Workplan: Williamsburg, Greenpoint, Bushwick HIV Care Network; 2005-06. (97)

Staten Island Service Delivery Plan: Staten Island HIV CARE Network, 2001. (98)

Service Delivery Plan Update: Williamsburg, Greenpoint, Bushwick HIV Care Network; 2001. (100)

Service Delivery Plan: East New York/Brownsville HIV Care Network; 1999. (101)

Service Delivery Plan: Central Harlem HIV Care Network of the New York Urban League; October 30, 1998. (105)

Towards a Comprehensive Plan for Syringe Exchange in New York City: Office of Special Populations, New York Academy of Medicine. (106)

Service Delivery Plan: East Harlem HIV Care Network; 1999. (107)

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CHAIN Report 2004-3 – Baseline Summary of NYC II Cohort: David Abramson, Columbia University Mailman School of Public Health; July 21, 2004, January 19, 2005. (126)

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Needs Assessment and Workplan for the Ryan White Title III Program: Hudson Headwaters Health Network; January 2005. (3)

Service Delivery Plan Workplan: Ryan White HIV Care Network of Northeastern New York; 2005-06. (90)

Service Delivery Plan for Northeastern New York: Ryan White HIV Care Network of Northeastern New York; January 2002. (104)

Regional Gaps Analysis Final Report: Ryan White HIV Care Network of Northeastern New York; January 2002. (115)

Service Delivery Plan for Northeastern New York: Ryan White Care Network of Northeastern New York; 2005. (161)

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Regional Service Plan: Binghamton Tri-County HIV Care Network; 2002, Updated September 2004. (51)

Regional Gaps Analysis Final Report: Binghamton Tri-County HIV Care Network; September 2003. (52)

HIV/AIDS Facts: Binghamton Tri-County HIV Care Network; December 29, 2004. (53)

Service Delivery Plan Workplan for Broome, Chenango & Tioga Counties: Binghamton Tri-County Ryan White Care Network; 2005-06. (89)

Buffalo (Western) Region

Service Delivery Plan: AIDS Network of Western New York; 2003. (1)

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Service Delivery Plan Workplan: AIDS Network of Western New York; 2005-06. (93)

Buffalo (Western) Regional Service Delivery Plan Update: AIDS Network of Western New York; 2004-2005. (162)

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Tri-County HIV/AIDS Resource Directory of Service Providers: Westchester County Department of Health; Winter 2003-2004. (151)

Mid-Hudson Region

Service Delivery Plan: Mid-Hudson HIV Care Network; 2002. (46)

Regional Gaps Analysis: Mid-Hudson HIV Care Network; 2003. (47)

HIV/AIDS Profile: AIDS Related Community Services; December 31, 2001. (48)

Service Delivery Plan Workplan: Mid-Hudson HIV Care Network; 2005-06. (88)

Dutchess County Resource Listing: Dutchess County Department of Health; August 2005. (156)

Nassau/Suffolk Region

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Barriers to HIV Care and Supportive Services Questionnaire Results: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; May 2004. (69)

Comprehensive Service Plan for HIV/AIDS in Nassau and Suffolk Counties: Nassau-Suffolk HIV Health Services Planning Council; October 2002. (70/99)

Federal Position Paper: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; 2004. (71)

State Position Paper: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; 2004. (72)

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Long Island HIV/AIDS 2001 Survey Results: Nassau-Suffolk HIV Health Services Planning Council; June 13, 2001. (74)

Long Island HIV/AIDS 2003 Consumer Survey Results: Nassau-Suffolk HIV Health Services Planning Council; August 13, 2003. (75)

Nassau-Suffolk Care Network Regional Gaps Analysis Final Report: Nassau-Suffolk HIV Care Network. (76)

HIV Care Network Regional Gaps Analysis: United Way of Long Island, Nassau-Suffolk Policy Advisory Committee, Division of Planning and Grants Management; July 13, 2003. (77)

Service Delivery Plan Workplan: Nassau-Suffolk HIV Care Network; 2005-06. (95)

HIV/AIDS Resource Guide, Nassau and Suffolk Counties: United Way of Long Island; 2004. (155)

Rochester (Finger Lakes) Region

Service Delivery Plan Workplan: Finger Lakes HSA. (92)

Finger Lakes Regional Service Delivery Plan, Preliminary Draft: Rochester Area Task Force on AIDS, Inc.; April 19, 2005. (102)

Regional Gaps Analysis; Finger Lakes Ryan White Care Network; April 2004. (160)

Syracuse Region

Regional Gaps Analysis Final Report: Central New York HIV Care Network; 2004. (58)

Service Delivery Plan: Central New York HIV Care Network; 2002. (59)

Service Delivery Plan Workplan: Central New York HIV Care Network; 2005-06. (91)

Other Documents

Assessment of the Housing Needs of Persons with HIV/AIDS: Upstate and Long Island Final Report; August 2004. (119)

An Evaluation of AIDS Institute HIV Case Management Services in Upstate New York and Long Island: Sue Lehrman, Ph.D., M.P.H., Graduate Management Institute, Union College; August 2000. (146)

Summary of Community Forum Participants and Written Comments

ROCHESTER
September 26, 2005

This forum focused on the Rochester (Finger Lakes) and Buffalo (Western) Ryan White Regions. In addition to presenters and AIDS Institute (AI) staff, 26 participants attended. Eight participants identified as Persons Living with HIV or AIDS. The following agencies were represented:

Action for a Better Community
AIDS Community Health Center/Rochester Area Task Force on AIDS
AIDS Network of Western New York
AIDS Rochester
American Red Cross/Buffalo Chapter
Baden Street Settlement
Catholic Charities Community Services
Finger Lakes Health Systems Agency
Genesee County AIDS Task Force/AIDS Network
HIV Mental Health Clinic/Strong Memorial Hospital
Huther-Doyle Memorial Institute
Liberty Research Group
MOCHA Project, Inc.
Rural Opportunities, Inc.
Buffalo Women's and Children's Hospital

SYRACUSE
September 27, 2005

This forum focused on the Syracuse and Binghamton Tri-County Ryan White Regions. In addition to presenters and AI staff, 15 participants attended. One participant identified as a Person Living with HIV or AIDS. The following agencies were represented:

AIDS Community Resources, Inc.
American Indian Community House
Broome County Health Department/Binghamton HIV CARE Network
Center for Community Alternatives
Central New York CARE Network
Central New York Health Systems Agency
Liberty Resources
Pediatric Designated AIDS Center/Upstate Medical University

Southern Tier AIDS Program
SUNY Upstate Medical University
SUNY Upstate Medical University – Designated AIDS Center
Syracuse University Center for Health & Behavior

BRONX
October 5, 2005

This forum focused on the five boroughs of New York City. In addition to presenters and AI staff, 19 participants attended. Three participants identified as Persons Living with HIV or AIDS. The following agencies were represented:

Health People
CitiWide Harm Reduction
Community Health Care Network
The Momentum Project
NYC Department of Corrections
Bronx Lebanon Hospital Center
Elmhurst Hospital Center
Palladia, Inc.
Argus Community Inc./Access II Program
Partnership for Family Health; Northern Manhattan HIV Consortium
The Osborne Association, Inc.
St. Barnabas Hospital
Bronx HIV CARE Network
Woodhull Hospital/RW-EIC Program
Citizen's Advice Bureau
Albert Einstein College of Medicine
Jacobi Medical Center

POUGHKEEPSIE
October 7, 2005

This forum focused on three regions: Mid-Hudson, Lower Hudson and Albany (Northeastern) Ryan White Regions. In addition to presenters and AI staff, 27 participants attended. Three participants identified as Persons Living with HIV or AIDS. The following agencies were represented:

AIDS Related Community Services (ARCS)
Dutchess Community College
Dutchess County Department of Health
Greyston Foundation, Inc.
HIV CARE Network of Northeastern New York
Hudson River Health Care

Legal Aid Society of NENY
Legal Aid Society of Rockland County
Legal Services of the Hudson Valley
Lower Hudson Region HIV CARE Network
Mid-Hudson Family Health Institute
NetWorth/Positive Action
NYS Department of Health Regional Office
Open Door Family Medical Center
PLWH/A Co-Chair
Rural Opportunities, Inc.
Mid-Hudson Region HIV CARE Network
Stephen Saunders Residence
Westchester County Department of Health
Whitney M. Young Jr. Health Center

DEER PARK, LONG ISLAND
October 11, 2005

This forum focused on the Nassau/Suffolk Ryan White Region. In addition to presenters and AI staff, 26 participants attended. Six participants identified as Persons Living with HIV or AIDS. The following agencies were represented:

Suffolk County Department of Health Services
Thursday's Child, Inc.
Nassau/Suffolk Title I Planning Council
Schrader Children's Hospital/Northshore – Long Island Health Systems Agency
Northshore University Hospital
Nassau County Department of Social Services
Options for Community Living
Hispanic Counseling Center, Inc.
FEGS – Positive Space
Nassau County Department of Drug and Alcohol Addiction
Nassau University Medical Center, East Meadow
SPARC (Title IV-funded program based outside of Pediatric AIDS Center at Stony Brook)
EOC of Nassau County
EOC of Suffolk County
North Shore Long Island Jewish Health Systems
EAC Inc., Food and Nutrition Program
Long Island Association for AIDS Care (LIACC)
Five Town Community Center, Inc.
New York Hospital Queens – Dental and Oral Medicine
Nassau/Suffolk HIV CARE Network

BROOKLYN
October 14, 2005

This forum focused on the five boroughs of New York City. In addition to presenters and AI staff, 30 participants attended. Twelve (12) participants identified as Persons Living HIV or AIDS. The following agencies were represented:

Alliance for Family Education Care and Treatment
Bedford Stuyvesant/Crown Heights HIV CARE Network
Brownsville/East New York HIV CARE Network
Callen Lorde Community Health Center
Church Avenue Merchants Block Association
Cicatelli Associates, Inc.
Coalition for Hispanic Family Services
Crown Heights Service Center, Inc.
Hispanic Projecto Family
HIV Center, SUNY Downstate Medical Center
Life Force: Women Fighting AIDS, Inc.
Miracle Makers/ENY CARE Network
MMI, Scatter Site Housing Program
Momentum Project
Outreach Project and St. John's Bread and Life Soup Kitchen
Project Hospitality
Staten Island University Hospital
The Brooklyn Hospital Path Center
Tri-Borough Home Care
Turning Point
Vida Care
Williamsburg/Greenpoint/Bushwick HIV CARE Network

MANHATTAN
October 14, 2005

This forum focused on the five boroughs of New York City. In addition to presenters and AI staff, 28 participants attended. Six participants identified as Persons Living with HIV or AIDS. The following agencies were represented:

Alianza Dominicana, Inc.
Betances Health Center
Body Positive
Cabrini Medical Center
Care for the Homeless
Cicatelli Associates, Inc.
Columbia University Dental School
Community Health Action of Staten Island

Community Healthcare Network/Caribbean House
Greenwich House
Harlem Hospital
Health First
Momentum Project
National Black Leadership Commission
New York Harm Reduction Education
Queens HIV CARE Network
Queens Hospital Center
Safe Space
Staten Island HIV CARE Network
SUNY Downstate Medical Center
The Lesbian, Gay, Bisexual and Transgender Community Center
Volunteers of America – Greater New York, Inc.
Woodhull Hospital

WRITTEN COMMENTS

Written comments were received from the following agencies:

AIDS Network of Western New York
Rochester Area Task Force on AIDS, Inc.
American Indian Community House
NETWORTH/Positive Action, Inc., Pleasant Valley, NY
Legal Services of the Hudson Valley
Westchester County Department of Health
Northeastern NY HIV CARE Network – Council of Community Services of NYS, Inc.
Suffolk Project for AIDS Resource Coordination (SPARC)
Health People, Bronx
Staten Island HIV CARE Network
Community Health Action of Staten Island
The Brooklyn Hospital Center
AIDS Community Research Initiative of America
Project Hospitality, Staten Island

NEW YORK STATE AIDS MILESTONES 1981-1989

1981

PCP in gay men
Rare cancer in gay men-NYC
First prison inmate with AIDS-NYS
First PCP in IDUs
First woman with AIDS-U.S..
First pediatric AIDS case-U.S..
CDC declares the new disease an epidemic

1982

GRID
GMHC established
First Haitian refugee with AIDS
First hemophiliac with AIDS
GRID renamed to AIDS
KS/AIDS Foundation founded
First safe sex pamphlet for gay men

1983

France isolates virus-LAV
Fears of casual transmission to children
NAPWA adopts The Denver Principles
First U.S. Conference on AIDS
NYSDOH AIDS Institute established
NYSDOH AIDS Advisory Council established

1984

U.S. isolates the retrovirus: HTLV-111
HHS Secretary predicts a brief epidemic and a cure by 1990
CSPs established (NYS)

1985

HIV antibody test licensed
All infants testing HIV+ believed to be infected
People with AIDS Coalition (NY) founded
Blood banks begin screening for HIV
1st International AIDS Conference-Atlanta
Rock Hudson dies
Ryan White barred from school
Designated AIDS Centers started (NYS)
Anonymous HIV C&T started (NYS)

1986

International Committee names HIV
WHO recommends needle exchange
AZT clinical trials
Surgeon General issues major report on AIDS
Condoms shown to prevent sexual transmission of HIV
AIDS Intervention Management System implemented (NYS)
HIV Clinical Guidelines Program (NYS)

1987

ACTG formed
HIV antibody test measures mother's antibody, not infant's
FDA approves AZT
CDC revises AIDS definition
ACT UP formed
ADAP established (NYS)
First national display of AIDS Memorial Quilt
AIDS leading cause of death for women in NYC
Maternal/Pediatric Program started (NYS)
IDU cases surpass gay men/MSM cases

1988

Women named fastest growing group
FDA speeds up approval process for experimental drugs
First World AIDS Day
1st Presidential Commission Report on AIDS
Chronic Care Initiatives started (NYS)
Supported Housing Programs (NYS)
HIV/AIDS Materials Initiative (NYS)

1989

Underground clinical trials of Compound Q
FDA approves ganciclovir for CMV
FDA approves Aerosolized Pentamadine
ACT UP demands release of ddI (Videx)
ACT UP introduces concept of parallel track drug development
CDC Guidelines for PCP prophylaxis
Adolescent AIDS cases increase
HIV Primary Care Programs: CHC & SA treatment settings begins (NYS)
Anonymous HIV C&T & Educ in Prisons (NYS)
HIV Clinical Educ Program begins (NYS)
HIV Clinical Scholars Program begins (NYS)

NEW YORK STATE AIDS MILESTONES 1990-1999

1990

Ryan White dies
Ryan White CARE Act passed
CDC calls for end to U.S. restriction on HIV-positive immigrants
Americans with Disabilities Act passed
1st National Women & HIV Conference
AZT Approved for Asymptomatics
Obstetrical Initiative started (NYS)
Medical Protocols 1st Edition (NYS)
Community Follow-Up Program (NYS)
Legal Services Initiative (NYS)
Anonymous HIV C&T in NYS correctional facilities begins
Nutrition Programs (NYS)
Case Management Services (NYS)

1991

FDA approves ddI (Videx)
Medicaid Managed Care Legislation
Dr. Acer convicted of infecting patient
Magic Johnson announces HIV+ status
Red ribbon becomes international symbol of AIDS awareness
Informed Health Care Worker Policy (NYS)
Ryan White Title II HIV CARE Networks established (NYS)
Pediatric/Adolescent Care Guidelines published (NYS)
Enhanced Fees for Physicians (NYS)
Transportation services (NYS)

1992

FDA approves use of ddC(Hivid)
FDA approves use of ddC(Hivid) with AZT
Democratic and Republican Conventions have HIV-positive speakers
Presidential campaign promises full funding of Ryan White CARE Act and lifting of HIV immigration ban
By 2000, HIV will leave more children motherless than all other causes combined
ADAP Plus started (NYS)
Medical Protocols 2nd Edition (NYS)
Multiple Service Agencies funded (NYS)
Syringe Exchange Regulations filed & programs approved (NYS)
HIV services for HIV + women & families (NYS)
HIV Quality of Care programs (NYS)

1993

Social Security Administration changes disability requirements
CDC revises AIDS definition
Concorde study shows AZT monotherapy not effective in averting AIDS
First AIDS Czar appointed
CDC, NIH and FDA declare condoms highly effective in preventing HIV
FDA approves Clarithromycin for MAC
Nicolas Rango and Michael Callen die
Newborn Testing Bill introduced (NYS)
Adolescent Initiative implemented (NYS)
Subcommittee on Newborn Testing formed (NYS)

1994

AIDS leading cause of death for Americans ages 25-44
ACTG 076 showed AZT reduced perinatal transmission by 2/3rds
Johnson & Johnson design home test kit
FDA approves D4T (Zerit)
Patsy Fleming appointed AIDS Czar
Statewide AIDS Service Delivery Consortium formed (NYS)
Prevention Planning Group formed (NYS)
Prevention Services for Adolescents & Young Adults (NYS)

1995

Delta Trial shows AZT with ddI or ddC improved treatment
Dual Combination Therapy becomes standard
FDA approves protease inhibitor Saquinavir
FDA approves 3TC in combination with AZT
FDA approves Saquinavir with nucleoside analogue antiretrovirals
1st White House Conference on AIDS
CDC issues Prenatal Counseling & Testing Guidelines
Permanency Planning Initiative started (NYS)
Pediatric PCR Testing Service begins (NYS)

1996

FDA approves two protease inhibitors
Triple Combination Therapy introduced
Viral Load Testing begins
Congress approves higher spending on AIDS programs
RW CARE Act reauthorized
Significant decline in the number of reported AIDS cases
Cover stories hailing AIDS breakthrough/ end of epidemic
African-Americans urge aggressive campaign against AIDS
HCRA appropriation for ADAP
Families in Crisis Report published (NYS)
Newborn Testing Legislation (NYS)
Prenatal Counseling & Recommended Testing (NYS)
Anonymous C&T in county correctional facilities begins (NYS)
Anonymous to confidential test conversion option implemented in NYS DOH ACT (NYS)
Leadership Training Institute founded (NYS)

1997

FDA approves 1st NNRTI-Delavirdine
FDA warns of protease inhibitor side effects
Decline in HIV perinatal transmission in U.S.
Importance of treatment adherence
New drug combinations extend life for PWAs
Decline in hospitalizations & deaths in U.S.
Chataugua County incident (NYS)
FDA approves Viracept for use with children
FDA approves Combivir
NIH/PHS Antiretroviral Treatment Guidelines published
NYS Interagency Task Force mandated
Waiver approved for HIV Special Needs Managed Care Plans (NYS)
NYS DOH HIV CTP introduced OraSure Testing into Services
HIVQUAL Project (NYS)

1998

FDA approves Sustiva and Ziagen
AIDSvax starts 1st human trial of AIDS vaccine in U.S.
CDC finds nearly 1/2 of HIV+ adolescent males infected through sex with adult males
African-American women 3 times more likely to die of AIDS than White or Hispanic women
First case of a resistant strain of HIV
Congress gives $156 million to fight AIDS in Black and Hispanic communities
Research indicates that needle exchange programs are effective
Ban continues on using federal funds for needle exchange programs
Treatment Adherence Initiative (NYS)

1999

FDA approves Agenerase (PI) for children
First CDC National HIV Prevention Conference
Vaccine development suffers setback
World AIDS Day Campaign focuses on people under 25
CDC/HRSA funded Criminal Justice Demonstration Project (NYS)
Expedited testing in delivery settings (NYS)

NEW YORK STATE AIDS MILESTONES 2000-2005

2000

FDA approves Trizivir
Resistance testing standard of care
Emergence of resistant viral strains
Increase in treatment failure
Finding that nonoxynol 9 may increase transmission of HIV
CDC reports: AIDS diagnosed more in black & Hispanic gay men than white gay men
AIDS declared a threat to national security
IOM reports: US does not have effective plan to combat AIDS in US
Ryan White CARE Act reauthorized
ADAP Plus Insurance Continuation (APIC) Program begins (NYS)
HIV Names Reporting & Partner Notification Implemented (NYS)
Families in Transition Act (NYS)
Expanded Syringe Access legislation enacted (NYS)
Community Action for Prenatal Care (NYS)
Prenatal care provider training starts (NYS)
Mental Heath Initiative (NYS)

2001

FDA licenses 1st nucleic Acid Test to screen for HIV and HCV
FDA approves Viread
FDA approves Nuclisens HIV-1 QT
20th anniversary of 1st published AIDS case
CDC study of 6 cities finds 30% of young, gay, black men are HIV+
Science confirms condoms effectiveness against HIV
Project WAVE begins (NYS)
Faith based initiatives begin (NYS)
Expanded Syringe Access Program begins (NYS)

2002

Dramatic decline in perinatal transmission in NYS: to 2.4%
FDA approves 600mg formulation of Sustivia
FDA approves 1st rapid HIV diagnostic test kit for U.S.
FDA approves VERSANT HIV-1 RNA 3.0 assay
U.S. Sec. Of State advocates condoms to prevent AIDS & STDs
Study finds 50% of Americans believe they can acquire AIDS through casual contact & support mandatory testing in high risk groups
Intensive outreach efforts to young, gay men of color (NYS)
Transitional case management in HR &SA programs (NYS)
1st annual HCV conference (NYS)

2003

FDA proposes warning for vaginal contraceptives with nonoxynol9
FDA approves FUZEON with other ARVs to treat advanced HIV in adults and children
FDA approves protease inhibitor, Reyataz
FDA approves new NRTI, Emtriva
CDC announces new 4-part initiative to reduce new HIV in US
HHS expands availability of rapid testing/ CLIA waiver
Rapid testing in Anonymous HIV C & T piloted and implemented statewide through 2004 in community sites and county jails and in DOCS (NYS)
HIV SNPs begin enrollment (NYS)
Family-Centered health care services (NYS)
Prevention services for women programs (NYS)
Youth Health care programs (NYS)
Reauthorization of ESAP (NYS)
New case management guidelines (NYS)
2nd annual HCV conference (NYS)
Families in Transition programs (NYS)
Centers of Excellence in Pediatric Care (NYS)

2004

FDA approves OraSure rapid test for HIV-2
FDA approves use of oral fluid with rapid, HIV, diagnostic test
FDA approves OraQuick rapid HIV ab test for HIV-1 / 2
FDA grants CLIA waiver to OraQuick ADVANCE rapid HIV-1/ 2 ab test for oral fluids
FDA approves 2 fixed-dose combination ARV drugs
Prevention for Positives campaign starts (NYS)
Increase in # of women's programs integrating rapid testing (NYS)
MSM workgroup recommends prevention & care needs of gay / MSM (NYS)
3rd annual HCV (NYS)

2005

HIV STOPS with ME prevention with positives campaign (NYS)
HIV counseling and Testing guidance (NYS)
Authorization of 2 new harm reduction/ syringe exchange programs

APPENDIX C

Compiled by NYSDOH AI

NYS AIDS timeline 2000s 1/3/2006

Unmet Need Calculation — New York State[1]

Input	Value	Data Source	
Population Sizes			
(1) Total Number of PLWH/A, through 12/2004	**125,473**	Jurisdiction specific surveillance data	
AIDS	70,134		
HIV+	55,339		
Care Patterns (Met Need)			
(2) Number of PLWH/A "In Care"			
A) Medicaid / ADAP	**71,207**	Total Medicaid / ADAP met need	
AIDS	51,080		
HIV+	20,127		
B) Veteran's Administration	**1,705**	Total VA met need	
AIDS	953		
HIV+	752		
C) Other Payer	**9,470**	Total Other Payer met need	
AIDS	5,293		
HIV+	4,177		
D) Total	**82,382**	Total NYS number of met need	
AIDS	57,326		
HIV+	25,056		
Calculated Result (Unmet Need)			
(3) Number of PLWH/A not "In Care"	**43,091**	34.34%	Total Unmet Need
	12,808	18.26%	AIDS Unmet Need
	30,283	54.72%	HIV+ Unmet Need*

1. Excerpt from NYS Ryan White CARE Act Title II Application 2006-07

*NYS DOH is aware of the high HIV unmet need estimate. As a result, a review of the coding algorithms that select the AIDS and HIV cases out of the Medicaid and ADAP systems has commenced. That review may involve chart validation and/or file matching and will take several months. Secondly, a review of the methodology itself that utilizes NYS-specific HIV rate codes and procedure codes to identify CD4, VL and ARV are being re-examined. It should be noted though that this methodology was developed and used in the original pilot study in cooperation with the researchers from the University of San Francisco, California.

Methodology for the New York State Unmet-Need Calculation

Data Systems Selected:

In this proposal, as in the pilot study[2], the NYS AIDS Institute used Medicaid and ADAP as the primary empirical data sources to calculate the numerator since these two programs serve the largest HIV/AIDS population in NYS. Veterans' Administration (VA) data containing patients added to the National database through the end of March 2004 was made available in July 2004. The information was provided on a one-time basis so the VA data used in the 2006 Unmet Need calculation is consistent with the VA data used in the 2005 Unmet Need calculation.

Information obtained from the AIDS Institute Quality of Care Review Program has been used to estimate the composition of payer mix beyond that which is included in the Medicaid, ADAP and VA systems.

Limitations of Data Systems:

The definition of HIV primary care used for the unmet-need analysis is limited to viral load tests, CD4 tests, and ARV therapies. The Medicaid and ADAP data systems are claims and payment systems for reimbursement and billing purposes, and are not clinical/ medical record systems, although clinical information can be extracted from the claims using ICD-9, CPT and NDC Codes.

Another limitation of the Medicaid and ADAP data systems is the time lag among service date, claim date, and the payment date.

The AIDS Institute Quality of Care Review Program uses a random sampling process of chart review.

Clinical/Medical Definitions Used For Examination of Medicaid/ADAP Files:

Evidence of Viral load test, and / or CD4 test, and/or ARV therapy - "Evidence" will be based on procedure codes for the viral load test, CD4 test, NYS Medicaid rate codes, and NDC drug codes for the ARV therapy.

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[2] Note that the original unmet-need project initiated by UCSF used NYS as one of the five pilot test sites from which to model the framework for HRSA's RW application mandated study.

Methodology:

1. The denominator (1) is the number of diagnosed PLWAIDS and PLWHIV reported as of the end of December 2004 by the NYS Department of Health Bureau of HIV/AIDS Epidemiology.
2. The numerator is derived from the following:

   (A) The number of NYS Medicaid recipients with HIV/AIDS was added to the number of ADAP recipients. The following criteria was then applied to calculate the met-need number for Medicaid and ADAP:

   > Number of recipients with reported (at least) 1 viral load or CD4 test or ARV therapy in the 12-month analysis period.

   (B) The VA data for NYS was compiled using the files posted to the VA website. A total met-need number for all recipients was calculated. Since the data did not contain a break-out of HIV and AIDS, the percentage of each of the two populations as represented in the Surveillance data was applied to the total number of VA met-need recipients.

   (C) A calculation totaling the number of other payer mix (Medicare, Private Insurance, Department of Corrections, etc.) was made utilizing the percentage of such other payers (10%) identified through the AIDS Institute's Quality of Care Review Program. The percentage was applied to the total PLWH/A to arrive at the total number of recipients covered by other payers. The percentage of met need calculated from the Medicaid, ADAP and VA data was assumed to be the same for the other payer mix population and applied to the total of other payer recipients to arrive at the met need number. The HIV / AIDS break down was calculated using the percentage of each of the two populations as represented in the Surveillance data.

   (D) The number of individuals identified in (A), (B) and (C) above was combined to generate total met need.
3. Unmet need is calculated by subtracting the met-need number (D) from the total population (1). The result is then divided by the total population (1).

Title II Program Component: ADAP				
Service Goal Statement: Ensure access to existing and emerging HIV/AIDS therapies.				
Objective/s:	**Service Unit Definition:**	**Quantity:** Number of People to be Served	**Quantity:** Total number of Service Units to be Provided	**Time Frame:**
1. Conduct outreach and enroll new applicants	**New enrollment**	3,500	3,500	12
2. Provide access to HIV drugs to enrolled participants	**Total Enrollment**	22,500	22,500	12
3. Reimburse for covered drugs	**Prescriptions**	19,300	714,000	12
4. Reimburse for lab monitoring	**Lab Tests**	9,200	24,500	12
5. Continue to assess utilization of therapies by various cohorts	**NA**	NA	NA	12
6. Provide continuation of health insurance for individuals with cost-effective policies	**New**	450	450	12
	Total	1,450	1,450	
	Premiums	1.350	12,250	
7. Promote and support adherence to therapies through treatment adherence initiatives	**Individual encounters**	1,000	800	12

Title II Program Component: CONSORTIA				
Service Goal Statement 1: Ensure that care systems statewide address the needs of all affected communities and populations.				
Objective/s:	**Service Unit Definition**	**Quantity:** Number of People to be Served	**Quantity:** Total number of Service Units to be Provided	**Time Frame:**
1. Provide ambulatory care to the uninsured and underinsured through ADAP Plus	**New enrollment**	3,300	3,300	12
	Total enrollment	21,250	21,250	
	Claims	16,300	255,000	
2. Provide home care services to the uninsured and underinsured through the HIV Home Care Program	**New enrollment**	125	125	12
	Total enrollment	180	180	
	Claims	80	2,500	
3. Provide primary care through contracts	**Visits**	3,485	24,870	12
4. Provide meals	**Meals**	955	99,996	12
5. Provide mental health services	**Visits**	2,751	27,511	12
6. Provide transportation services	**Trips**	1,892	24,550	12
7. Provide case management services	**Encounters**	5,395	76,458	12
8. Provide other supportive services	**Various (visits, encounters, sessions, housing units, etc.)**	37,284*	62,780	12
9. MAI: Provide services to increase minority participation in care and ADAP:				12
- Outreach	**Encounters**	20,000	750	
- Education	**Encounters**	7,000	350	
- Referral	**Referrals**	2,200	2,200	
- Enrollment	**Enrollments**	1,000	1,500	
10. Facilitate regional planning and coordination of HIV services through 16 networks/lead agencies	**Network progress and performance**	N/A	N/A	12
11. Address the needs of special populations and gaps in services throughout the state through statewide network (SASDC)	**SASDC progress and performance**	N/A	N/A	12

*Includes approximately 19,574 people served through outreach.
Some service contracts are scheduled to be resolicitated in 2005, therefore some projections reflect a six month period.

Service Goal Statement 2: Adapt to changes in the delivery and financing of HIV/AIDS care.				
Objective/s:	**Service Unit Definition**	**Quantity:**		**Time Frame:**
		Number of People to be Served	Total number of Service Units to be Provided	
12. Continue activities related to managed care, supported by a variety of sources. These activities include: ▪ **Planning and development of managed care plans for persons with HIV, known as HIV Special Needs Plans (SNPs).** ▪ **Certify HIV SNPS.** ▪ **Review managed care organizations to assess capacity to deliver services to persons with HIV and quality of such services.** ▪ **Provide information to SNPs and to mainstream managed care plans on CARE Act providers and other HIV service providers in their catchment areas with whom they must link.** ▪ **Consumer education on managed care, including development of a curriculum.** ▪ **Assess quality issues and facilitators of and barriers to care as persons with HIV transition from fee-for-service to managed care.**	**N/A**	N/A	N/A	12

Service Goal Statement 3: Managed quality and document outcomes.				
Objective/s:	**Service Unit Definition**	**Quantity:**		**Time Frame:**
		Number of People to be Served	Total number of Service Units to be Provided	
1. Continue quality assurance and evaluation activities including: ▪ **Quality of Care Program** ▪ **Furnish consultation and assistance to providers in implementing CQI activities, including HIVQUAL;** ▪ **Case management quality** ▪ **Maternal/pediatric HIV program evaluation** ▪ **Assess access, client satisfaction, and quality issues through client cohort project** ▪ **Leadership Training Institute (LTI) evaluation** ▪ **Assess performance through review and monitoring of providers** ▪ **Implement URS; collect and analyze URS data**	**N/A**	N/A	N/A	12

NEW YORK STATE
FY 2005 RYAN WHITE TITLE II IMPLEMENTATION PLAN

Title II Program Component: Emerging Communities				
Service Goal Statement: To support health care and supportive services for persons living with HIV/AIDS in the ECs: Buffalo, Rochester.				
Objective/s:	Service Unit Definition:	Quantity*: Number of People to be Served	Quantity*: Total number of Service Units to be Provided	Time Frame:
BUFFALO EC **1. Provide mental health services**	**Visits**	20	140	12
2. Provide substance use counseling	**Visits**	40	240	12
3. Provide adherence services	**Encounters**	32	145	12
4. Provide direct emergency financial assistance	**Requests/Claims**	14	14	12
5. Provide other services (Outreach)	**Sessions**	1,148	150	12
ROCHESTER EC **1. Provide case management services**	**Encounters**	195	2,995	12
2. Provide transportation	**Trips**	70	3,040	12
3. Provide other services				
- Outreach and Information	**Sessions**	10	5	12
- Advocacy	**Visits**	100	200	12
- Supportive Housing	**Units/Encounters**	100	382	12
- Individual Level Intervention	**Visits**	70	125	12

NEW YORK CITY EMA
FY 2005 RYAN WHITE TITLE I IMPLEMENTATION PLAN

Objectives	Service Unit Definitions	Number of Clients	Number of Units
Priority 1: State Administered Drug Reimbursement Program			
Service Goal: Improve health outcomes of uninsured and underinsured PLWHA.			
1. Ensure that PLWHA in the EMA have access to medications and related treatment by supporting New York State ADAP.	**Prescriptions**	13,734	464,380
Priority 2: Ambulatory/Outpatient Care			
Service Goal 2A: Improve the health outcomes through the provision of outpatient health care services to uninsured and underinsured PLWHA, especially women and minorities and PLWHA with co-morbidities including homelessness, AOD, and mental illness.			
1. Provide comprehensive HIV primary medical care in underserved communities, including programs that offer specialty services for women, and people who need on-site substance abuse interventions and mental health services. [45 programs]	**Client visits**	10,471	109,572
2. Provide HIV related medical care and supportive services care in homeless shelters and SROs. [One program]	**Client visits**	456	7,650
3. Provide HIV primary and specialty care by collaborating with the NYSDOH AIDS Institute to reimburse providers who provide these services through the NYS HIV Uninsured Care Program.	**Client visits**	13,058	192,619
Service Goal 2B: Maintain a seamless continuum of care for PLWHA who migrate between Puerto Rico and New York City.			
1. Coordinate medical care and case management and nutritional services for PLWHA who migrate between New York and Puerto Rico. [Two programs]	**Client Visits**	408	6,828
Service Goal 2C: Improve the health outcomes of PLWHA with co-morbidities.			
1. Improve the medical management of people co-infected with Hepatitis C with programs that provide screening and treatment services in HIV medical care settings. [Nine programs]	**Client Visits**	2,430	14,865
2. Assist PLWHA with active TB in complying with drug regimens and prevent TB infections from progressing to active disease through programs that provide direct supervision of medication compliance and supportive services. [Four programs]	**Client visits**	328	11,530
Service Goal 2D: Increase access to comprehensive medical care for HIV infected individuals who use emergency rooms for health care needs or receive services in harm reduction settings.			
1. Fund HIV related assessment teams in hospital based emergency care centers and harm reduction centers to ensure early HIV testing and engagement in HIV primary care. [Three programs]	**Client visits**	1,772	3,748

NEW YORK CITY EMA
FY 2005 RYAN WHITE TITLE I IMPLEMENTATION PLAN

Objectives	Service Unit Definitions	Number of Clients	Number of Units
Service Goal 2E: Improve the health outcomes of minorities living with HIV/A by encouraging early entry into HIV primary care and supporting maintenance in care.			
1. **MAI -** Increase availability of counseling and testing in areas of high HIV prevalence at key points of access such as ERs, STD clinics, SROs and homeless shelters. [Two programs]	**Client visits**	3,444	4,689
2. **MAI –** Provide services that promote retention in HIV primary care to individuals who do not maintain connections to care or who are identified as at risk for dropping out of care. [Ten programs]	**Client visits**	2,725	15,149
Priority 3: Substance Abuse Services			
Service Goal 3A: To increase access to care and engage PLWHA who have a history of alcohol or other drug use and are outside the networks of traditional services.			
1. Provide low threshold, easily accessible hard reduction, recovery readiness and relapse prevention services to PLWHA who are using drugs, relapsing or in recovery and provide support to clients to engage them in HIV primary care. [30 programs]	**Client visits**	78,943	125,950
2. Provide low threshold AOD services to address the multiple needs of families affected y HIV and AOD use. Programs offer services that enhance the family's ability to function while addressing the HIV infected family member's health and social service needs. [Eight programs]	**Client visits**	15,942	25,077
Service Goal 3B: Increase access to health and supportive services for HIV positive inmates and releasees.			
3. Provide HIV infected inmates incarcerated at Rikers Island with services to coordinate primary care and linkages to supportive services upon release from prison. [Five programs]	**Client visits**	35,316	14,868
Priority 4: Mental Health Services			
Service Goal: 4A Improve mental health functioning though increased access to mental health services for PLWHA.			
1. Provide licensed outpatient mental health services as part of a comprehensive and integrated approach to meeting the needs of families living with HIV/AIDS. Programs include services that focus on adolescents. [12 programs]	**Client visits**	7,049	26,268
2. Provide licensed outpatient mental health services to meet the needs of PLWHA who are also mentally ill and chemically addicted, and seriously and persistently mentally ill. [Ten programs]	**Client visits**	15,207	27,393

Objectives	Service Unit Definitions	Number of Clients	Number of Units
3. Provide licensed outpatient mental health services in mental health settings, in addition to integration with other service settings including primary care, alcohol and other drug use treatment programs, housing programs. [16 programs]	**Client visits**	13,302	23,699
Priority 5: Housing Assistance			
Service Goal 5A: To reduce and prevent homelessness among PLWHA			
1. Provide assistance to PLWHA in securing appropriate housing including emergency housing funds and short-term rental assistance. [Six programs]	**Client visits**	1,011	15,199
2. Provide transitional housing and supportive services to homeless persons with special needs (e.g. severe and persistent mental illness, recurrent substance abuse), or from special populations (e.g. women with children, seniors). [Six programs]	**Client visits**	5,660	18,492
3. Provide emergency rental start-up assistance-realtors' fees and short-term rental assistance-for PLWHA who are not eligible for NYC HASA. [One program]	**Client visits**	2,190	5,550
4. **MAI** – Provide transitional housing and supportive services in targeted geographic areas for PLWHA. [Three programs]	**Client visits**	782	7,620
Priority 6: Case Management			
Service Goal 6A: Improve access to HIV primary care and other related services.			
1. Provide assistance in obtaining benefits and help individuals gain access to core services including primary care. Coordinate services needed by individuals to stay in care. [40 programs]	**Client visits**	5,970	96,524
Priority 7: HIV/AIDS Treatment Adherence			
Service Goal 7A: To improve health outcomes of PLWHA through programs to assist in adherence with treatment regimens			
1. Assist PLWHA who are in care, but are at risk for dropping out of care, through treatment adherence consortia administered by the NYSDOH AIDS Institute. [Seven programs]	**Client visits**	1,176	10,332
2. Provide education, support, and counseling to PLWHA to make informed choices concerning treatment options and adherence. [19 programs]	**Client visits**	3,599	19,936

Objectives	Service Unit Definitions	Number of Clients	Number of Units
3. **MAI** – Treatment adherence consortia utilize a comprehensive approach to assisting PLWHA in targeted geographic areas who are in care but at risk for non-adherence. [Three programs]	**Client visits**	584	4,134
Priority 8: Home Health Care			
Service Goal 8A: To improve health outcomes of uninsured PLWHA through increased access to home health care services			
1. Provide comprehensive home health care services to uninsured or underinsured PLWHA. [Four programs]	**Client visits**	827	17,683
2. Provide reimbursement to licensed home health agencies for services provided to clients who are uninsured or under-insured through the NYSDOH AIDS Institute HIV Uninsured Care program.	**Client visits**	77	1,690
Priority 9: Food Bank/ Home Delivered Meals			
Service Goal 9A: To improve the nutritional status of PLWHA			
1. Provide culturally competent food and nutrition services to PLWHA using community-based agencies that provide meals 7 days per week through home delivered meals, congregate meals and/or pantry bags. [14 programs]	**Client meals**	11,155	636,002
Priority 10: Oral Health			
Service Goal 10A: Increase access to and improve dental and oral health care for PLWHA.			
1. Provide comprehensive dental and oral health care services. [Five programs]	**Client visits**	281	2,539
2. **MAI** – Provide oral health care services that are integrated within HIV care centers. [One program]	**Client visits**	108	1,236
Priority 11: Housing Related Service			
Service Goal 11A: To provide access to enhanced services for populations with special needs			
1. Provide substance abuse and mental health services to PLWHA living in scattered-site housing and supported SROs. [30 programs]	**Client visits**	21,010	44,592
Priority 12: Psychosocial Support Services			
Service Goal 12A: To provide access to supportive counseling and information to PLWHA and their families			
1. Provide supportive counseling services to clients whose need for services is not the result of an American Psychiatric Association Diagnostic and Statistical Manual (DSM) IV diagnosis. [Eight programs]	**Client visits**	3,916	9,439
Priority 13: Outreach			
Service Goal 13A: To engage and promote access to care for PLWHA who are unconnected to care and support services			

NEW YORK CITY EMA
FY 2005 RYAN WHITE TITLE I IMPLEMENTATION PLAN

Objectives	Service Unit Definitions	Number of Clients	Number of Units
1. Promote early access to services, especially hard-to-reach populations, such as the homeless, those actively using alcohol and other drugs, gay men of color, adolescents and some native and immigrant populations who are less likely to be reached through routine case finding or traditional street outreach programs. [11 programs]	**Client visits**	20,346	40,573
2. **MAI** – Identify PLWHA not in care and provide them direct linkages to needed medical care and other services that will help them to access and maintain themselves in care. [13 programs]	**Client visits**	7,322	30,909
3. **MAI -** Provide services to newly released HIV-infected inmates through a 24-hour drop-in transitional center with linkages to comprehensive health, mental health, housing, AOD and other support services. [One program]	**Client visits**	180	5,544
Priority 14: Day/Respite Care for Adults			
Service Goal 14A: To allow PLWHA to continue living independently in their communities			
1. Low threshold day treatment services for PLWHA who are in need of a structured service setting but are ineligible for enrollment in a licensed Article 28 day treatment program. [Three programs]	**Client visits**	15,600	23,732
Priority 15: Transportation			
Service Goal 15A: To increase access to care and services through provision of transportation services to mobility-impaired PLWHA			
1. Provide transportation services to PLWHA to ensure access to HIV health and supportive care services. [Two programs]	**Client visits**	525	24,188
Priority 16: Legal Services			
Service Goal 16A: Facilitate access to HIV related primary care services and appropriate support services by legal advocacy to remove barriers to care.			
1. Provide legal services to assist clients with issues such as access to benefits, discrimination, estate planning, custody planning.[19 programs]	**Client visits**	6,494	25,479
Priority 17: Buddy Services			
Service Goal 17A: To improve the quality of life of PLWHA by supplementing professional care.			
1. Assist clients with activities of daily living, provide crisis intervention, or escort clients to appointments through the use of trained volunteers. [Three programs]	**Client visits**	1,093	11,746

NEW YORK CITY EMA
FY 2005 RYAN WHITE TITLE I IMPLEMENTATION PLAN

Objectives	Service Unit Definitions	Number of Clients	Number of Units
Priority 18: Program Support			
Service Goal 18A: To improve the capacity and quality of HIV/AIDS service provision through assistance to providers with organizational development, capacity building, and training issues.			
1. Provide technical assistance to HIV/AIDS service organizations through individualized assistance, training workshops and clinics focusing on: developing organizational resources; managing change; managing limited resources; and continuous quality improvement. Funding is also supports a web-based technical assistance clearinghouse. [17 programs]	**TA Encounters**	3,017	22,904
2. Provide technical assistance to community based organizations in the development of housing programs for PLWHA, and to educate CBOs about how to overcome the barriers to effective development of housing programs. [Two programs]	**TA Encounters**	638	5,481
Service Goal 18B: To empower PLWHA to participate in HIV-related community planning, and policy and program development.			
1. The PLWHA Leadership Training Institute (LTI) is a joint project of NYCDOH and the NYSDOH AIDS Institute serving as an ongoing resource center for skills training and support. LTI helps PLWHA develop and maximize their potential so that they are able to contribute to policy formulation, program development, service delivery and program evaluation.	**Trainings**	TBD	TBD
2. To support an AIDS education and advocacy group, which conducts monthly meetings of PLWHA, provides technical support for consumer advisory boards, publishes newsletters, and serves as a resource to provider organizations on treatment adherence-related issues. [One program]	**Group Sessions & Newsletters**	NA	37
Service Goal 18C: To provide data management support to Title I organizations.			
1. Maintain the infrastructure to assist providers in complying with the HRSA mandated aggregate reporting requirements and to maintain URS, an integrated reporting system, to collect uniform data from providers that can be utilized for contract monitoring, evaluation, and strategic planning.	NA	NA	NA
2. **MAI** - Support MAI programs under the above objective.	NA	NA	NA

NEW YORK CITY EMA
FY 2005 RYAN WHITE TITLE I IMPLEMENTATION PLAN

Objectives	Service Unit Definitions	Number of Clients	Number of Units
Service Goal 18D: To provide supportive program and service information to assist the Planning Council in fulfilling its mandated roles.			
1. Fund initiatives used by the Planning Council to develop the needs assessment and comprehensive plan for HIV services. Information is used to develop and target service priorities, and allocate funds.	NA	NA	NA
2. **MAI** – Perform the EMA-wide outcome evaluation of MAI programs.	NA	NA	NA
Service Goal 18E: To provide supportive program and service information to assist the Planning Council in fulfilling its mandated roles			
1. Fund the Coordinated Quality Management Program to measure health and supportive services.	NA	NA	NA
Priority 19: Planning Council Support			
Service Goal 19A: To support Planning Council activities for priority setting and grant allocation			
1. Fund staff to support the Planning Council, including the Tri-County Steering Committee, and assist with its mandated roles and responsibilities related to needs assessment, development of a comprehensive plan, priority setting, allocation funds and the assessment of the efficiency of the administrative mechanism.	NA	NA	NA
Sunset Priority 20: Health Education/Risk Reduction			
Service Goal 20A: Increase the knowledge and skills of consumers and providers concerning HIV treatment, and health and support services			
1. Provide education and training designed to promote access to care and compliance with prescribed treatments in order to improve the quality of life and reduce mortality for PLWHA. [Eight programs]	**Client Visits**	2,884	2,257
2. **MAI** – Promote access to HIV care services and increase compliance with treatment by providing education and counseling to individuals to assist them in making decisions about treatment strategies. [11 programs]	**Client Visits**	4168	8651
Sunset Priority 21: Permanency Planning			
Service Goal 21A: To assist families with planning for the long term care of children affected by HIV			
1. Provide permanency planning and transitional support to HIV-infected parents/families planning for the long-term care of their children. [Ten programs]	**Client Visits**	2,228	10,651

Nassau/Suffolk
FY 2005 Ryan White Title I Implementation Plan

Service Priority Name: **AMBULATORY/OUTPATIENT MEDICAL CARE**				Page 1 of 22
Service Priority Number**: 1.1 - 1.2**				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To ensure the availability of timely, quality primary and specialty care for every HIV infected/affected/at risk adult, child and adolescent in the Nassau-Suffolk EMA (including those who are undocumented).*				
Service Goal: *To ensure access to HIV/AIDS ambulatory/outpatient medical care for PLWH/A in the Nassau-Suffolk EMA for HIV infected individuals* **.(1.1)**				
Objective/s	**Service Unit Definition**	**.**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide co-located, comprehensive primary care services for HIV+ men and women, including: medical, provision of specialty care, management of chronic conditions, medication management and gynecological care. Screening for identification of mental health and substance abuse problems, appropriate referrals for further therapy, treatment adherence, patient education and counseling on health issues.	45 minute office visit-includes supplemental education 15 minute telephone consultation with either client and family or other health professional	385	1,850 5,244	03/01/05 to 02/28/06
Service Goal: *To ensure access to HIV/AIDS ambulatory/outpatient medical care for PLWH/A in the Nassau-Suffolk EMA, specifically to the area's under-serviced East End.(1.2)*				
Objective: Provide co-located, comprehensive primary care services for HIV+ men and women, including: medical, provision of specialty care, management of chronic conditions, medication management and gynecological care. Screening for identification of mental health and substance abuse problems, appropriate referrals for further therapy, treatment adherence, education and counseling on health issues on the East End.	45 minute office visit-includes supplemental education 15 minute telephone consultation with either client and family or other health professional	180	1,920 4,992	03/01/05 to 02/28/06

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Service Priority Name: **STATE DRUG REIMBURSEMENT PROGRAM**				Page 2 of 22
Service Priority Number: 2				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To enable PLWH/A to receive necessary medications and to access primary care as needed.*				
Service Goal: *To enable PLWH/A to receive necessary medications and to access primary care as needed.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide access to prescription drugs, supplements and primary care via New York State's ADAP and ADAP+ programs.	ADAP ADAP+	170	453 341	03/01/05 to 02/28/06

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Service Priority Name: **TRANSPORTATION**	Page 3 of 22
Service Priority Number: 3	Prepared by Deidre Gehrke

Comprehensive Plan Goal: *To ensure that HIV infected individuals in Nassau and Suffolk Counties have adequate transportation to access medical care and supportive services.*

Service Goal: *To ensure access to HIV/AIDS medical care and psychosocial support for PLWH/A in the Nassau-Suffolk EMA by providing transportation.*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: Provide non-reimbursable transportation in order to increase an HIV/AIDS infected person's ability to access primary health care substance abuse treatment or psychosocial support.	taxicab ride: one-way MetroCard van ride: one-way	735	39,600 2,900 1,700	03/01/05 to 02/28/06

Service Priority Name: **HOUSING ASSISTANCE**

Service Priority Number: 4

Comprehensive Plan Goal: *To ensure access to HIV/AIDS medical care for PLWH/A in the Nassau-Suffolk EMA by financially assisting the PLWH/A to obtain suitable housing.*

Service Goal: *To ensure access to HIV/AIDS medical care for PLWH/A in the Nassau-Suffolk EMA by financially assisting the PLWH/A to obtain or maintain suitable housing.*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: Emergency financial assistance for eligible PLWH/A with first month's rent, current month's rent, and/or moving expenses.	1st month's rent current month's rent moving expenses	155	270	03/01/05 to 02/28/06

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Service Priority Name:	**ORAL HEALTH CARE**			Page 4 of 22
Service Priority Number: 5				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To ensure access to general HIV/AIDS dental care for PLWH/A in the Nassau-Suffolk EMA.*				
Service Goal: *To ensure access to general HIV/AIDS dental care for PLWH/A in the Nassau-Suffolk EMA.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide access to appropriate HIV-related dental care which includes diagnostic, preventative and therapeutic services.	45 minute office visit	680	2,970	03/01/05 to 02/28/06

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Service Priority Name:	**LEGAL SERVICES**			Page 5 of 21
Service Priority Number: 6				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To ensure that PLWH/A receive appropriate legal services.*				
Service Goal: *To ensure that PLWH/A receive appropriate legal services.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: To assist PLWH/A to obtain legal services that include, but are not limited to: Powers of Attorney, do not resuscitate orders, wills, trusts, bankruptcy proceedings, interventions necessary to ensure access to eligible benefits, discrimination, confidentiality, landlord/tenant matters, custody issues, visitation, and child support .	45 minute office visit 15 minute phone contact court or hearing appearance home/hospital visits	325	3,645 2,276 2,734 455	03/01/05 to 02/28/06

Service Priority Name:	**SUBSTANCE ABUSE SERVICES**			
Service Priority Number: 7.1 - 7.2				
Comprehensive Plan Goal: *To ensure access to HIV/AIDS sensitive substance abuse services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*				
Service Goal: *To ensure access to HIV/AIDS substance abuse treatment programs for PLWH/A in the Nassau-Suffolk EMA.(7.1)*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Substance Abuse - General) Provision of substance abuse treatment, counseling, and education that are designed to respond to a PLWH/A's culture, health behavior, recovery beliefs and that support recovery, prevent relapse, and address MICA (Mentally Ill Chemically Addicted) issues.	45 minute office visit 60 minute group session 15 minute telephone consultation	70	1950 1910 450	03/01/05 to 02/28/06

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Service Priority Name:	**SUBSTANCE ABUSE SERVICES: OUTPATIENT**	Page 6 of 22
Service Priority Number: 7.2		Prepared by: Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to HIV/AIDS sensitive substance abuse services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*

Service Goal: *To advocate for access to HIV/AIDS substance abuse treatment programs and to assist clients in adherence to these treatments, specifically targeting the African Americans and People of Color in the Nassau-Suffolk EMA.(7.2)*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: (Substance Abuse Services: PTPOC-MAI) Provision of substance abuse treatment, counseling, and education that are designed to respond to a PLWH/A's culture, health behavior, recovery beliefs and that support recovery, prevent relapse, and address MICA (Mentally Ill Chemically Addicted) issues.	45 minute office visit 60 minute group session 15 minute phone intervention	48	667 638 145	03/01/05 to 02/28/06

Service Goal: *To advocate for access to HIV/AIDS substance abuse treatment programs and to assist clients in adherence to these treatments, specifically targeting the African Americans and People of Color in the Nassau-Suffolk EMA.(7.2)*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: (Substance Abuse Services: PTPOC non-MAI) Provision of substance abuse treatment, counseling, and education that are designed to respond to a PLWH/A's culture, health behavior, recovery beliefs and that support recovery, prevent relapse, and address MICA (Mentally Ill Chemically Addicted) issues.	45 minute office visit 60 minute group session 15 minute phone intervention	24	344 329 74	03/01/05 to 02/28/06

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Service Priority Name:	**MENTAL HEALTH SERVICES**	Page 7 of 22
Service Priority Number: 8.1 - 8.3		Prepared by Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to HIV/AIDS mental health services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*

Service Goal: *To ensure access to mental health services for PLWH/A (and their affected collaterals) in the Nassau-Suffolk EMA.* (8.1)

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: (Mental Health: General) Comprehensive behavioral health assessment services in order to provide individual and family psychotherapy to cope with chronic illness, medical management, treatment adherence, role and lifestyle changes, crisis intervention, and stress. Intake/support services include assistance in applying for Medicaid.	45 minute psychiatric evaluation 60 minute group 15 minute phone intervention	125	523 1,485 742	03/01/05 to 02/28/06

Service Priority Name:	**MENTAL HEALTH SERVICES *Continued***	Page 8 of 22
Service Priority Number: 8.1 - 8.3		Prepared by Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to HIV/AIDS mental health services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*

Service Goal: *To ensure access to mental health services for PLWH/A, specifically targeting African Americans or Gay, Lesbian, Bi-sexual, and Transgendered individuals (and their affected collaterals) in the Nassau-Suffolk EMA.(8.2)*

Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Mental Health: Specific) Comprehensive behavioral health assessment services in order to provide individual and family psychotherapy to cope with chronic illness, medical management, treatment adherence, role and lifestyle changes, crisis intervention, and stress. Intake/support services include assistance in applying for Medicaid.	45 minute psychiatric evaluation 60 minute group 15 minute phone intervention	50	145 200 420	03/01/05 to 02/28/06

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Service Priority Name: **MENTAL HEALTH SERVICES** ***Continued***	Page 9 of 22
Service Priority Number: 8.1 - 8.3	Prepared by Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to HIV/AIDS mental health services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*

Service Goal: *To ensure access to mental health services for PLWH/A (and their affected collaterals) specifically targeting people of color in the Nassau-Suffolk EMA.(8.3)*

Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Mental Health: PTPOC-MAI) Comprehensive behavioral health assessment services in order to provide individual and family psychotherapy to cope with chronic illness, medical management, treatment adherence, role and lifestyle changes, crisis intervention, and stress. Intake/support services include assistance in applying for Medicaid.	45 minute psychiatric evaluation 60 minute group 15 minute phone intervention	74	313 889 444	03/01/05 to 02/28/06

Service Priority Name: **MENTAL HEALTH SERVICES** ***Continued***				Page 10 of 22
Service Priority Number: 8.1 - 8.3				Prepared by Deidre Gehrke
Comprehensive Plan Goal: *To ensure access to HIV/AIDS mental health services in order to maintain PLWH/A in medical care in the Nassau-Suffolk EMA.*				
Service Goal: *To ensure access to mental health services for PLWH/A (and their affected collaterals) specifically targeting people of color in the Nassau-Suffolk EMA.(8.3)*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Mental Health: PTPOC- non MAI) Comprehensive behavioral health assessment services in order to provide individual and family psychotherapy to cope with chronic illness, medical management, treatment adherence, role and lifestyle changes, crisis intervention, and stress. Intake/support services include assistance in applying for Medicaid and therapeutic support for children and adolescents.	45 minute psychiatric evaluation 60 minute group 15 minute phone intervention	150	665 1,890 945	03/01/05 to 02/28/06

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Service Priority Name: **FOOD BANK/HOME DELIVERED MEALS**	Page 12 of 22
Service Priority Number: 11	Prepared by Deidre Gehrke

Comprehensive Plan Goal: *To provide personal hygiene products and household cleaning supplies to eligible PLWH/A in the Nassau-Suffolk EMA.*

Service Goal: *To provide personal hygiene products and household cleaning supplies to eligible PLWH/A in the Nassau-Suffolk EMA.*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: (Food Bank/Nutrition) Assist eligible PLWH/A with personal hygiene items, and household cleaning supplies.	personal hygiene packages	68	210	03/01/05 to 02/28/06

Service Priority Name:	**TREATMENT ADHERENCE SERVICES**	Page 13 of 22
Service Priority Number: **12.1 - 12.2**		Prepared by: Deidre Gehrke

Comprehensive Plan Goal: T*o advocate for access to HIV/AIDS treatment programs and to assist clients in adherence to these treatments, specifically targeting the African Americans and People of Color in the Nassau-Suffolk EMA.*

Service Goal: *To advocate for access to HIV/AIDS treatment programs and to assist clients in adherence to these treatments in the Nassau-Suffolk EMA.(12.1)*

Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Treatment Adherence Services) Intensive treatment adherence consultations designed to address barriers to adherence such as substance use, psychological, cultural and socio-economic issues. Education modules based on HIV Medication, Readiness for Treatment, Disease Progression, and the Benefits of Adherence.	30 minute face-to-face consultation 15 minute phone intervention 4 hour training	154	301 128 483	03/01/05 to 02/28/06

Comprehensive Plan Goal: T*o advocate for access to HIV/AIDS treatment programs and to assist clients in adherence to these treatments, specifically targeting the African Americans and People of Color in the Nassau-Suffolk EMA.*

Service Goal: *To advocate for access to HIV/AIDS treatment programs and to assist pregnant women, children and youth in adherence to these treatments, specifically targeting people of color in the Nassau-Suffolk EMA.(12.2)*

Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Treatment Adherence Services-PTPOC) Provide access to culturally sensitive assistance to ensure adherence to a treatment plan for women and children. Provide home visitation, telephone follow-up and referrals for clients in need of assistance with medication and treatment.	15 minute office visit 15 minute home visit 15 minute phone intervention	36	960 240 264	03/01/05 to 02/28/06

Service Priority Name: **CASE MANAGEMENT SERVICES: PRE-RELEASE**				Page 14 of 22
Service Priority Number: 13				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To ensure access to services for soon-to-be-released incarcerated PLWH/As in Nassau-Suffolk EMA.*				
Service Goal: *To ensure access to services for soon-to-be-released incarcerated PLWH/As in the Nassau-Suffolk EMA.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide pre-release counseling and referrals to inmates of the Nassau and Suffolk County Correctional Facilities in order to ensure they will access case management, medical and psychosocial support services in the EMA.	45 minute case management assessment 60 minute group session 30 minute post-discharge follow-up	120	1,332 805 960	03/01/05 to 02/28/06

Service Priority Name: **OTHER SUPPORT SERVICES**				
Service Priority Number: 14				
Comprehensive Plan Goal: *To ensure access to HIV/AIDS-sensitive complementary care for PLWHA.*				
Service Goal: *To ensure access to HIV/AIDS-sensitive complementary care for PLWH/A.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: (Complementary Therapies) Improve the quality of life and mobility, relieve treatment side effects and pain, and increase well being through the use of chiropractic care, acupuncture, and massage. Acupressure is also administered to babies, children, and pregnant women.	acupuncture acupressure massage chiropractic	135	245 790 1,898 306	03/01/05 to 02/28/06

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Service Priority Name: HEALTH EDUCATION/RISK REDUCTION	Page 15 of 22
Service Priority Number: 15	Prepared by: Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to appropriate and culturally sensitive HIV/AIDS information for PLWH/A in the Nassau-Suffolk EMA .*

Service Goal: *To ensure access to appropriate and culturally sensitive HIV/AIDS information for PLWH/A in the Nassau-Suffolk EMA.*

Objective/s	Service Unit Definition	Quantity		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: Develop culturally and linguistically appropriate materials and workshops targeting PLWH/A concerning services available in the EMA, as well as treatment and medical issues relevant to their care.	60 minute workshops distribution of up-dated books*	96	121 2,200*	03/01/05 to 02/28/06

*Updated "Committed to Living" - Ryan White Title I programs in EMA will continue to be distributed to agencies and clients.

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Service Priority Name:	**CHILD CARE SERVICES**	Page 16 of 22
Service Priority Number: 16		Prepared by: Deidre Gehrke

Comprehensive Plan Goal: *To ensure access to HIV/AIDS medical and psychosocial care for PLWH/A in the Nassau-Suffolk EMA by offering child care services to dependent children.*

Service Goal: To ensure access to HIV/AIDS medical and psychosocial care for PLWH/A in the Nassau-Suffolk EMA by offering child care services to dependent children.

Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide relief for the eligible primary caregiver in order to increase his or her ability to access treatment, medical care and psychosocial support.	4-hour individual home care or agency based group	36	135 261	03/01/05 to 02/28/06

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Service Priority Name:	**DAY or RESPITE CARE FOR ADULTS**			Page 17 of 22
Service Priority Number: 17				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To ensure access to HIV/AIDS-sensitive adult day health care for PLWH/A in the Nassau-Suffolk EMA.*				
Service Goal: *To ensure access to HIV/AIDS-specific adult day health care for PLWH/A in the Nassau-Suffolk EMA.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Outreach to providers and consumers to encourage participation in adult day health care program and to improve client participation in the program.	60 minute home visits 45 minute on-site visits	108	871 449	03/01/05 to 02/28/06

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Service Priority Name: **NUTRITIONAL COUNSELING**	Page 18 of 22
Service Priority Number: 18	Prepared by: Deidre Gehrke

Comprehensive Plan Goal: To ensure the availability of timely, quality nutritional counseling for HIV infected infants, children, adolescents, and pregnant women in Suffolk County

Service Goal: *To ensure access to HIV/AIDS nutritional services for PLWH/A, specifically in patients receiving treatment for HIV/AIDS at local designated AIDS center.*

Objective	Service Unit Definition	Quality		Time Frame
		# of People to be Served	Total # of Service Units to be Provided	
Objective: Maintain or improve the nutritional status of HIV-infected clients receiving treatment services in program that targets pregnant women, infants, children and adolescents.	nutritional assessment during clinic visit nutritional education	96	738 738	03/01/05 to 02/28/06

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Service Priority Name:	**CAPACITY BUILDING**			Page 19 of 22
Service Priority Number: 19				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To assist minority community based organizations reach their projected client numbers and service unit goals.*				
Service Goal: *To assist minority community based organizations with reaching their projected client numbers and service unit goals.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: An existing Ryan White Title I minority CBO will provide fiscal, staff, board, evaluation, and quality assurance technical assistance to funded Title I service providers.	technical assistance, either phone or site visit	3 Agencies	100	03/01/05 to 02/28/06

Service Priority Name:	**HEALTH INSURANCE**			
Service Priority Number: 20				
Comprehensive Plan Goal: None yet formulated.				
Service Goal: To ensure access to the ADAP Plus Insurance Continuation Program (APIC) for PLWH/A in the Nassau-Suffolk EMA.				
Objective	**Service Unit Definition**	**Quality**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: To pay the first month's insurance premium in order for HIV infected individuals to be eligible for APIC funding.	first month's payment			03/01/05 to 02/28/06

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Service Priority Name: **REFERRAL FOR HEALTH CARE/SUPPORTIVE SERVICES**				Page 20 of 22
Service Priority Number: 21				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *Not yet formulated.*				
Service Goal: *To ensure access to HIV/AIDS-sensitive services PLWH/A in the Nassau-Suffolk EMA.*				
Objective	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: The direction of an HIV infected individual to a service in person or through telephone, written, or other type of communication	15 minute office visit 15 minute home visit 15 minute phone contact			03/01/05 to 02/28/06
Service Priority Name: **SUBSTANCE ABUSE SERVICES: RESIDENTIAL**				
Service Priority Number: 22				
Comprehensive Plan Goal: *To ensure access to HIV/AIDS sensitive substance abuse services for PLWH/A in the Nassau-/Suffolk EMA .*				
Service Goal: *To insure access to HIV/AIDS substance abuse treatment programs for PLWH/A in the Nassau-Suffolk EMA.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provision of substance abuse treatment problems in an inpatient health service setting (short-term).				03/01/05 to 02/28/06

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Service Priority Name:	**PROGRAM SUPPORT**			Page 21 of 22
Service Priority Number: 23				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To provide technical assistance to Title I funded agencies.*				
Service Goal: *To provide technical assistance to Title I funded agencies.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide targeted technical assistance, including ongoing programmatic and fiscal support and review for the Title I funded agencies.	N/A	N/A	N/A	03/01/05 to 02/28/06
Service Priority Name:	**PLANNING COUNCIL SUPPORT**			
Service Priority Number: 24				
Comprehensive Plan Goal: *Staff a Planning Council that meets the requirements of the CARE Act.*				
Service Goal: *Staff a Planning Council that meets the requirements of the CARE Act.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Provide effective planning support, including documentation, training, professional and clerical staff support to the EMA's Planning Council.	N/A	N/A	N/A	03/01/05 to 02/28/06

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Service Priority Name:	**QUALITY MANAGEMENT**			Page 22 of 22
Service Priority Number: 25				Prepared by: Deidre Gehrke
Comprehensive Plan Goal: *To develop a comprehensive quality management program for all priorities.*				
Service Goal: *To develop and conduct quality management activities consistent with federal guidelines and to implement a client level data collection system.*				
Objective/s	**Service Unit Definition**	**Quantity**		**Time Frame**
		# of People to be Served	**Total # of Service Units to be Provided**	
Objective: Identify indicators for priority areas for which the Planning Council is in the process of developing standards of care.	N/A	N/A	N/A	03/01/05 to 02/28/06

APPENDIX E-4

Service Priority Name: Primary Medical Care				
Service Priority # 1.a	**FY 2005 Allocation $365,000**			**Time Frame: 3/1/05- 2/28/06**
Service Goal 1: Provide HIV primary medical care according to PHS and NIH guidelines.				**Reference Comprehensive Services Plan Goal: A,D,E**
Objectives	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
vide HIV Primary Medical Care per PHS/NIH standards.	Primary Care Visit (30 min. / unit)	160	625	Access to care, parity of geographic, comprehensive, quality services,
1b. Provide 100% of patients with appropriate specialty care referrals.	Referral and follow up (15 min./unit)	160	625	Special populations, maintenance in care, quality, comprehensiveness of service
1c. Meet with clinical and community case managers for case conferencing.	Case Conferencing (30min. / unit)	160	320	Ensure engagement in primary care, quality
Service Goal 2: Provide enhanced HIV medication adherence and support				**Reference Comprehensive Services Plan Goal:**
2a. Provide individualized medication adherence intake and assessment.	Adherence Intake (60 min. / unit)	160	160	Remain engaged in care/ adherence, comprehensiveness, quality of service
2b. Provide adherence specific support session	Adherence Session (30 min./unit)	25	120	Remain engaged in care/ adherence, comprehensiveness, quality of service
2c. Assess and refer clients to appropriate support services.	Intake, assess & plan (1 hr. / unit)	50	50	**Access and engagement in care, WICY**
Service Goal 3: Respond to CDC/HRSA Prevention with Positives Initiative.				
3a. Assess and provide harm/risk reduction methods and partner notification assistance.	Risk reduction session (15min./unit)	160	220	CDC/HRSA Prevention with Positives initiative

APPENDIX E-4

Service Priority Name: Complementary Therapies				
Service Priority # 1.b	**FY 2005 Allocation $15,000**			**Time Frame: 3/1/05- 2/28/06**
Service Goal 1: Provide access to complementary therapies				**Reference Comprehensive Services Plan Goal: A,E**
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1a. Provide acupuncture treatment as indicated by standards of care.	Acupuncture Therapy ($500 cap/client)	20	300	Parity/ comprehensiveness of service, special populations
1b. Provide osteopathic manipulation as indicated by standards of care		10	60	Parity/ comprehensiveness of service, special populations
1c. Follow –up as documented through medical case management.	Follow up (15 min/unit)	30	60	Parity/ comprehensiveness of service, special populations

Service Priority Name: Mental Health				
Service Priority # 2.a	**FY2005 Allocation $35,000**		**Time Frame: 3/1/05 – 2/28/06**	
Service Goal 1: Support PLWH who are eligible for mental health services			**Reference Comprehensive Services Plan Goal: A,C,E**	
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1a. Provide mental health support services to PLWH.	Support monitoring (30 min/unit)	5	50	Special Populations, quality and comprehensiveness of care
1b. Provide intensive support services to multiply diagnosed (MICA, HIV+) clients.	Support monitoring (30 min/unit)	8	75	Special populations, quality and comprehensiveness of care

APPENDIX E-4

Service Priority Name: Substance Abuse				
Service Priority # 2b	**FY2005 Allocation $100,000**		**Time Frame: 3/1/05 – 2/28/06**	
Service Goal 1: Support PLWH who are eligible for substance abuse services.			**Reference Comprehensive Services Plan Goal: A,C,E**	
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1a. Provide substance abuse support services to PLWH.	Support monitoring (30 min/unit)	18	125	Special populations, increasing access to populations with increased HIV prevalence
1b. Provide intensive support services to multiply diagnosed (MICA, HIV+) clients.	Support monitoring (30 min/unit)	7	75	Special populations, quality and comprehensiveness of care
1c. Provide Substance Abuse treatment in a group setting.	Supportive Group work (1hr./unit)	10	100	Comprehensiveness of care
1d. Coordinate and monitor SA and Primary Medical Care Services.	Case Monitoring (30 min./unit)	25	50	Ensuring PLWH remain in care
1e. Conduct outreach and training to service providers to facilitate more effective linkages.	Outreach/Linkage (30 min./unit)	15	25	Comprehensiveness, quality, appropriateness of services
Service Goal 2: Provide intensive substance abuse support services to IDUs.			**Reference Comprehensive Services Plan Goal: C,D**	
2a. Conduct outreach and education to PLWH who are IDUs.	Outreach/ Education (30 min/unit)	25	100	Special populations, increasing access to populations with increased HIV prevalence

APPENDIX E-4

Service Priority Name: Case Management				
Service Priority # 3 FY2005 Allocation: $140,000 (including $50,000 MAI funds)				**Time Frame: 3/1/05 – 2/28/06**
Service Goal: Provide community Case Management services to PLWH.				**Reference Comprehensive Services Plan Goal: B,C,E**
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1. Assess and complete service plan for *new* clients.	Assessment (60min./unit)	25	60	Provide access to HIV continuum of care
2. Reassess and update service plan for *established* clients.	Reassessment (30min. / unit)	75	215	Ensure engagement in primary care
3. Provide intensive Case Management to *African American and Hispanic* PLWH/A.	Face-to-face encounter (30min. / unit)	47	210	Needs of special populations
4. Participate in case conferencing with Primary Care and MH/SA programs.	Case Conferencing (30mins. /unit)	48	116	Ensure engagement in primary care
5. Assess and provide harm/risk reduction methods and partner notification assistance.	Risk reduction session (15min./unit)	75	160	CDC/HRSA Prevention with Positives initiative

Service Priority Name: AIDS Drug Assistance Program				
Service Priority # 4 FY2005 Allocation $10,000			**Time Frame: 3/1/05 – 2/28/06**	
Service Goal : Demonstrate local support and ensure continued access to primary care medical services and medications.			**Reference Comprehensive Services Plan Goal: D,E**	
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1. Continued access to ADAP for eligible PLWH.	ADAP services/payment	100	1800	Access to care, comprehensiveness of service, quality, maintenance in care

APPENDIX E-4

Service Priority Name: Transportation				
Service Priority #5	**FY2005 Allocation $ 21,400**		**Time Frame: 3/1/05 – 2/28/06**	
Service Goal :			**Reference Comprehensive Services Plan Goal: A,B,E**	
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1. Provide transportation to medical and psycho-social appointments.	One way rides	70	660	Provides access to the HIV continuum of care, and ensures engagement in primary care

Service Priority Name: Early Intervention Services				
Service Priority # 6	**FY2005 Allocation $220,000 (including $12,482 MAI funds)**		**Time Frame: 3/1/05 – 2/28/06**	
Service Goal: Identify PLWH and provide linkages to HIV primary medical care.			**Reference Comprehensive Services Plan Goal: B,C,D,E**	
Objectives	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1. Conduct outreach sessions to targeted, high risk populations.	Outreach (1 outreach session /unit)	200	600	Access to care where HIV prevalence increases, unmet need, geographic parity, cultural appropriateness, special populations, WICY
2. Locate and engage PLWH who are not in care.	Outreach & Engagement (15 min./unit)	70	200	Access to care where HIV prevalence increases, unmet need, geographic parity, cultural appropriateness, special populations, WICY
3. Link identified PLWH to primary medical care.	Referrals (.5 hr./unit)	25	100	Access to care where HIV prevalence increases, unmet need, geographic parity, cultural appropriateness, special populations, WICY
4. Locate, engage, and link African American and Hispanic PLWH who are not in care.	Outreach & Engagement (15 min./ unit)	55	250	Access to care where HIV prevalence increases, unmet need, geographic parity, cultural appropriateness, special populations, WICY

5. Link African American and Hispanic women, infants, children and youth PLWH to primary medical care.	Referrals (30 min/unit)	10	30	Access to care where HIV prevalence increases, unmet need, geographic parity, cultural appropriateness, special populations, WICY
6. Assess and provide harm/risk reduction methods and partner notification assistance.	Risk reduction session (15 min/unit)	110	330	CDC/HRSA Prevention Initiative

Service Priority Name: Nutrition

Service Priority # 7 FY2005 Allocation $80,000	**Time Frame: 3/1/05 – 2/28/06**
Service Goal : Provide home-based nutrition services to promote optimal health for PLWH.	**Reference Comprehensive Services Plan Goal:**

Objective/s	Service Unit Definition	Quantity		HRSA Objectives
		# of People to serve	Total # of Service Units To Be Provided	
1. Provide home delivery of meals for PLWH and their collaterals	Meals Provided	60	21,840	Provides access to the HIV continuum of care, and ensures engagement in primary care
2. Ensure nutritional assessment for clients (i.e. through primary care provider, other referral sources, or with contracted nutritionist).	Nutritional Assessment Follow up	40	40	Needs of special populations

Service Priority Name: Emergency

Service Priority # 8 FY2005 Allocation $25,000	**Time Frame: 3/1/05 – 2/28/06**
Service Goal: Administer & provide emergency financial assistance, including a food pantry.	**Reference Comprehensive Services Plan Goal:**

Objective/s	Service Unit Definition	Quantity		HRSA Objectives
		# of People to serve	Total # of Service Units To Be Provided	
1. Provide intake to assess and stabilize clients' emergency situations.	Intake (60min. / unit)	40	80	Provide access to HIV continuum of care

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APPENDIX E-4

Service Priority Name: Capacity Development				**Time Frame: 3/1/05 – 2/28/06**
Service Priority/Program Support		**FY2005 Allocation $7,000**		
Service Goal 5A: Provide learning experiences that increase and enhance clinical excellence, cultural appropriateness, and the quality of services within the EMA.				**Reference Comprehensive Services Plan Goal: A,B,C**
Objective/s	**Service Unit Definition**	**Quantity**		**HRSA Objectives**
		# of People to serve	**Total # of Service Units To Be Provided**	
1. Arrange a minimum of 5 trainings for local service providers	Training session and associated materials	100	5	Increase service providers' ability to deliver effective HIV/AIDS primary medical care and health-related support services. Increase access to the HIV/AIDS service system and reduce disparities in care among underserved PLWH.
2. Facilitate quarterly providers Round Table sessions		30	4	Comprehensiveness, quality, appropriateness of services

Appendix F

Attachments to be sent to HRSA

Resource Directories

-Directory of Resources and Services, New York State AIDS Institute – 2001 (all funding sources)
-New York City Service Directory – July 2005 (Title I)
-Tri-County HIV/AIDS Resource Directory of Service Providers – Winter 2003-2004 (Westchester, Putnam and Rockland -- Part of Title I NYC EMA)
-Nassau and Suffolk Counties HIV/AIDS Resource Guide - 2004 (Title I)
-Dutchess County Resource Listing - 2005 (Title I)
-Agencies Funded Under Other Ryan White Titles (Titles III and IV, Part F -- Dental, AETC, SPNS)

About the AIDS Institute 2004

New York State HIV/AIDS Surveillance Semiannual Report

For cases diagnosed through June 2004; issued November 2005

Resource Guide for Site Visit Monitoring

(New York State Department of Health AIDS Institute - revised November 2004

Acknowledgements

Many individuals and organizations contributed to making this document complete. Deep appreciation is extended to: all Persons Living with HIV or AIDS who contributed their insight and real life experiences; advocates and providers who work on the frontlines and unselfishly took the time to provide source documents, comments and feedback; colleagues from Titles I, II, III and IV and Part F who provided numerous documents and valuable input; AIDS Institute staff who comprised the SCSN Team, analyzing numerous source documents, drafting material, and presenting at Community Forums (Humberto Cruz, Mona Scully, Gloria Maki, Mary Ellen Mancinelli, Rhea Temblador, John Fuller, Lavinia Morrison, Wanda Jones-Robinson, Hope Plavin, Star Dowling, Nicole Snow, and Sheri Senecal); Bureau of Community Support Services staff directed by Jay Freedman and other AI staff who responded to numerous inquiries or helped to set up and staff Community Forums; AI Administration and Contract Management staff directed by Valerie White who provided data management and logistical support to every aspect of this project; and the Bureau of HIV/AIDS Epidemiology directed by Donna Glebatis who provided tailored data reports. Special appreciation is extended to Gloria Maki, primary author of the document; Mary Ellen Mancinelli, primary editor and organizer; Star Dowling for endless patience and production of the final document; and to each person whose name is not specifically mentioned but who contributed to making this document comprehensive and accurate.