



Faces of AIDS: Lives at the Epicenter
Photos by John Sann & Alex Brown

Tri-County
**HIV/AIDS Needs
Assessment Update**
2004

**Update to the 2002 Needs Assessment
New York HIV Health and Human Services Planning
Council 2004**

**Prepared by McClain and Associates, Inc.
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Authors

McClain and Associates, Inc.: Matthew McClain and Sue Lehrman, Ph.D.

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HIV Health and Human Services Planning Council of New York

Noemi Nagy, Community Co-Chair, Steve Hemraj, Finance Officer, Rafael Abadia, Co-Chair, PLWA Advisory Group, Joe Pressley, Chair, Planning and Evaluation Committee, Susan Abramowitz, Ph.D., Co-Chair, Data Committee, Spence Halperin, MSW, Co-Chair, Data Committee.

Office of AIDS Policy Coordination, New York City Department of Health and Mental Hygiene

Frank Oldham, Jr., Robert Cordero, David Klotz, Sean Dwyer, Stephen Bailous, Grace Moon, Beth Cohen Barusek, Ingrid Gonzalez, Matthew Lesieur, Christopher Miller, Rafael Molina, Cliff Mosley, Robert Shiau, and Clarissa Silva.

Bureau of HIV/AIDS Services, New York City Department of Health and Mental Hygiene

Marjorie Hill, Ph.D., JoAnn Hilger

HIV/AIDS Surveillance Unit, New York City Department of Health and Mental Hygiene

Susan Forlenza, MD, MPH

New York State Department of Health, AIDS Institute

Bruce Agins, MD, MPH, Humberto Cruz, MA, Ira Feldman, Dennis Tsui, Ph.D., Judy DeLorenzo, Robb Gass, MA, MPH

Mailman School of Public Health, Columbia University

Peter Messeri, Ph.D., Angela Aidala, Ph.D, David Abramson, MA, MPhil

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act
CDC	Centers for Disease Control and Prevention
CHAIN	Community Health Advisory Information Network, Columbia University
DOHMH	Department of Health and Mental Hygiene
EMA	Eligible Metropolitan Area
HIV	Human Immunodeficiency Virus
HRSA	Health Resources and Services Administration
MHRA	Medical and Health Research Association of New York City, Inc.
OAPC	Office of AIDS Policy Coordination
OI	Opportunistic Infection
PLWHA	Persons Living with HIV/AIDS
Ryan White	Ryan White CARE Act

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The *Faces of AIDS: Lives at the Epicenter* examines HIV/AIDS at the center of the epidemic – New York City. It is the stories, pictures, and lives of those who live day to day with the disease in the five boroughs of New York City. The portraits' subjects range from young children to the elderly, and reflect the ethnic and racial diversity of New York City's population. Photographs by John Sann and Alex Brown.

This 2004 Update to the 2002 Initial Needs Assessment is also available on the official website of the HIV Health and Human Services Planning council of New York at www.nyhiv.org.

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Readers Guide

The purpose of this needs assessment is to define and describe service needs and gaps in services for people living with HIV disease. This enables planning, priority-setting, and allocation of resources in local communities. In the context of HIV/AIDS funding, one objective of a needs assessment is to assure that Federal Ryan White CARE Act Title I funding is targeted where it is most needed. HIV/AIDS needs assessments also draw a comprehensive picture of an area's needs so that all resources can be spent in the most effective manner.

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*. That document, published by the Planning Council in March 2002, was used to develop the *Comprehensive Strategic Plan for HIV/AIDS Service 2002-2005*.

The New York City Department of Health and Mental Hygiene (NYC DOHMH) Office of AIDS Policy Coordination (OAPC) supports the entire planning process, including this needs assessment. OAPC provides professional and administrative support to the Planning Council, which sets priorities and allocates CARE Act Title I funds. Title I funds are granted by the Federal government to eligible metropolitan areas (EMAs) that are disproportionately affected by the HIV/AIDS epidemic. The New York EMA consists of New York City and the counties of Westchester, Rockland, and Putnam (known as the "Tri-County Region"). Funding is to support the provision of care and treatment services. A separate needs assessment and corresponding update were prepared for the Tri-County Region.

Title I grants are awarded to the chief elected official of the city or county that administers the public health agency providing services to the greatest number of people with AIDS in the area. In the New York EMA, the Title I grant is awarded to the Mayor of New York City, and the NYC DOHMH is the designated grantee. Consistent with the CARE Act Amendments of 2000, the Planning Council is responsible for establishing the service priorities to which Title I funds are allocated within the New York EMA.

The Planning Council will include this needs assessment update in the body of evidence used to set priorities and determine resource allocations for Title I resources. The Planning Council conducts much of the detailed work of planning through six Work Groups, additional input from subcommittees, planning groups, and the PLWHA Advisory Group. Community forums and Consumer Advisory Board (CAB) surveys also provide important information. Furthermore, the OAPC organizes multiple Data Day Symposia to support and facilitate the Planning Council's planning and priority setting. Researchers from the NYC DOHMH, the New York State AIDS Institute, Columbia University, The New York Academy of Medicine, Laurence A. Pagnoni Associates, and other New York institutions participate in the Data Days to present data pertinent to the planning process.

This update was designed to be consistent with the CARE Act Amendments of 2000 that sets guidance as promulgated by the HIV/AIDS Bureau, HRSA. The major elements of the needs assessment are:

- An Executive Summary
- An updated epidemiological profile that identifies trends and describes the current status of the epidemic in New York City, specifically the prevalence of HIV and AIDS among defined sub-populations
- Overview of data on persons with HIV and AIDS who are not in care
- Updated information on service needs, gaps, resources, and barriers to care
- Recommendations

Needs assessment, like any step in planning, is not a completely precise process. Even the most comprehensive and rigorous needs assessment will have missing or even conflicting information. It is the responsibility of the Planning Council to apply its best effort, analysis, and judgment in considering all the information that is available to its members in defining gaps, developing goals and objectives, and setting priorities.

This needs assessment was developed using a variety of methods and types of data. We gathered and analyzed quantitative and qualitative data drawn from a wide range of existing data sources. Indeed, a large volume of source material was condensed into a manageable collection of essential needs assessment data where approximately 80 documents were gathered and analyzed.

A number of special meetings were held to facilitate the data collection. Of particular note, representatives from the Planning Council, Community Health Advisory Information Network (CHAIN), the AIDS Institute, MHRA, and NYC DOHMH were consulted to describe how data from their organizations could be utilized. As the Needs Assessment Update progressed, representatives from these entities provided additional input and comments.

The needs assessment update is a tool. Its structure and organization was drawn from HRSA guidance and technical assistance materials, from *the 2002 Needs Assessment and Comprehensive Plan*, input from the NYC DOHMH, MHRA, and from direction provided by the OAPC. This update is intended to provide the

Planning Council and its Work Groups and committees with a common base of evidence for use in its decision-making.

Data Sources and Citations

This appendix lists all the data sources used for developing this update through May 1, 2004. The OAPC, NYC DOHMH, MHRA and CHAIN provided many of the documents. Every document is given a unique code number beginning with #130 (the 2002 Needs Assessment listed 129 documents). All documents were studied for their relevance to the needs assessment update and planning process.

Throughout the document, readers will find sources referenced using a unique code number. In addition, where available, the specific page or slide number of that document is cited. This is intended to give the reader the ability to note specific objective evidence for future planning-related decision-making.

For example, “The strongest theme across the five forums was the need to increase the availability of, and access to, HIV services (186:2)” appears at the beginning of chapter 5. A reader interested in more information would first turn to this section and look up document #186, Community Forum Report, Spring 2004, HIV Health and Human Services Planning Council of New York, April 5, 2004, NYCDOH/OAPC. On page 2 of that document will be found the specific information cited in Chapter 5.

CHAIN Background

The CHAIN study (Community Health Advisory Information Network, Columbia University) is a 10-year longitudinal HIV cohort study examining the interrelatedness among HIV, access to care, poverty and various co-morbidities (i.e. mental health, substance abuse) and the behavioral, social and service-related characteristics of people living with HIV/AIDS. The original CHAIN cohort was recruited in 1994 and 1995, and a refresher cohort was added in 1998. These individuals represented HIV-positive adults in the city who first became aware of their HIV status or received an AIDS diagnosis between 1980 and 1997. As the epidemic has shifted and the city’s service system has grown it has become increasingly important to add the voices of individuals more recently diagnosed with HIV or new to the system of care. In the summer of 2002, a new cohort was added to help inform the decisions of the Planning Council and the Work Groups (156:2). A similar cohort was established in the Tri-County region in 2001.

Needs Assessment Update: Definitions for Reference

Certain definitions are important to keep in mind:

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

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

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

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

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

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

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

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

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

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

Executive Summary

Epidemiology Update, Unmet Need Findings, Other Key Findings

Broadly speaking, data examined in the preparation of the Needs Assessment Update 2004 are consistent with the findings presented in the 2002 Needs Assessment:

- Persons with HIV/AIDS who seek care and services can get them in New York City;
- Housing is a significant unmet or partially unmet need in New York City for people living with HIV/AIDS;
- Qualitative and quantitative data is available on the characteristics and needs of the populations of people living with HIV/AIDS in New York City, but certain data gaps also exist; and
- Gaps exist due to the fact that persons diagnosed with HIV before June 2000, who are not in care, are not known in the Surveillance Registry.

This is not to suggest that changes in Title I priority setting and resource allocations are unwarranted. Evidence in both documents exists that supports changes and improvements, as does the EMA's *Comprehensive Strategic Plan 2002-2005*. Recommendations are included in Section 6.

Updated Epidemiological Data

With the exception of new data available through named HIV reporting, begun in 2000, the epidemiological landscape of HIV/AIDS in New York City has not changed dramatically since the publication of the Initial Needs Assessment in 2002.

As of April 2003, 83,249 New Yorkers were known to be living with HIV, 55,818 of whom had an AIDS diagnosis (204:1). Among persons diagnosed with and living with AIDS as of 2003, the proportion of women is increasing (132:18). This is also true for the proportion of youth and persons aged 50 and above (132:17).

Named reporting of HIV infection began on June 1, 2000 (137:12). A large proportion of persons newly diagnosed with HIV infection have evidence of

advanced infection at the time of diagnosis. In 2002, 25% of them 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 40 and above had a disproportionately high percentage of late diagnoses (204:2).

Information on Persons Not in Care

HRSA has mandated that a single “unmet need” estimate be part of an overall needs assessment which supports comprehensive service planning. It can be concluded that the EMA is meeting expectations regarding development of the estimate of unmet need required by the CARE Act Amendments of 2000.

Based on the HRSA definition of “unmet need”, and using Medicaid and ADAP claims data, as well as NYC DOHMH surveillance data, adjusted for individuals covered by private insurance or receiving VHA health care coverage, 32% of those living with HIV/AIDS in New York City were found to have “unmet need” (200:10). A detailed description of the limitations in the methodology used to estimate “unmet need” can be found on page 38.

Owing to methodological challenges and inexperience in interpreting the meaning of the “unmet need” estimation, care should be exercised at this time when using this calculation to make changes in the EMA’s 2005 priorities and resource allocations. Despite limitations, the Medicaid and ADAP databases offer the best data on people living with HIV/AIDS available in New York State for the calculation of unmet need.

Several other approaches have been used in New York City to examine the issue of delayed entry into care, including examination of CHAIN and NYC DOHMH surveillance data. HIV surveillance reporting is relatively new and still being refined and CHAIN involves self-reported data based on a sample of HIV infected individuals, not the entire population. Nonetheless, these two sources document a significant gap in accessing care (146:12). According to the HIV/AIDS surveillance data, in 2002, 38% of individuals newly diagnosed with HIV (non-AIDS) lacked evidence of entry into care within 12 months of their HIV diagnosis (141:12), and CHAIN found that 20% of its cohorts were found to have delayed entry into medical care by at least four months (1:191).

The most critical factor associated with delayed testing or treatment tends to be whether or not the individual is experiencing symptoms. Beyond this, delayers tend to be current or historic drug users, have mental health difficulties, be homeless or unstably housed, have no regular sources of income, or have histories of incarceration.

Delays occur because the perceived costs of HIV care-seeking (concerns about stigma and rejection, retention, and fears of social and legal consequences of revealing risk behavior) are greater than the perceived benefits. Clients are less

likely to delay entry into care if testing sites actively facilitate entry into the medical system (141:1).

General Information Since 2002

Service Needs and Gaps

The Planning Council is responsible for setting priorities and allocating resources to determine how best to meet the needs of individuals living with HIV/AIDS. The Council should link available assessment of service needs, gaps and barriers to make sound decisions about service priorities and use of resources.

The purpose of this document is to present a summary of the data sources to inform the HIV Health and Human Services Planning Council of New York in setting priorities and allocating resources for FY 2005. This summary contains information from various sources, including researchers, health care providers and the community. The summary is designed to provide a comprehensive portrait of the HIV epidemic and its service gaps in the New York Eligible Metropolitan Area (NY EMA).

The Planning Council utilizes information garnered from the Comprehensive Care Model for guidance in priority setting and resource allocation (210:3). CHAIN developed an “ideal” model of an HIV care system, one that encompasses both health and social services within a continuum of care. Central to this model HIV care system is comprehensive medical care with the desired end result of improved health status (reduction in HIV transmission and lower viral load). In this model, case management has been shown to assist individuals engage in medical care and maintain continuity, either directly or through risk-reducing supportive services or through logistical services. (See pg. 11 for detailed information.)

In 2003 the following service gaps were identified for CHAIN participants: a 50% gap in AOD, 38% for patient-provider communication, 30% for comprehensive case management, 24% for comprehensive medical care and 23% for professional mental health services. (210:4). Mapping of these gaps revealed (204:4) that the geographical distribution of service gaps tends to mirror the epidemiology of PLWA's in the sub-borough areas and that Ryan White-funded agencies tend to cluster around populations of those experiencing service gaps and also tend to be close to public transportation.

Additionally, CHAIN has conducted a multivariate analysis (a statistical model that enables the reader to examine the independent effect of population demographics and system characteristics on outcomes) examining service gaps and strategic planning progress indicators (206:13). Based on this analysis, the original CHAIN cohort reported a lower physical health score; men had medication adherence difficulties; Brooklyn residents had the most difficulty in obtaining comprehensive medical care; the new CHAIN cohort had an episode of unstable housing in the past 6 months; and being white was identified with

experienced barriers to medical and social services care. (See pg. 45 for detailed information.)

Ryan White Title I Program Summary Report data for the period March 2002-February 2003 were consistent with CHAIN data regarding the geographic distribution of services (197:64). These data also revealed an 8% increase in new client encounters in FY 2002 and that women, Hispanics, and those over 50 years of age were over-represented among new clients.

AOD Work Group

The AOD Workgroup furthers four goals: 1) Improve the health of AOD users; 2) Improve the housing stability of AOD users; 3) Reduce AOD-related harm; and 4) Ensure the effective communication, coordination, and collaboration among consumers and service providers.

Service gaps continue to exist among persons with HIV/AIDS in New York City in need of alcohol and drug counseling and treatment services, with gaps distributed proportionately across boroughs and race groups (142:22). Among the CHAIN cohort, utilization of drug treatment appears to be declining, although the need itself is not declining, thus leading to a widening service gap (161:2). Exposure to trauma and violence among AODs (which itself is highly prevalent among CHAIN participants) is a predictor of not maintaining continuous medical care, which suggests that providers should screen for such exposure to identify patients at risk of being lost to care (157:5). Meanwhile, measures related to delaying entry to care and receipt of supportive mental health services among the new and old CHAIN participants are similar (206:5).

Health Services Work Group

The Health Services Work Group furthers four goals: 1) Ensure that people living with HIV achieve and maintain optimal health and well being; 2) Provide access to care for people with HIV disease throughout the NY EMA; 3) Ensure that HIV care and services are high quality; and 4) Respond to changes in publicly financed HIV care and services.

HIV-related health care in the NY EMA is widely available across a range of settings, and is generally of high quality (145:5-10). Once connected to care, very high proportions of CHAIN participants retain the same primary care provider (87%) (161:2) and access to ARV treatment has increased each year since 1996 without differences between gender, risk, or race/ethnicity (201:10). Evidence from CHAIN and Title I HIV Quality Management program suggests that shortfalls in provider performance are evident in such areas as provider attitudes (161:2), discussing partner notification (161:2), and treatment adherence (201:16).

In a multivariate analysis based on *Strategic Plan* Indicators, CHAIN identified a number of factors associated with five selected outcomes. For example, the most salient factors associated with clients reporting poorer physical health were

problem drug use, a t-cell count of less than 500, age over 50 years old, poor mental health, having experienced barriers to accessing care, and being a respondent in the original cohort. This analysis considered a number of factors that might have been related to the specific outcome: gender, age, race/ethnicity, HIV risk, borough, drug use history, mental and physical health, continuity of medical care, the comprehensiveness of medical care, and the year of HIV diagnosis (206:13). The EMA's Minority AIDS Initiative (MAI), which targets persons of color who are either not already in care or who are at risk of dropping out of care, appears to be effective (document 152). Persons reached by MAI programs show improvement in health outcomes including adherence to treatment and improved CD4 and viral load measures (document 149).

Housing Work Group

The Housing Work Group furthers three goals: 1) Increase the volume of housing units that are appropriate for people living with HIV/AIDS; 2) Expedite access to existing housing and provide supportive services for people living with HIV/AIDS; and 3) Improve the quality of housing in which people with HIV/AIDS are living.

Persons in appropriate housing are 4 times more likely to receive ongoing medical care than persons who are homeless or unstably housed (143:2). Housing and housing-related services remain largely unmet needs across the EMA, despite the large number of people living with HIV/AIDS (26,800) who receive housing assistance from HASA, an increase of 11.5% over a 2-year period (143:2). CHAIN documented a relationship between homelessness/unstable housing and past experience of trauma and violence, dynamics contributing to delayed care seeking. Other factors associated with homelessness or unstable housing are being male, problem drug use, and young age (20-34 years). The new CHAIN cohort was far more likely than the original cohort to have experienced an episode of unstable housing and/or homelessness (206:5).

Infrastructure Work Group

The Infrastructure Workgroup furthers two goals: 1) Empower people living with HIV to make informed personal health choices and assist providers in delivering quality HIV services; and 2) Strengthen the continuum of care for persons living with HIV by building the capacity of service providers.

An important factor in reducing morbidity and mortality is information on what medical or social services are available and where they exist affects when persons seek assistance. CHAIN found that overall, there were no statistically significant differences in the percent of people who reported delaying or not seeking medical or social services because they did not know where to go to for services when the new cohort was compared with the original CHAIN cohort. However, women were more likely than men to delay or not seek services because they don't know where to get specific medical or social services (206:5). In terms of meeting the second goal, quality of care data collected by the Title I HIV Quality Management Program suggests providers need capacity building

and technical assistance services to support and enhance delivery of quality services. Other factors contributing to low scores on quality of care indicators include gaps in care coordination and communication due to weak infrastructure.

Mental Health Work Group

The Mental Health Workgroup furthers two goals: 1) Ensure a continuum of appropriate, high quality mental health care and services; and 2) Facilitate access, engagement, and retention in care by providing integrated mental health care and services.

Mental health needs persist across the EMA. Among CHAIN participants, mental health service gaps are reported in all boroughs (142:26) and across all race groups (142:27). Over 90% of CHAIN participants reported one or more traumatic events in their lifetime (157:2). However, 63% percent of respondents with very low mental health did not report receiving professional mental health services in the prior 6-month period. (210:9). New York State HIV Quality Management Program data suggests provider adherence to standards of care, although coordination between mental health and primary care was poorly documented (201:18).

Social Services Work Group

The Social Services Work Group furthers four goals: 1) Provide a comprehensive range of available and accessible HIV-related social service programs; 2) Ensure effective communication, coordination and collaboration among social services, medical, housing and other service providers; 3) Ensure that people living with HIV disease have access to the knowledge, skills, and assistance necessary for them to successfully navigate and utilize services within a changing service delivery system; and 4) Ensure the delivery of high quality social services.

New needs assessment data are available for case management, nutrition, and social services for persons over age 50. Case management service gaps exist across all boroughs (142:30) and race groups (142:31). A further analysis of case management service gaps found that while white and Latino are more likely to report a service need for case management in the comprehensive care model, women are significantly more likely to experience a service gap (document 190). When compared to earlier cohort, there were no significant differences emerged in various social service needs reported by the new CHAIN cohort, suggesting a general level of stability in met and unmet social service needs. One exception was among 20-34 year olds, who were more likely to have unresolved problems in legal matters, child care, or food services than older CHAIN respondents.

New York State HIV Quality Management Program data show that coordination of care was documented less than half the time (201:20). Assuming that an absence of documentation reflects accurately an absence of service coordination, improvements in service coordination, particularly with primary care, are warranted.

When comparing respondents who had comprehensive case management to those to those who did not, we found that people without comprehensive case management were also more likely to report comprehensive medical service gaps, supportive mental health gaps, both financial and permanent housing service gaps, and transportation gaps. (210:11) This suggests that had these people had comprehensive case management they might not have experienced these co-occurring service gaps.

Recommendations

Using the Unmet Need Estimation

The HRSA-mandated unmet need estimate is a multi-year process. This Needs Assessment Update summarizes the output of the first cycle of effort around this complex, and relatively new approach by the CARE Act in identifying a population not in care. Although caution should be exercised at this time when using this calculation to make current changes in the EMA's 2005 priorities and resource allocations, as reliable data becomes more accessible, the estimation will increasingly become more useful. We recommend continuing to pursue improvements in accessing reliable data as well as continuing to find additional means to shed more light on the population of persons not in care.

In the interim, the *Planning Council is urged to consider ways of addressing the barriers to improve engagement in care and to strengthen the current system of institutional linkages and maintenance in care.* Existing priorities can be re-prioritized or enhanced based on best practices and evidence from health services research efforts.

The NYC DOHMH, as the designated grantee, and MHRA, work in partnership with the Planning Council in developing sound service models. The Planning Council may undertake actions that are appropriate to its legislatively mandated duties such as, but not limited to, the following:

- Lead the development of an EMA-wide unified goal for HIV/AIDS prevention interventions and care services;
- Take a position to affirm (or re-affirm) its desire for the EMA's service delivery models to have the capacity to address clients' barriers to improve engagement in care;
- Take a position to enhance linkages, referrals, and maintenance in care;
- Select new Planning and Evaluation initiatives that expand the EMA's knowledge of the effectiveness of service delivery models, that identify the barriers to effective linkage and referral, and that describe strategies to address them; and
- Target technical assistance resources to activities that enable providers to adapt and improve their service delivery models to increase retention in care and to improve linkage and referral of clients.

Data and Planning

More immediately useful are new data on those persons who delay entry into care, and on delayed HIV testing in general. Policy recommendations flowing from the *Delayed Entry to HIV Care* study include the following (146:27-29):

- Provide more realistic information about treatment, particularly at the time of pre- and post-test counseling;
- Improve the ease, speed and convenience of HIV testing;
- Assure better linkages to medical care for people who test positive;
- Expand the availability of culturally sensitive providers;
- Explore regulatory or funding changes to provide medical care at community-based organizations (especially Article 28 providers), rather than relying on partnership arrangements;
- Address contextual factors (housing, prior involvement with medical care, social isolation) during testing and counseling; and
- Educate legal and benefits policy makers and service providers on the consequences of an HIV/AIDS diagnosis.

To these we add the recommendation that the EMA adapt service delivery systems and proactive patient navigation models of care that provide linkages to medical care for people who test positive, and intensify the focus on those specific populations who are known to delay testing and access to care. This would be accomplished by reducing known barriers that are within the realm of the health and supportive services system, such as facilitating entry into care at the point of a positive test result, regardless of type of setting. Continued attention to the data and evaluation gaps discussed in the 2002 Needs Assessment is also recommended.

Updated Epidemiologic Data

New Population Data on the HIV/AIDS Epidemic

Methods and Introduction

The Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC) have collaborated to define epidemiological questions to be addressed in an integrated profile to be prepared by each jurisdictional area receiving Title I funding. The New York City Integrated Epidemiological Profile is due to be published shortly after completion of the Needs Assessment Update.

This section of the Needs Assessment Update answers three questions relative to New York City:

- 1) What are the sociodemographic characteristics of the general population?
- 2) What is the scope of the HIV/AIDS epidemic?
- 3) What are the indicators of HIV infection risk?

Sociodemographic Characteristics of the General New York City Population

New York City far exceeds other large U.S. cities in terms of the number of AIDS cases diagnosed through June of 2000. Although the City has 3% of the US population, almost 16% of people living AIDS in the US reside in NYC and 24% of the perinatally infected children, and 17% of AIDS deaths in the US have occurred in NYC. (137:4)

Tables 1 and 2, presented below, are based on the most recent US Census Bureau data.

Table 1: New York City Population by Borough

City & Borough	2002 Census Population		% Change from 2000	Median House-hold Income (2000)	% Foreign Born (2000)	% of Persons 25+ with Bachelor's Degree
	Number	% of Total				
Bronx	1,354,068	17.7	1.6	\$27,611	29.0	14.6
Brooklyn	2,488,194	30.8	0.9	\$32,135	37.8	21.8
Manhattan	1,546,856	19.1	3.3	\$47,030	29.4	49.4
Queens	2,238,815	27.7	0.4	\$42,439	46.1	24.3
Staten Island	457,388	5.7	3.1	\$55,039	16.4	23.2
New York City Total	8,085,321	100.0	1.5	\$38,660	36.1	26.8

Data from *New York QuickFacts* from US Census Bureau

Table 2: 2000 New York City Population by Race/Ethnicity

Race/Ethnicity	Bronx Percent	Brooklyn Percent	Manhattan Percent	Queens Percent	Staten Island Percent	New York City Total
White (Non-Hispanic)	14.5	34.7	45.8	32.9	71.3	35.2
Black (Non-Hispanic)	31.2	34.4	15.3	19.0	8.9	24.8
Hispanic	48.4	19.8	27.2	25.0	12.1	27.5
Asian	2.9	7.5	9.3	17.5	5.6	9.8
American Indian/Alaska Native	0.3	0.2	0.2	0.3	0.1	0.2
Native Hawaiian/Pacific Islander	<0.1	<0.1	<0.1	<0.1	<0.1	<0.1
2 or More Races (Non-Hispanic)	2.0	2.8	1.9	4.1	1.8	2.8
Other Non-Hispanic	0.6	0.7	0.4	1.3	0.2	0.8

Data from *New York QuickFacts* from US Census Bureau

The above tables articulate the following:

- Between 2000 and 2002 the US population grew by 2.5%, while overall the population of New York City grew only 1.5%. However, growth in Manhattan and Staten Island exceeded the national average.
- Manhattan, Staten Island and Queens exhibit factors generally associated with better economic conditions: higher median household incomes and higher proportions of individuals with bachelor's degrees. Manhattan and Staten Island have the largest proportions of Whites and the smallest proportions of Black/non-Hispanics.
- Bronx and Brooklyn exhibit factors generally associated with worse economic conditions: lower median household incomes, the highest proportions of Black/non-Hispanics, and lower proportions of individuals with Bachelor's degrees.

The prevalence of persons known to be living with HIV/AIDS (PLWHA) and the percent known to be living below the poverty line, by borough, is shown in Chart 1 (137:7). This chart indicates that the highest number of diagnosed individuals is found in the Bronx and that, with the exception of Manhattan, there tends to be a correspondence between the prevalence of PLWHA and the percentage of individuals living in poverty. Manhattan has the highest prevalence of PLWHA, but has a lower percentage of individuals living in poverty than the Bronx or Brooklyn.

Chart 1

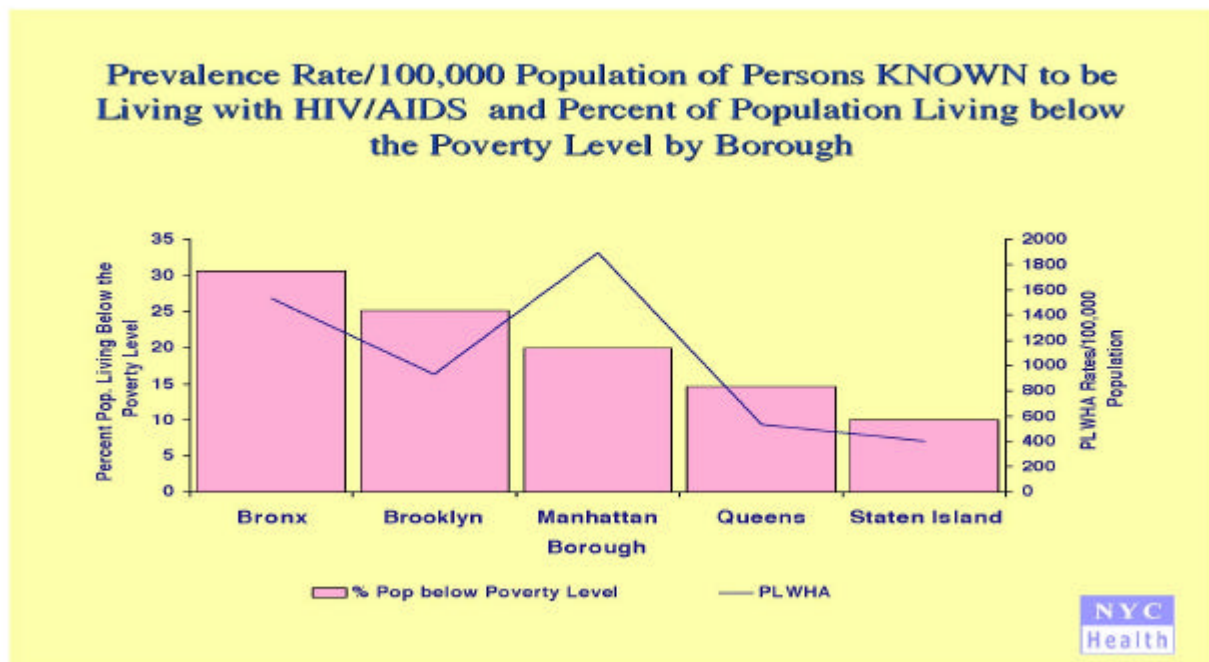


Chart 2 reveals, compared to the population in general, that in 2001 Manhattan and Bronx had a disproportionately high share of the NYC AIDS population, while Queens, Staten Island and Brooklyn had a lower share (137:6).

Chart 2

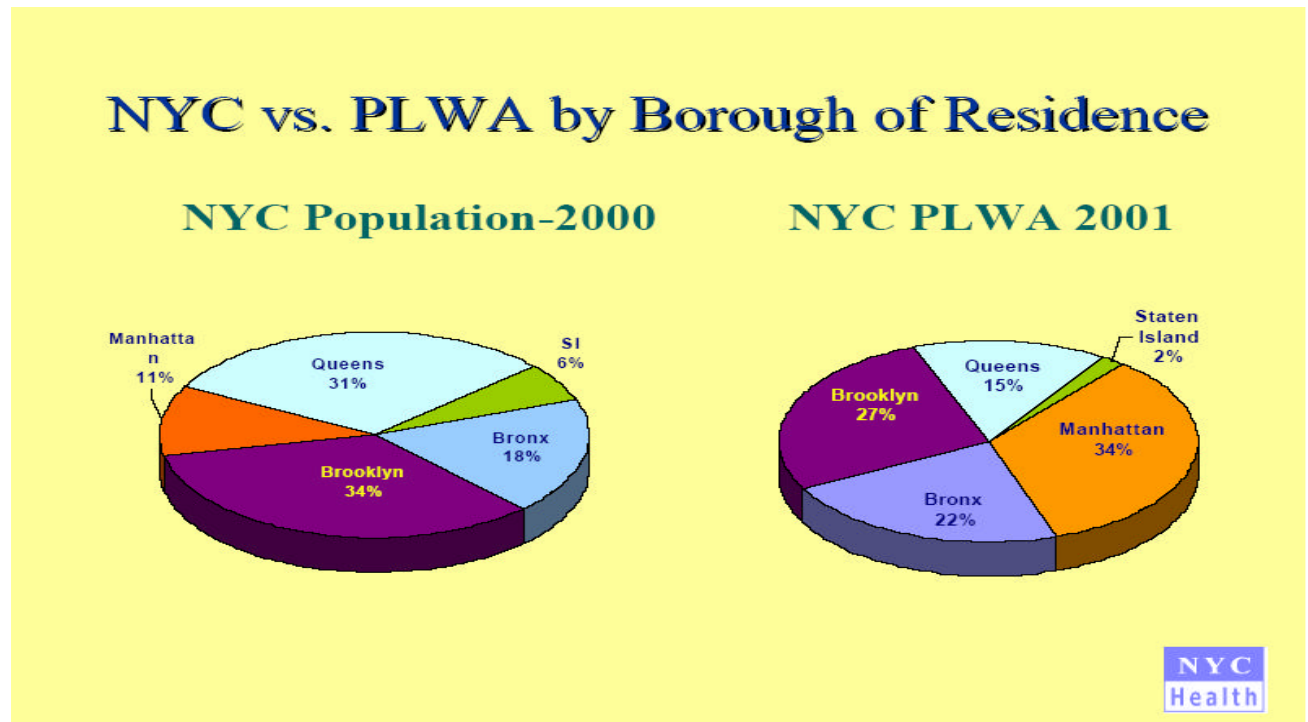
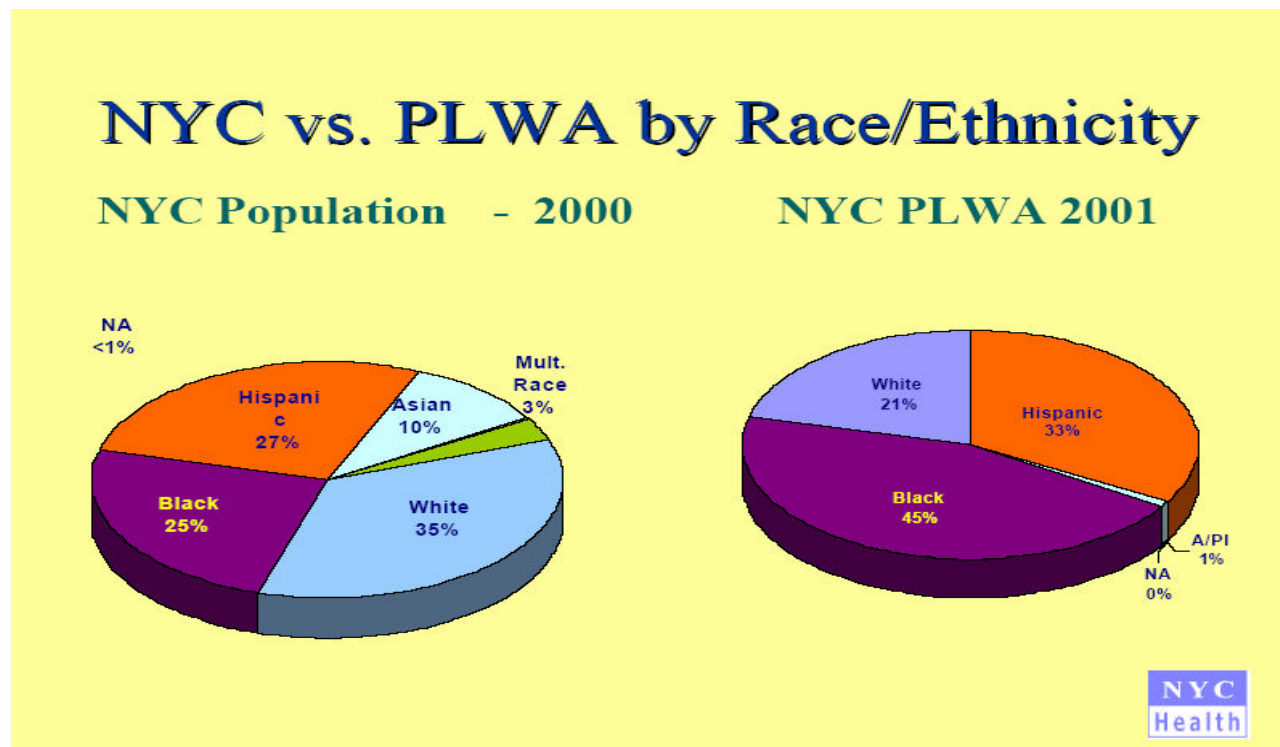


Chart 3 reveals that, compared to the population in general, in 2001 the proportion of Blacks and Hispanics with AIDS was disproportionately high (137:5).

Chart 3



Scope of the HIV/AIDS Epidemic in New York City

Cumulatively, 137,168 New Yorkers have been diagnosed with AIDS since 1981. Sixty-one percent of these individuals have died. Mortality from HIV dropped sharply beginning in 1996, but New Yorkers continue to die of HIV (Chart 4). In 2002, 1,712 persons died of HIV-related causes and 2,448 persons with HIV or AIDS died of all causes. (204:1)

Tables 3 through 5, below, rank causes of death, for various age groups, in New York City in 2001. They show that AIDS is a significant cause of death in New York City, ranking fifth among all causes of death for the entire population, and first among causes of death for those in the 25 to 34 year old category as well as those in the 35 to 44 year old category.

**Table 3: Ranking of Five Leading Causes of Death Among
Persons of All Ages, NYC, 2001**

Cause of Death	Rank	Number of Deaths	Percent	Rate per 100,000 Population
Diseases of Heart	1	24,203	40.2	302.2
Malignant Neoplasms	2	14,041	23.3	175/3
Influenza and Pneumonia	3	2,505	4/2	31/3
Cerebrovascular Diseases	4	1,887	3.1	23/6
HIV Disease	5	1,774	2.9	22.2
Total from all Causes		60,218		

Source: NYC DOHMH Vital Statistics Death Registry

**Table 4: Ranking of Five Leading Causes of Death Among
Persons 25-34 Years of Age, NYC, 2001**

Cause of Death	Rank	Number of Deaths	Percent	Rate per 100,000 Population
HIV Disease	1	194	15.1	14.2
Assault (Homicide)	2	193	15.0	14.1
Accidents (Except Poisoning by Psychoactive Substance)	3	150	11.7	11.0
Use of or Poisoning by Psychoactive Substance	4	150	11.7	11.0
Malignant Neoplasm	5	143	11.1	10.5
Total from all Causes		1,286		

Source: NYC DOHMH Vital Statistics Death Registry

**Table 5: Ranking of Five Leading Causes of Death Among
Persons 35-44 Years of Age, NYC, 2001**

Cause of Death	Rank	Number of Deaths	Percent	Rate per 100,000 Population
HIV Disease	1	638	21.1	50.5
Malignant Neoplasms	2	526	17.4	41.2
Diseases of the Heart	3	356	11.8	28.2
Use of or Poisoning by Psychoactive Substance	4	333	11.0	26.4
Accidents (Except Poisoning by Psychoactive Substance)	5	188	6.2	14.9
Total from all Causes		3,020		

Source: NYC DOHMH Vital Statistics Death Registry

Table 6 below shows a summary of HIV-related death rates from 1998 – 2002 by neighborhoods. The table shows that certain neighborhoods, including Bedford, Fort Greene, Mott Haven, Tremont and Morrisania, East Harlem and Central Harlem have persistently exceeded the New York City HIV-death rates by at least two fold (these neighborhoods are *italicized* in the table).

Table 6: Death Rates per 100,000 Population from HIV disease by Health Center District of Residence, New York City, 1998-2002

Death Rates per 100,000 Population from HIV Disease by Health Center District of Residence					
	Rate (1998)	Rate (1999)	Rate (2000)	Rate (2001)	Rate (2002)
Health Center District					
New York City	27.0	27.6	24.5	22.2	21.4
Manhattan	34.7	33.9	31.9	26.8	26.3
<i>Central Harlem</i>	72.7	76.2	68.7	61.4	51.7
<i>East Harlem</i>	58.1	62.1	50.7	52.9	55.8
Kips Bay-Yorksville	11.0	12.3	7.0	4.5	6.6
Lower East Side	41.8	42.6	44.9	36.7	30.1
Lower West Side	35.0	29.9	31.3	23.9	23.2
Riverside	31.6	27.8	29.0	24.6	27.0
Washington Heights	23.6	22.5	19.0	14.3	17.6
Bronx	41.1	45.9	38.5	37.2	34.1
Fordham-Riverdale	33.0	27.3	29.1	26.9	22.0
<i>Morrisania</i>	71.9	94.7	77.9	64.2	56.5
<i>Mott Haven</i>	47.8	59.3	47.6	50.5	46.9
Pelham Bay	18.3	19.3	15.1	20.0	14.3
<i>Tremont</i>	62.5	74.0	64.0	62.1	55.2
Westchester	32.3	32.0	21.2	21.2	27.2
Brooklyn	26.5	25.5	25.8	22.6	22.1
Bay Ridge	6.7	4.2	5.2	2.9	4.4
<i>Bedford</i>	50.2	47.2	53.0	48.2	46.1
Brownsville	38.4	38.4	36.8	35.8	35.1
Bushwick	39.4	41.6	37.2	32.0	36.7
Flatbush	18.7	18.9	16.5	14.5	16.0
<i>Fort Greene</i>	55.3	49.3	62.9	46.5	45.9
Gravesend	7.4	8.8	7.4	10.0	8.1
Red Hook-Gowanus	27.4	32.2	35.9	26.0	26.9
Sunset Park	18.2	10.6	14.3	10.2	5.6
Williamsburg-Greenpoint	24.4	23.7	25.6	24.3	16.8
Queens	11.0	11.6	9.1	9.0	8.5
Astoria	12.7	12.7	7.0	9.6	7.0
Corona	11.7	9.6	6.0	7.4	6.8
Flushing	5.7	3.7	4.0	3.8	4.0
Jamaica East	17.8	23.4	19.8	16.7	14.0
Jamaica West	11.6	14.1	12.6	12.6	13.5
Maspeth-Forest Hills	8.5	8.2	4.7	4.4	5.1
Richmond	12.9	13.7	7.4	9.2	11.0

Source: NYC DOHMH, Vital Statistics

The HIV/AIDS Surveillance unit relies on laboratories and providers for case reporting. As of March 31, 2003, over 83,000 New Yorkers were diagnosed and known to be living with HIV or AIDS. This included 27,431 with HIV (non-AIDS) and 55,818 with AIDS. However, the true number of PLWHA in NYC is higher. It is estimated that at least 25% of persons living with HIV have never been tested and another 25% of people were not diagnosed with HIV until they were diagnosed with AIDS. In addition, there is a time lag between the time of diagnosis and the time of case reporting, resulting in delays in case reporting. (153:3). Furthermore, persons diagnosed with HIV prior to June 2000 who are not in care are not reportable under New York State HIV Reporting Law. As a result, reporting of persons with HIV underestimates the number of persons diagnosed who are not in care.

Chart 4 provides an overview of reported AIDS cases, PLWHA and AIDS deaths in NYC from the early 1980s through 2002. Although complex, this chart provides a wealth of trend information, including milestones in the treatment of the disease and corresponding changes in its progression. Note also that, from 2000 on, HIV surveillance data (representing the start of named HIV reporting) has been added to the chart. (153:1)

Chart 4
Reported AIDS Cases, PLWHA and Deaths, New York City 1981 – 2002

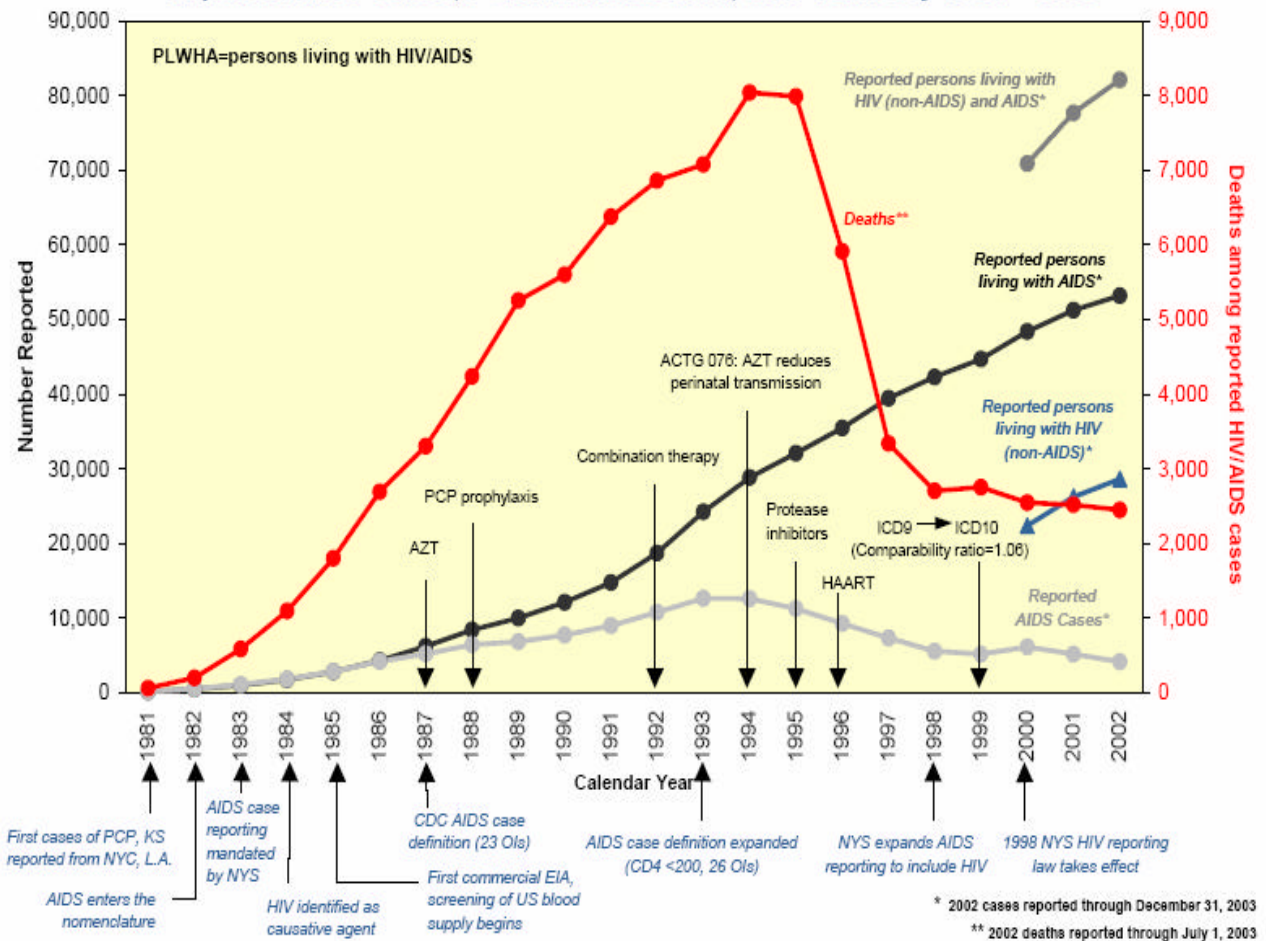


Chart 5 shows AIDS case rates per 100,000 population for men and women. The difference in case rate by gender has varied from being three times as large a rate in men compared to women in 1990 to a little over twice in 2001. Among persons diagnosed with and living with AIDS, the proportion of women is increasing. (132:18).

Chart 5: AIDS Case Rate/100,000 Population by Gender and Year of Diagnosis

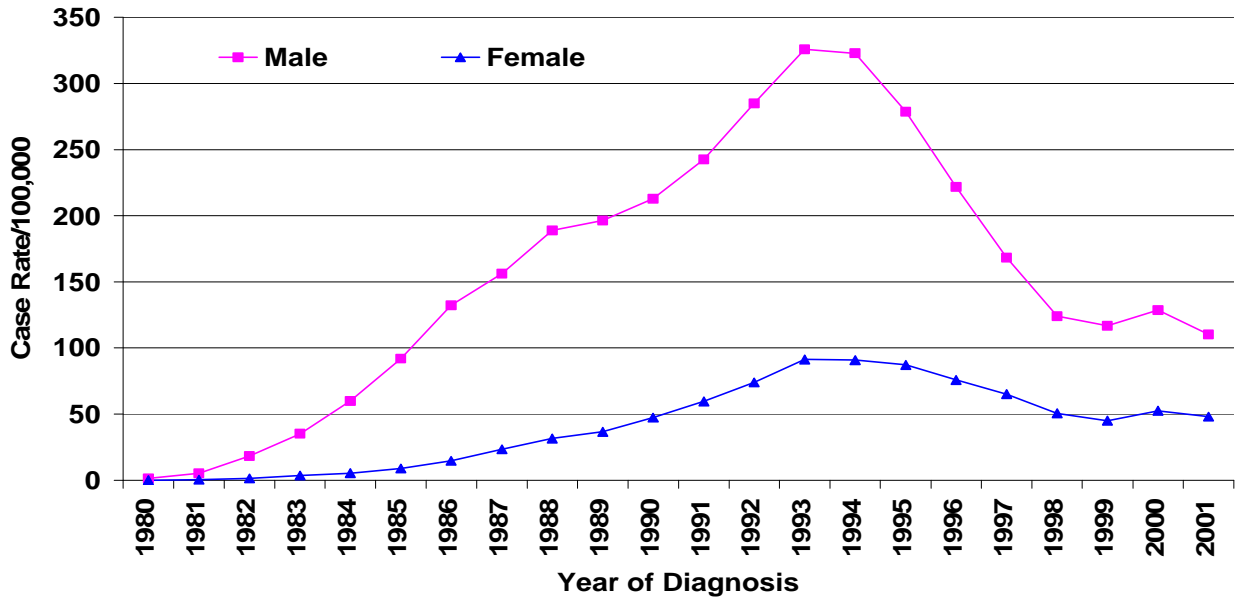


Chart 6 shows the distribution of AIDS case rates in men by race and year of diagnosis (132:10). Early on, the case rates were similar for black, Hispanic and white men. However, in the late 80's, the case rates in black and Hispanic men increased more than that for white and Asian men, although the differences have declined in recent years. Chart 7 reveals similar trends among women by race/ethnicity (132:13).

Chart 6: Adult AIDS Case Rates/100,000 Population in Men by Race/Ethnicity and Year of Diagnosis

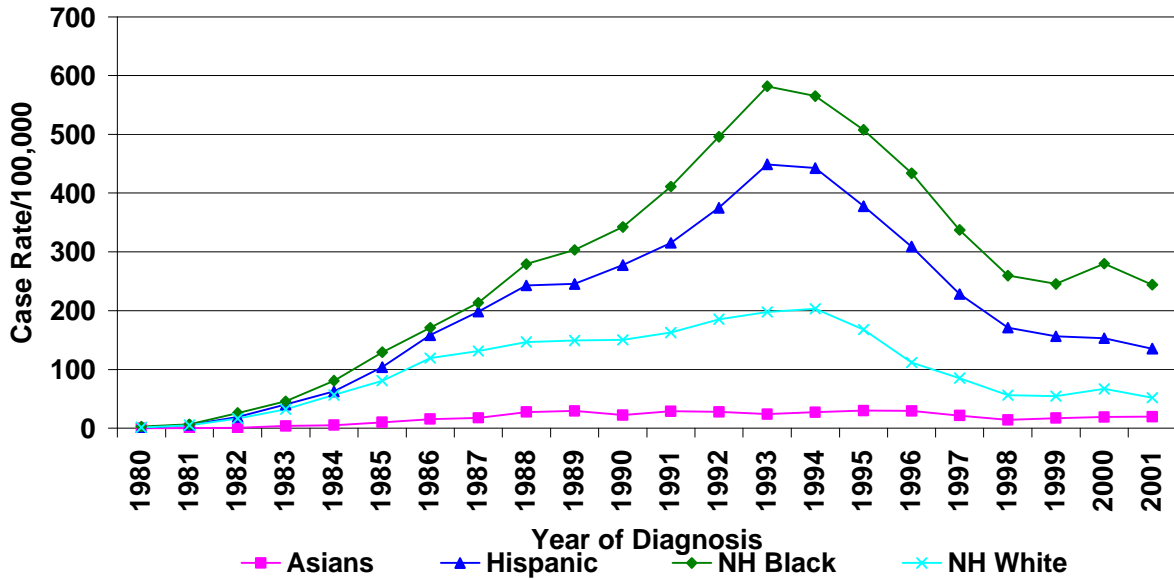


Chart 7: Adult AIDS Case Rates/100,000 Population in Women by Race and Year of Diagnosis

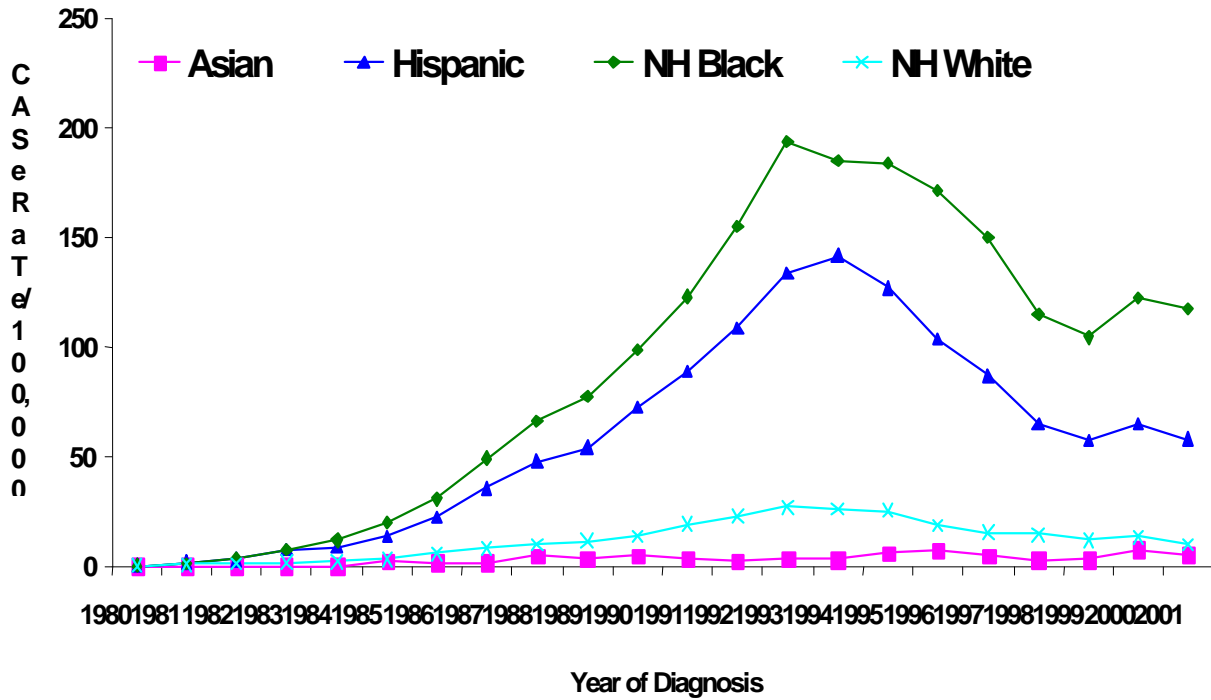


Chart 8 shows that throughout the epidemic, the most heavily impacted have been persons in their 30's and 40's. Although an increase has been noted in those above 50 in 2000 and 2001, it is probably too early to determine if this is a trend. (132:17).

Chart 8: Adult AIDS Case Rates/100,000 Population in Category by Age Group and Year of Diagnosis

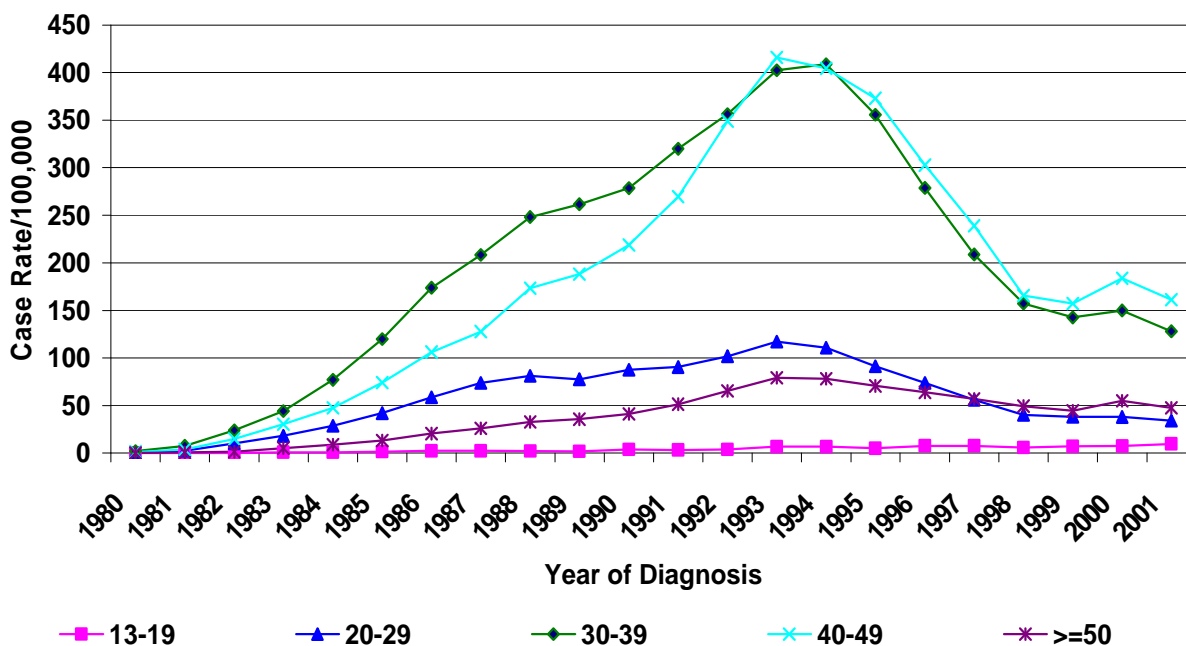


Table 6 summarizes characteristics of “special populations” in New York City as presented at the November 2003 Data Day. (144:3-14)

**Table 6: Planning Council Data Day 2
Presentation Describing Issues Associated with “Special Populations”
(These populations were identified and described in the FY 2004 Title I application as those disproportionately affected by the AIDS epidemic.)**

Youth (13-24)

- Low prevalence (estimated at 0.15%).
- Estimated to comprise 2.4% of PLWHA in NYC.
- Predominately African-American (53%) and Hispanic.
- High rates among young MSM (12.1% for those in the 15-22 year age bracket).
- Represent 6.5% of new FY2001 clients.
- Transmission perinatal or sexual.
- Appointments during after school hours may assist youth in accessing care.

Injection Drug Users

- 150,000-200,000+ in the EMA.
- Most prominent population in the epidemic (estimated prevalence of 10-20%).
- Declining prevalence? A Manhattan phenomenon?
- 88% of HIV+ IDUs are African-American or Hispanic.
- The majority live below the poverty line.
- Poly-drug use is a problem.
- Active use is associated with late entry into care and missed doses.

Other Substance Users

- 725,000+ problem substance users in the EMA.
- Unknown prevalence.
- Have a need for flexible treatment options.
- There appears to be a resurgence of drug use among MSM.

MSM of Color

- Estimated 100,000 in the EMA.
- Estimated prevalence of 10%.
- 14% of all PWAs are MSM of color.
- Especially high rates among African Americans (33% among 23-29 year-olds).
- Increased risk of depression, suicide, substance use, and violence.
- Barriers – poorly developed service infrastructure, racism/homophobia.

White/Anglo MSM

- Estimated 86,000 in the EMA.
- Estimated prevalence of 9%.
- Increased risk of depression, suicide, substance use, and violence.
- Possible resurgence of MSM transmission due to links with drug use, Internet sex, commercial sex venues and private parties.
- Barriers – homophobia.

Women

- 29% of PWAs in NYC.
- Growing share of epidemic.
- 92% are African-American or Hispanic.
- Majority are infections from heterosexual exposure.
- Easier to qualify for Medicaid than men.
- Barriers – poverty, child care, transportation problems, lack of women-centered services.
- 40% of new FY2001 clients were women.

Homeless

- Questions of how to define. 40,000 average daily NYC shelter census.
- Key neighborhoods: Harlem, South Bronx, Bedford-Stuyvesant, East New York.
- A growing problem.
- High prevalence of substance abuse and mental illness.
- Unstable housing associated with diminished health care access and utilization.

Mentally Ill

- More than one million people with mental illness in the EMA.
- Unknown prevalence.
- One-quarter of CHAIN cohort has evidence of a mental health disorder.
- Untreated mental health disorders associated with loss of benefits, poor adherence.

Immigrants

- More than three million foreign-born in the EMA (36% of the population).
- 6,082 immigrants are living with AIDS.
- Unknown prevalence.
- Title I is the safety net for the undocumented.
- Barriers – language, lack of culturally appropriate services, limited access to information, fear of deportation

Correctional Population

- 108,464 inmates in 2002.
- Estimated 7-10% prevalence (higher among women).
- Estimated 10,000 HIV+ individuals pass through the NYC/DOC system annually.
- 92% of HIV+ inmates are African-American or Hispanic.
- Barriers – lack of discharge planning, limited financial means, untreated substance abuse and mental health disorders.

Indicators of HIV Infection Risk in New York City

Named reporting of HIV infection began on June 1, 2000. In the first full calendar year (2001) of HIV reporting, 5,020 New Yorkers were diagnosed with HIV (non-AIDS), and 5,160 were diagnosed with AIDS. In the second full calendar year (2002) of HIV reporting, 4,170 New Yorkers were diagnosed with HIV (non-AIDS), and 4,155 were diagnosed with AIDS. (137:12). It is important to note the types of individuals who are not reportable under NYS Regulations and Law (137:23):

- Persons diagnosed with HIV prior to June 2000, who are in care but without HIV illness or AIDS.
- Persons diagnosed with HIV prior to June 2000, but not in care.
- Persons with HIV who have not been diagnosed, are not in care and don't know their status.

This lack of complete data may mean that (137:24):

- HIV data, while possibly reflecting earlier infection, are incomplete and not population based.
- HIV cases reflect persons who have been infected for varying periods of time.
- HIV data are less than complete in terms of individuals who are not in care or undiagnosed.
- Data are limited for understanding those not in care and the HIV infected population as a whole.

Table 7 below indicates that many people are diagnosed late in the course of their HIV infection, after they already have an opportunistic infection or low CD4 count. In 2002, 25% of persons diagnosed with HIV first learned that they were infected with HIV at the time they were diagnosed with AIDS. (204:2)

Table 7 further indicates that late diagnoses do not vary substantially by gender, race/ethnicity, mode of transmission, or residence, although individuals 40 and above had a disproportionately high percentage of late diagnoses.

Table 7. Characteristics of Adults/Adolescents (=13 yrs) Diagnosed with HIV and/or AIDS in 2001 and PLWHA as of December 31, 2001

	Total			Concurrent with AIDS*			HIV Without AIDS		
	No.	%	Rate per 100,000	No.	%	Rate per 100,000	No.	%	Rate per 100,000
Sex									
Male	4,223	65.0	137.8	1,342	69.1	43.8	2,881	63.3	94.0
Female	2,271	35.0	64.6	599	30.9	17.0	1,672	36.7	47.6
Unknown									
Age Group**									
13-19	134	2.1	18.5	17	0.9	2.3	117	2.6	16.2
20-29	1,036	16.0	81.5	194	10.0	15.3	842	18.5	66.3
30-39	2,359	36.0	175.0	653	33.6	48.4	1,706	37.5	126.5
40-49	1,919	29.5	169.3	655	33.7	57.8	1,264	27.8	111.5
50-59	778	12.0	91.5	306	15.8	36.0	472	10.4	55.5
60+	268	4.1	21.4	116	6.0	9.3	153	3.4	12.2
Race/Ethnicity									
Black	3,475	53.5	224.4	1,106	57.0	71.4	2,369	52.0	153.0
Hispanic	1,912	29.5	114.7	550	28.3	33.0	1,362	29.9	81.7
White	991	15.2	40.2	253	13.0	10.3	738	16.2	29.9
Asian/Pacific Islander	87	1.3	13.2	29	1.5	4.4	58	1.3	8.8
Native American	8	0.1	65.3	2	0.1	16.3	6	0.1	49.0
Unknown	21	0.3	9.4	1	0.1	0.4	20	0.4	8.9
Borough									
Manhattan	1,807	27.8	134.4	465	24.0	34.6	1,342	29.5	99.8
Brooklyn	1,816	24.9	91.7	605	31.2	30.5	1,211	26.6	61.1
Bronx	1,618	28.0	156.3	443	22.8	42.8	1,175	25.8	113.5
Queens	868	13.4	46.8	321	16.5	17.3	547	12.0	29.5
Staten Island	115	1.8	31.8	53	2.7	14.7	62	1.4	17.2
Unknown	270	4.2		54	2.8		216	4.7	
Current Clinical Status									
HIV	3,878	61.1	58.9				3,878	85.2	58.9
AIDS	2,616	38.9	39.8	1,941	100.0	29.5	675	14.8	10.3
All	6,494	100.0	98.7	1,941	29.9	29.5	4,553	70.1	69.2

PLWHA=persons living with HIV/AIDS

- ¹ For events occurring January through March 2003 and reported by December 31, 2003. Surveillance relies on laboratories and providers to report cases (see box below). Case reporting is 85% complete within 9 months.
- ² HIV diagnosed concurrently with AIDS (within 31 days of HIV diagnosis). Includes 34 cases in whom HIV was diagnosed in March 2003 and AIDS was diagnosed in April 2003.
- ³ AIDS was diagnosed in 2003 and includes concurrent HIV/AIDS diagnosis.
- ⁴ For HIV and AIDS diagnoses, age at diagnosis; for PLWHA, age as of March 31, 2003; and for deaths, age at death.
- ⁵ Includes persons with CDC-defined heterosexual risk in addition to persons with probable heterosexual transmission: Persons with a history of: a) sexual intercourse with an HIV-infected person of the opposite sex, an injection drug user, a bisexual male, or a person with hemophilia/coagulation disorder, b) heterosexual prostitution (sex work or exchange of sex for drugs), c) sexual contact with a prostitute of the opposite sex, d) multiple sex partners of the opposite sex, e) sexually transmitted disease, f) crack/cocaine use, or g) immigration from a country where heterosexual transmission of HIV predominates.
- ⁶ Includes individuals with no risk information reported by the provider and for whom an expanded investigation has not been completed.

Table 7 graphically demonstrates the success of current treatment regimens in decreasing the number of perinatally HIV-infected children. Transmission peaked in 1990 with 320 cases diagnosed. By 2001, only 24 infected infants were diagnosed with HIV infection. (153:4)

Chart 9 demonstrates the success of current treatment regimens in decreasing the number of perinatally HIV-infected children. Transmission peaked in 1990 with 320 cases diagnosed. By 2001, only 24 infected infants were diagnosed with HIV infection. (4:153)

Chart 9
Perinatally HIV-infected Children Reported to the NYC DOHMH by Year of Birth

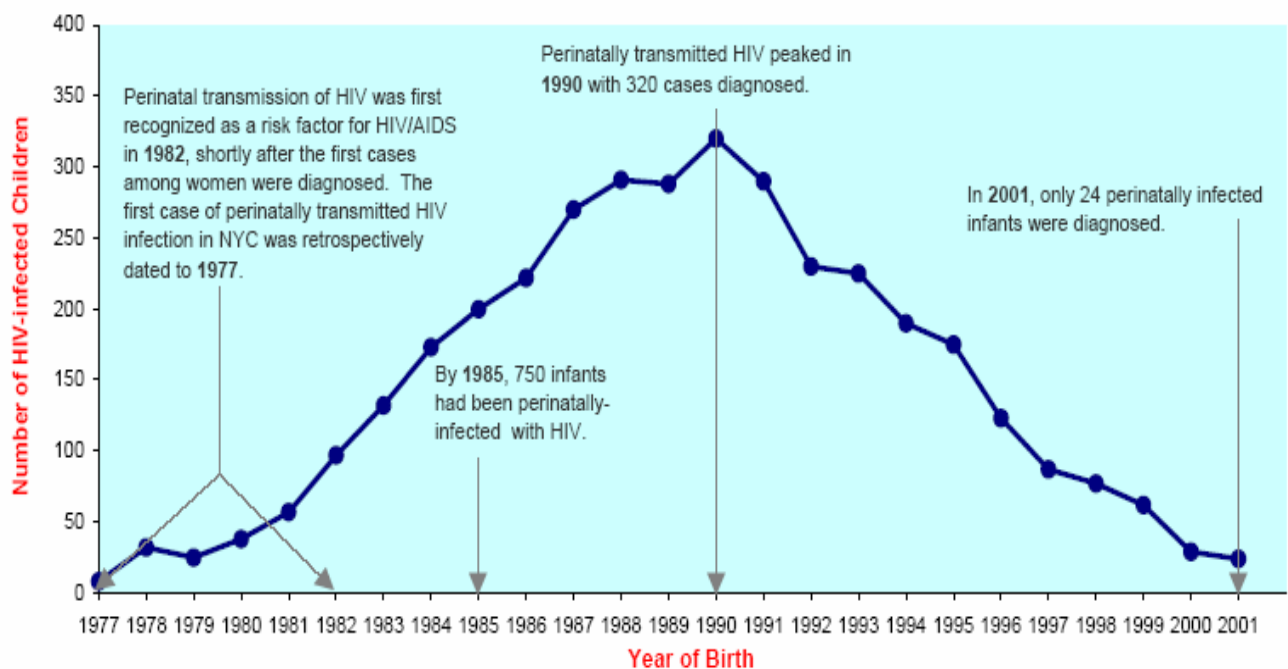
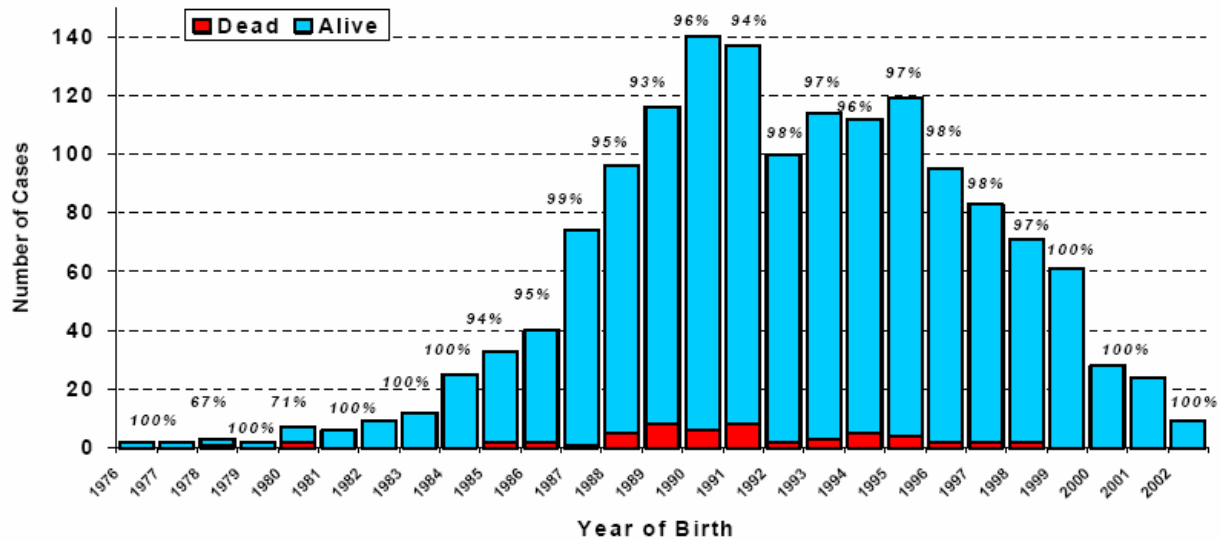


Chart 10

Survival Rates of 1,517 Pediatric HIV (not AIDS) Cases, by Year of Birth, as of June 2003, NYC



Due to the advancement of HIV and AIDS care and research, 95% of children perinatally infected with HIV (but not AIDS) before 13 years of age, including those who were born before 1990, do not progress to AIDS (206:6). Chart 10 shows that survival rates of pediatric HIV cases have significantly improved over time. As more and more children infected with HIV at birth are now living longer, it is important to remember that this population requires care and treatment services designed to meet its unique developmental and psychosocial needs.

Chart 11

1,282 HIV-infected Youth 13-19 Years of Age Living in NYC as of December 2003 by Borough of Residence at Diagnosis

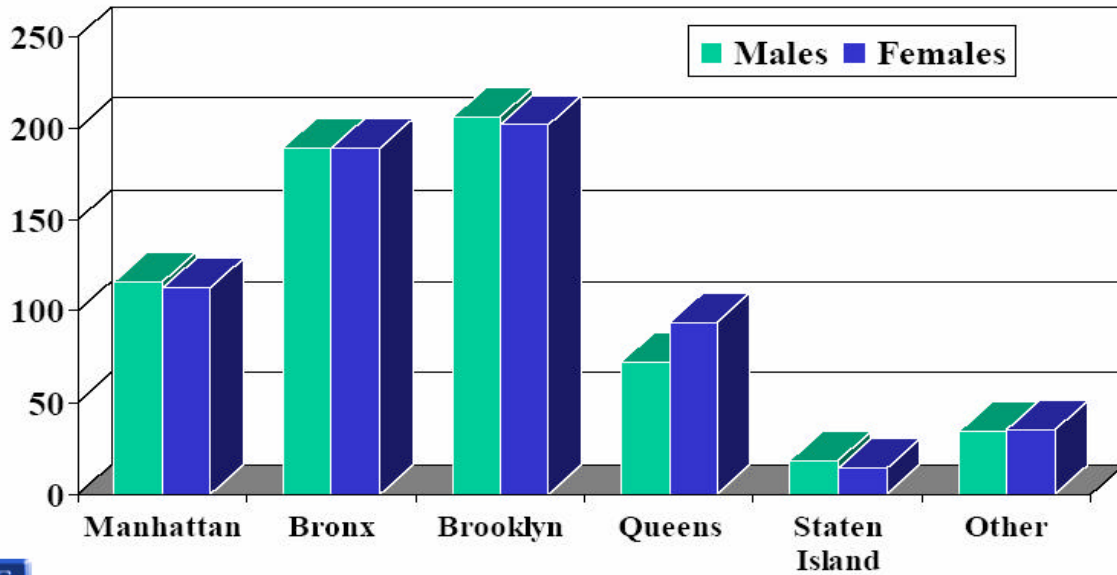


Chart 11 shows the borough of residence at diagnosis for HIV-infected youth. These data, similar to NYC surveillance data, reveals that the Bronx, Brooklyn and Manhattan share higher proportionate rates.

Summary and Conclusions

With the exception of new data available through named HIV reporting, begun in 2000, the epidemiological landscape of HIV/AIDS in New York City has not changed dramatically since the publication of the Initial Needs Assessment in 2002. New York City far exceeds other large U.S. cities in terms of the number of AIDS cases diagnosed through June of 2000. Although the City has 3% of the US population, almost 16% of people living AIDS in the US reside in NYC and 24% of the perinatally infected children, and 17% of AIDS deaths in the US have occurred in NYC (137:4).

As of October 2003, a cumulative total of 137,168 New Yorkers have been diagnosed with AIDS since 1981. Sixty-one percent of these individuals have died. Mortality from HIV dropped sharply beginning in 1996. As AIDS mortality has decreased in all categories annually, the number of people living with AIDS has also increased in all categories (with the exception of IDUs, which has remained the same since 2000) (204:1).

Despite a decrease in death rates, AIDS is a significant cause of death in New York City, ranking fifth among all causes of death for the entire population, and first among causes of death for those in the 25 to 34 year old category as well as those in the 35 to 44 year old category (Source: NYC DOHMH Vital Statistics Registry).

The distribution of AIDS is not proportional to the New York City population. Manhattan and Bronx have a disproportionately high share of the AIDS population, while Queens, Staten Island and Brooklyn have a disproportionately low share (137:6). The proportion of Blacks and Hispanics with AIDS is disproportionately high. (137:5). Among persons diagnosed with and living with AIDS, the proportion of women is increasing (132:18). This is also true for the proportion of youth and persons aged 50 and above (132:17). With the advent of mandated testing and effective treatment regimens, the number of perinatally HIV-infected children has declined dramatically from 320 cases diagnosed in 1990 to only 24 diagnosed in 2001 (153:4).

Although HIV surveillance data provide an incomplete picture of people living with HIV in the NY EMA, the data do show that a large proportion of persons newly diagnosed with HIV infection have evidence of advanced infection at the time of diagnosis. In 2002, 25% 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 40 and above had a disproportionately high percentage of late diagnoses (204:2).

Information on Persons Not in Care

Individuals who are “not in care” are examined from two related perspectives: “unmet need” and delayed entry into care.

HRSA has mandated¹ that a single “unmet need” estimate be part of an overall needs assessment which supports comprehensive service planning. This measure is presented and discussed.

An individual may delay entry into HIV care by delaying diagnosis, delaying entry into care after diagnosis, or at some point dropping out of care. Delayed entry into care is also examined.

After each of these topics is presented, findings are summarized and conclusions presented.

It is important to note that those with “unmet need” substantially overlap with those who “delay entry into care”. These topics are presented separately because of HRSA focus on the calculation and submission of a single “unmet need” number.

Unmet Need

Unmet need for HIV primary health care is defined by HRSA as no evidence of any of the following during a specified 12-month time frame (200:4-6):

- viral load testing;
- CD4 count; or
- provision of anti-retroviral therapy.

New York City’s approach to calculating “unmet need” (200:8-9) involves using combined data from the Medicaid and ADAP claims files to form the numerator of the “unmet need” equation (i.e., those “in care”) and NYC Department of Health HIV/AIDS Surveillance data

¹ The Title I year 2004 application required information on the resources, personnel, and timelines in place to complete an unmet need estimate. The 2005 grant application will require inclusion of an actual estimate of unmet need. Once this single number estimate has been calculated (or separate estimates for those with HIV and AIDS), the grantee must determine the characteristics and location of those not in care and assess their service needs and gaps. (3)

to form the denominator of the “unmet need” equation (i.e., the total number of individuals who have a diagnosis of HIV disease). The most recent calculations were based on data from 10/1/2000 to 9/30/2001 (the Federal Fiscal Year)² and yielded the following results (200:10):

- 32% were found to have “unmet need” when the AIDS and HIV (non-AIDS) populations were combined and adjusted for those covered by private insurance or receiving Veterans Health Administration (VHA) health care coverage^{3, 4}.

Limitations to the approach outlined exist in both the numerator and the denominator⁵, however these are arguably the best data sources currently available for the calculation of “unmet need.”

It should be noted that these unmet need estimates substantially exceed an estimate published in the 2002 Initial Needs Assessment that 2,250-7,200 people in NYC knew their HIV status but were not connected to care due to the HRSA’s definition of “unmet need”. (page 27 of Initial Needs Assessment).

² Calculations for the Title I year 2005 application will include paid Medicaid and ADAP claims from FFY 2003.

³ In this calculation the denominator (the number of people known to be living with HIV, but not AIDS, and aware) was supplied by the New York City Department of Health and Mental Hygiene (NYC DOHMH) HIV/AIDS Surveillance data from 2001. All HIV (not-AIDS) individuals in the Medicaid/ADAP databases that met HRSA criteria for having “met need” were included in the numerator (8 & 9).

⁴ The adjustment was arrived at by adjusting the calculation reflected in item #3 by 15% to include those covered under private insurance or who receive VHA health care coverage. The 15% adjustment is based on the following: 10% - the random sampling process used in the AIDS Institute Quality of Care Review Program indicates 10% of persons are non-Medicaid and non-ADAP; 5% of VA factor estimate. All such individuals were assumed to have met needs.

⁵ In terms of the numerator: Both the Medicaid and ADAP databases are administrative data bases used for claims processing – they were not intended to be used to extract clinical information. All individuals included in the numerator of this calculation have at some point in time received health care services reimbursed by ADAP or Medicaid and all are identified as HIV positive in the database, using screening mechanisms that utilize rate code, ICD-9 or procedure code identifiers of AIDS/HIV, but we don’t know why not all are “in care”. Reasons could be clinical, personal, or might involve a failure of the provider to bill for services or errors in notation of rate or procedure code in the claims database. (Source: personal discussion with New York State AIDS Institute’s Ira Feldman).

In terms of the denominator: Limitations to the use of surveillance data in this calculation include incomplete reporting of HIV status, particularly given the fact that reporting only commenced in 2000. This results in an undercount the number of people living with HIV resulting in an underestimate of “unmet need” (source: personal discussion with NYC DOHMH’s Dr. Susan Forlenza).

Summary and Conclusions

- It can be concluded that the EMA is meeting expectations regarding development of the estimate of unmet need required by the CARE Act Amendments of 2000.
- Based on the HRSA definition of “unmet need”, and using Medicaid and ADAP combined with HIV surveillance data, claims data adjusted for individuals covered by private insurance or receiving VHA health care coverage, 32% of those living with HIV/AIDS in New York City were found to have “unmet need” (200:10). Furthermore, according to NYC DOHMH, due to the limitations of HRSA’s definition of “unmet need”, the resulting figure will be an underestimate of the actual “unmet need” within the population.
- Owing to methodological challenges and inexperience in interpreting the meaning of the “unmet need” estimation, care should be exercised at this time when using this calculation to make changes in the EMA’s 2005 priorities and resource allocations.

Delayed Entry into Care

Several sources – NYC DOHMH HIV surveillance data and CHAIN data⁶ – provide information on delayed entry into HIV care in New York City. Despite some data limitation⁷, these two sources found a significant gap in accessing care. HIV/AIDS surveillance data found 38% of individuals newly diagnosed with HIV (non-AIDS) in 2002 lacked evidence of entry into care within 12 months of their HIV diagnosis.⁸ (141:12, 209:20) and 20% of CHAIN participants were found to have delayed entry into medical care by at least four months (191:1).

These sources were also used to examine those who delayed receipts of initial HIV testing. According to HIV/AIDS surveillance data, 25% of persons diagnosed with HIV during 2002 had an AIDS diagnosis within 90 days of their HIV diagnosis suggestive of a delay in testing or care (2:204). CHAIN reported that 25% of participants learned about

⁶ CHAIN data come from the Delayed Entry to HIV Care study conducting by Columbia University in 2003 using a combination of CHAIN data, key informant interviews, focus groups, and a review of the literature. A “Delayer into care” is defined as someone who: 1) waits more then 3 months after the diagnostic HIV test to present for treatment evaluation or 2) is diagnosed with HIV at the time of presentation for care with: fewer than 200 CD4 cells (indicating an advanced state of disease course, even if no AIDS-defining illness has occurred) or 3) one or more AIDS –defining illnesses (per CDC definition).

⁷ Limitations to the use of surveillance data as used in these calculations include incomplete reporting of persons diagnosed with HIV, particularly given the fact that reporting only commenced in 2000, and incomplete submission of laboratory results, which results in the undercounting of the number of people living with HIV and/or the number of people who are determined to be “in care” (source: personal discussion with NYC DOHMH’s Dr. Susan Forlenza). CHAIN data are limited by the fact that they are based on client self-report and come from a sample of the population only and do not include all HIV-infected New Yorkers.

⁸ Persons age 13 and above, who were diagnosed with HIV with a first positive Western Blot (WB) test or via a provider report form during calendar year 2002, and without a concurrent AIDS diagnosis within 90 days of their HIV diagnosis, were included in the denominator. All such individuals were matched with the NYC DOHMH Lab NYC database to identify those who had received a provider ordered viral load or CD4 count. These were included in the numerator.

their HIV diagnosis because they were very ill or were in hospital with an HIV-related disease (191:1).

DOHMH HIV/AIDS surveillance data found:

- By race/ethnicity, the smallest proportion of persons with laboratory evidence of unmet need is whites. There were too few Asian /Pacific Islanders and Native Americans to evaluate entry into care.
- The smallest proportion of persons with evidence of unmet need by risk was MSM.
- Persons with no reported risk had the largest proportion with laboratory evidence of unmet need.
- There was little difference in the proportion of persons with evidence of unmet need care by age group.

The CHAIN study found that, for the most part, the characteristics of delayers did not vary based on whether they were in the original cohort or the new cohort. Delayers tend to (146:12):

- Not be experiencing symptom;
- Be a current or historic drug user;
- Have mental health difficulties;
- Be homeless or unstably housed;
- Have no regular source of income; and
- Have a history of incarceration.

Emerging factors related to delay were found among the recent CHAIN cohort (146:12). They tend to be younger persons (<35yrs) and more recent immigrants.

According to the CHAIN study, what happens at testing sites is important to subsequent care seeking (146:14). If no information is provided about treatment, or only general information given, clients are more likely to delay than if the testing site actively facilitates entry into medical care.

CHAIN has also found that delayers report similar barriers at each phase of the continuum of care, including testing, receipt of results, referral to treatment, and receipt of treatment. In summary delay occurs because the perceived costs of HIV care-seeking are greater than the perceived benefits. (141:1). Barriers include:

- Fear of stigma and its consequences;
- Fear of anticipated treatments;
- A lack of knowledge about the course of the disease;
- A lack of knowledge regarding the potential benefits of treatment;
- Being distracted or inhibited by other life conditions or co-morbidities (e.g., hepatitis C, homelessness, mental illness, serious drug use);
- Fear of the unknown and denial;

- Difficulty in following up on agency referrals;
- Lack of time;
- Other systems barriers (e.g., immigrant status, child custody issues, income maintenance concerns);
- Fear of a loss of self-control;
- Distrust of providers; and
- Problems/issues related to paperwork.

Among persons who delay entry into HIV medical care, the most common reason for eventually seeking care was a general decline in health or contraction of an opportunistic infection.

Regarding perinatally infected children, HIV/AIDS Surveillance data revealed that (141:28):

- There was no difference in the proportion “in care” based on race/ethnicity;
- By 2001, 93% of children were in care; and
- Although only 10% resided in Queens, 18% from Queens were not in care.

A New York Community Health Survey telephone survey conducted between May and June 2002, found HIV testing was low in neighborhoods where more persons reported HIV risk factors (including Lower Manhattan, Chelsea-Greenwich Village, South Bronx, and Western Queens-Long Island City) than in neighborhoods where fewer persons reported risk factors. (135:30)

Summary and Conclusions

There are limitations to both CHAIN and NYC DOHMH surveillance data – the sources of information on delayed entry into care in New York City. HIV surveillance reporting is relatively new and still being refined and CHAIN involves self-reported data based on a sample of HIV infected individuals, not the entire population. However, results on delayed entry into care from these two sources demonstrate a significant gap in accessing care (146:12). HIV/AIDS surveillance data found 38% of individuals newly diagnosed with HIV (non-AIDS) in 2002 lacked evidence of entry into care within 12 months of their HIV diagnosis.⁹ (141:12) and 20% of CHAIN participants were found to have delayed entry into medical care by at least four months (1:191).

The most critical factor associated with delayed testing or treatment tends to be whether or not the individual is experiencing symptoms. Beyond this, delayers tend to be current

⁹ Persons age 13 and above, who were diagnosed with HIV with a first positive Western Blot (WB) test or via a provider report form during calendar year 2002, and without a concurrent AIDS diagnosis within 90 days of their HIV diagnosis, were included in the denominator. All such individuals were matched with the NYC DOHMH Lab NYC database to identify those who had received a provider ordered viral load or CD4 count within 360 days of their HIV diagnoses. These were included in the numerator.

or historic drug users, have mental health difficulties, be homeless or unstably housed, have no regular sources of income, and/or have histories of incarceration.

Furthermore, CHAIN found that among its first cohort, delays occur because the perceived costs of HIV care-seeking (concerns about stigma and rejection, retention, and fears of social and legal consequences of revealing risk behavior) are greater than the perceived benefits. Clients are less likely to delay entry into care if testing sites actively facilitate entry into the medical system (141:1).

General Information Since 2002

Service Needs and Gaps

Five community forums were conducted throughout New York City in the Spring of 2004. One forum was held in each borough. The forums were designed to identify the needs of individuals affected with and affected by HIV/AIDS and document gaps in services and in communities (186).

Community Forums

The strongest theme across the five forums was the need to increase the availability of and access to HIV services (186:2). Speakers also noted gaps in a particular area in specific neighborhoods or boroughs. Most commonly addressed topics across all boroughs were:

- Housing;
- Food and nutrition;
- Transportation;
- Client advocacy/legal services;
- Culturally competent services;
- HIV prevention education for youth;
- Family support services;
- Equitable distribution of resources, and
- Access to primary medical care.

Consumer Advisory Board (CAB) Survey

In addition to the community forums, the OAPC conducted a New York City-wide Consumer Advisory Board (CAB) Survey in March 2004. The purpose of the survey was to ensure that Ryan White Title I funding priority recommendations are in line with consumer and organization needs. Similar to findings from the community forums, the most commonly identified service gaps were:

- Housing;
- Legal services;
- Food and nutrition;

- Home care and supportive services, and
- Transportation.

CHAIN Service Gaps

A November 2003 CHAIN presentation identified the following service gaps for CHAIN participants, by major service category. Gaps were calculated by dividing the number of people not receiving a needed service by the total number of people needing that service. Thus the higher the percentage, the larger the gap (142:11):

- 20% gap for medical care;
- 20% gap for case management;
- 42% gap for mental health services;
- 59% gap for AOD services; and
- 64% gap for housing.

Additionally, CHAIN has conducted a multivariate analysis (a statistical model that enables the reader to examine the independent effect of population demographics and system characteristics on outcomes) examining service gaps in New York City. This analysis examined potential factors (gender, age, race/ethnicity, HIV risk category, borough of residence, drug use history, mental and physical health scores, continuity of medical care, comprehensive medical care, and year of HIV diagnosis) for the five outcomes or performance measures used by the Work Groups in the Strategic Plan: 1) Reporting a lower physical health score; 2) Being adherent to HIV medication; 3) Reporting comprehensive medical care; 4) Having an episode of unstable housing in the past 6 months; and 5) Experience barriers to medical or social services care. This analysis looked at each effect as if all the other factors are equal. For example, the analysis of men controlled for other effects such as being Latino, living in the Bronx, or having a high t-cell count. If after conducting this analysis men are still significantly healthier, this holds regardless as to whether the men are Latinos, live in the Bronx, or have high t-cell counts.

The table below illustrates major outcomes (**bold**) and their associated factors (**bulleted**) (206:14).

<i>Factors most significantly associated with...</i>				
Reporting a lower physical health score	Being adherent to HIV medications	Reporting comprehensive medical care (provider available 24 hours, for well-visit, and for health advice)	Having an episode of unstable housing in the past 6 months	Experiencing barriers to medical or social services care
<ul style="list-style-type: none"> - Original cohort - Problem drug users - T-cell less than 500 - Age over 50 years - Low mental health - Experienced barriers 	<ul style="list-style-type: none"> - Men - Latinos - Reporting comprehensive medical care - Not reporting barriers to health or social service care 	<ul style="list-style-type: none"> - Living in Brooklyn - having continuous medical care - Being white or Latino - Not having low mental health score - Not reporting barriers to health or social service care 	<ul style="list-style-type: none"> - New cohort - Men - Problem drug users - Living in Manhattan - Age 20-34 years - Current or former drug user 	<ul style="list-style-type: none"> - Being white - Not reporting comprehensive medical care - Having a low physical health score

A subsequent April 2004 CHAIN geographical mapping analysis of service gaps among the NYC CHAIN participants reveals the following (204:4):

- The geographical distribution of service gaps tends to mirror the epidemiology of PLWA's in the sub-borough areas. There are several notable exceptions. West Queens has a larger gap in case management and professional mental health services than expected and West Queens and North Brooklyn have a smaller treatment adherence service gap than expected.
- Ryan White-funded agencies tend to cluster around populations of those in need and also tend to be close to public transportation. This is less true in South Queens and South Brooklyn.
- The maps included in the CHAIN document, offer an initial attempt to identify geographic areas with the biggest service gaps for each individual service (i.e., AOD service, comprehensive case management services, etc.).

Finally, the Ryan White Title I Program Summary Report for the period March 2002-February 2003 (released in April 2004), summarizes quantitative Title I programmatic data collected by HIV Care Services of MHRA in its contract monitoring role for the Title I program. Major findings of the report are (197:64):

- The number of new client encounters continued to grow in FY 2002, to a total of 32,083 (up from 29,641 the previous year).
- Geographic analyses of new enrollment shows that Title I clients are coming from those areas of the city hit hardest by the epidemic.
- Women and Hispanics are over-represented among new clients compared to HIV surveillance data: 40% of new clients are women compared to 30% reported by surveillance, and 38% of new clients are Hispanic compared to 32% reported by surveillance.
- Persons 50 years of age and older are under-represented among new Title I clients when compared to HIV surveillance: 16% are new clients while 25% are reported by surveillance.

The information that follows explores identified service gaps in more detail and is organized by New York City HIV Planning Council Work Group.

Each section is followed by a summary and conclusions.

AOD Work Group

A July 2002 CHAIN study on exposure to trauma and violence found that recent substance abuse and low mental health scores are the strongest predictors of not maintaining continuous medical care (157:5).

A July 2002 CHAIN report on patterns of medical care and substance abuse providers found that prevalence of current substance abuse and drug treatment utilization have decreased over time (161:2).

A November 2003 CHAIN presentation indicates the following AOD service gaps exist by borough for CHAIN participants (142:22):

- New York City in total: 60%
- Bronx: 59%
- Brooklyn: 52%
- Manhattan: 62%
- Queens: 71%
- Staten Island: 56%

This same report revealed the following AOD service gaps exist by race/ethnicity for CHAIN participants (142:23):

- New York City in total: 60%
- White, non-Hispanic: 70%
- Black, non-Hispanic: 58%
- Hispanic: 58%

In a May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* the new CHAIN cohort was compared to the original CHAIN cohort. There were no statistically significant differences in the proportion of current or past drug users (206:5):

- Who delayed entry into care because of barriers experienced – original cohort 18%; new cohort 17%.
- Who had objective need for mental health services and reported that they received professional or supportive mental health services – original cohort 50%; new cohort 60%.

Summary and Conclusions

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 race groups (142:22). Among the CHAIN cohort, utilization of drug treatment appears to be declining (161:2). Exposure to trauma and violence among AODs (which itself is highly prevalent among CHAIN participants) is a predictor of not maintaining continuous medical care, which suggests that providers should screen for such exposure to identify patients at risk of being lost to care (157:5). Meanwhile, measures related to delaying entry to care and receipt of supportive mental health services among the new and old CHAIN participants are similar, which gives users of CHAIN information confidence in the use of new CHAIN data (206:5).

Health Services Work Group

Based on Service Gaps and Strategic Plan Progress Indicators analysis conducted by CHAIN (206:13):

- 51% of PLWHA of the new cohort had improved survival and health outcomes;
- 72% of the new cohort who receive health services adhered to treatment; and
- 76% of PLWHA remained connected to services once in the care continuum.

An April 2002 CHAIN communication on drug holidays within the CHAIN cohort found that 28% reported a drug holiday in the past 6 months, of which $\frac{3}{4}$ decided on their own to interrupt treatment. The average length of the interruption was about 21 days (158:1).

Another CHAIN report in July 2002 on patterns of medical care and substance abuse providers found (161:2):

- The percentage of individuals retaining the same primary medical provider has continuously increased from 77% to 87%.
- The percentage of persons reporting no primary medical provider has decreased from 9% to 2%.
- The primary reason for changing providers for half of the responses indicated provider attitudes, while a third changed out of necessity such as the practice closed or moved or the respondent left the nursing home or jail.

Very few did not have a medical provider (2%) and these persons were significantly less likely to be on HAART (161:2).

A July 2002 CHAIN communication on exposure to trauma and violence found that PLWHAs who have experienced violence, especially personal violence, are less likely to maintain continuous engagement in medical care (157:3). However, a CHAIN memo in July 2002 regarding partner notification noted that only 7% of persons reporting a current medical provider indicated that their doctor or medical provider had asked for the names of sexual or needle-sharing partners (162:2).

A later CHAIN report (November 2002) on people over 50 years old found that older CHAIN participants are in poorer physical health and report higher prevalence of chronic

conditions and diseases, but they do not differ in mental health status (164:2). The same report found no significant difference in use of medical services across age groups or differences in reported barriers to receiving medical care. According to a February 2003 CHAIN report (154:11-17):

- Approximately 13% of male CHAIN participants reported having unsafe sex with a woman who was not HIV positive or whose status was unknown during the most recent study period and 8% similarly reported having unsafe sex with another male during that period. Twenty-eight percent of female CHAIN participants reported having unsafe sex with a man who was not HIV positive or whose status was unknown during the most recent study period.
- Based on data from the most recent study period, approximately 8% of male CHAIN participants reported engaging in sex exchanges (for money or drugs) and 7% of female CHAIN participants reported engaging in sex exchanges during the most recent study period.
- Over time, unsafe sex among CHAIN participants has declined, with the exception that during the most recent study period an increase was seen in men (both MSM and men who have sex with women) and women.
- The greatest predictors of men having unprotected sex are a recent history of exchanging sex for money or drugs, homelessness, the MSM risk exposure group, or having a spouse or partner.
- For women the strongest predictors of having unprotected sex are homelessness, being younger, or having a regular sex partner. Homeless women are 4.4 times more likely to exchange sex than women with stable housing.
- These data suggests that prevention for positives should be a priority.

Per a November 2003 CHAIN presentation, the following medical care service gaps exist by borough for CHAIN participants (15:142):

- | | |
|---------------------------|-----|
| • New York City in total: | 20% |
| • Bronx: | 23% |
| • Brooklyn: | 24% |
| • Manhattan | 17% |
| • Queens: | 17% |
| • Staten Island: | 15% |

This same presentation found that there were few differences in medical care service gaps based on race/ethnicity (16:142) or based on CD4 Counts (17:142).

In the May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* the health of CHAIN participants was measured as self reported health status and adherence¹⁰, by T-cell counts, and based on whether needed health care services were received¹¹. (206:3)

¹⁰ A more subjective measure was a single global question rating current health from excellent to poor. A more objective measure of physical health was calculated by applying the Physical Component Summary Scale (PCS) of the SF36, which is a standardized set of questions that correlate with stage of disease.

Overall, the new CHAIN cohort reported similar experiences and health characteristics when compared to the original CHAIN cohort. This suggests that the health system did not change dramatically in New York City – either for the better or for the worse – over this period of time. Specific health findings for the new CHAIN cohort included (206:4):

- Approximately one-third reported T-cell counts above 500;
- Approximately three-quarters said they had been adherent (representing a slight rise from the original cohort); and
- Approximately three-quarters indicated they had received continuous and comprehensive care.

There were several subgroup differences (206:4):

- Problem drug users¹² were more likely to report poor health.
- Black respondents were less likely to report receiving comprehensive medical care, and also less likely to report being completely adherent.
- Being male and Latino was related to increased adherence.
- Receiving comprehensive medical care was related to increased adherence.
- Not experiencing barriers to health or social service care was related to increased adherence.

In a November 2003 technical CHAIN report (180:7), it was found that being on HAART medications and complete adherence to HAART regimens had a strong and predictable association with treatment success.¹³ Minimal association was reported between treatment success and other independent factors. Recent homelessness was the social variable that had the strongest negative impact on treatment success. There was some indication that younger age, having a recent HIV diagnosis, and current drug use might also be associated with reduced treatment success.

A 2001 AIDS Institute-published consumers' guide to quality of HIV care presents scores by clinic on results of measuring five quality of care indicators. Most scores for facilities in the New York EMA are in the 80%-90% range, reflecting a consistently high level of quality HIV care across a range of settings (145:5-10).

¹¹ An assessment of clinical care was established in one of two ways. In the first, a scale was developed in conjunction with the AIDS Institute, capitalizing on three criteria: the number of visits reported over a period of time, a report of a complete physical exam, and a report of recent blood work. The second strategy for assessing clinical care was drawn from standards of care developed by the World Health Organization. Primary HIV medical care was considered to be "comprehensive" if a provider was available for well-visits, for health advice and information, and was accessible 24 hours a day if needed.

¹² That is, individuals who had ever used crack, cocaine, or heroin three or more times a week, for a month or more; or who had ever injected drugs; or who were problem alcoholics.

¹³ This same 2003 technical CHAIN report, found that self-reported viral loads were generally acceptable indicators for statistical analysis of treatment success and failure (7).

According to an April 2004 presentation, the New York State HIV Quality Management Program, selected data from 2002 revealed the following:

Regarding outpatient care –

- Access to ARV has increased each year studied (1996-2003) without differences between gender, risk or race/ethnicity. The facility at which care was provided and year were the most important predictors of receiving HAART. (201:10)
- Appropriate management of patients stable on ARV therapy occurred 73%. (201:14)
- Pelvic exams and PAP smears were conducted 73% of the time among women. (201:15)

Regarding treatment education –

- Social support barriers to treatment adherence were assessed 70% of the time. (201:16)
- Medication adherence was assessed and described quantitatively every four months 56% of the time. (201:16).
- Treatment education was provided quarterly and covered a list of pre-set topics 68% of the time. (201:16).

Regarding adult day treatment centers –

- 90% of the time a comprehensive medical examination was completed within 30 days of admission. (source: taken directly from reported data)
- 86% of the time a substance abuse assessment was completed within 30 days of admission. (source: taken directly from reported data)

Regarding home health care –

- 70% of the time monthly HIV-related education was provided covering at least one of three identified topics. (201:17)
- Monthly pain assessments were conducted 91% of the time. (201:17)
- Treatment adherence was discussed and measured with the results recorded in the medical chart 33% of the time. (201:17)

According to a May 2002 report on chronic diseases and clinical co-morbidities among CHAIN participants (155:2):

- Eight of ten CHAIN participants reported being diagnosed with at least one of the 10 chronic conditions examined.¹⁴

¹⁴ The 10 chronic conditions are: asthma, other breathing problems, hypertension, heart problems, diabetes, arthritis or rheumatism, kidney disease, hepatitis, active TB infection, and cervical disease (women only).

- Lifetime prevalence for the chronic conditions examined was highest for hypertension (30%), asthma (26%), active tuberculosis infection (22%), and arthritis or rheumatism (22%).
- Aging is associated with increased risk for six of the ten chronic diseases.
- There are no easily identified patterns between chronic health conditions and gender, ethnicity and education.
- Drug use and smoking are linked to active TB and hepatitis, but they are associated with lower prevalence of diabetes.
- Length of exposure to HIV is associated with increased risk of active TB and hepatitis.
- The presence of chronic conditions is only weakly associated with increased use of medical care services.

A report from the New York State Department of Health AIDS Institute, reported that HIV Special Needs Plans (SNPs) are managed care plans opened solely to those with HIV. Consumers with HIV infection have the choice of remaining in fee-for-service Medicaid, enrolling in an HIV SNP, or enrolling in a mainstream Medicaid managed care plan. In the first half of 2003, five SNPs received Certificates of Authority in New York City, enabling them to enroll clients. As of April 1, 2004, 625 individuals had enrolled in one of these programs. (188:1)

MAI Initiatives

According to a Pagnoni and Associates evaluation of the Minority AIDS Initiative (MAI) in NYC, MAI programs are generally targeted at individuals who are either not already in care or are at risk of dropping out of care (152:2).

Among those clients participating in 12 MAI funded education/treatment programs, as reported in an April 2004 document (152:1-3):

- 57% of participants showed improved adherence to treatment.
- 56% showed improved CD4 counts (61% for those who reported adhering to their HIV medications).
- 64% improved their viral load or continued to have an undetectable viral load (72% for those who reported adhering to their HIV medications).
- Participants who adhered to their treatment improved more than those who did not.
- Participants with initially lower CD4 counts and/or higher viral loads improved more than their counterparts.
- Participants who improved adherence to their prescribed treatment improved more than those who did not.
- Participants who had prescribed medications at the time they entered the programs improved more than those who did not.
- Participants who stayed in their programs continued to benefit.

The MAI also funds 13 “Access to Care” programs and 10 “Maintenance in Care” programs. Access to Care programs are based in CBOs and health care organizations that provide outreach and referral services to members of the target population who are

not in care. (149:2). Maintenance in Care programs are provided by health care organizations which provide intensive follow-up and supportive services to help members of the target population stay connected to care. (149:2). Evaluation of these programs yielded the following selected results:

- The programs were successful in targeting appropriate populations.
- Participants had a 25% improvement in perception of general health and a 25% improvement in the perception of mental health. (149:9)
- Adherence rates improved from a baseline of 87% to 93% after program participation. (149:10)

Summary and Conclusions

HIV care in the NY EMA is widely available across a range of settings, and is generally of high quality (145:5-10). Once connected to care, very high proportions of CHAIN participants retain the same primary care provider (87%) (161:2) and access to ARV treatment has increased each year since 1996 without differences between gender, risk, or race/ethnicity (201:10). Additional CHAIN evidence suggests that the health system in New York City has not changed over time, although certain subgroup differences exist (206:4), and some shortfalls in provider performance are evident in such areas as provider attitudes (161:2), discussing partner notification (161:2), and treatment adherence (201:16). Meanwhile, the percentage of CHAIN participants reporting no medical provider dropped to just 2% (161:2). Where self-reported medical care gaps exist, they are evenly distributed across all boroughs and race groups (164:2). CHAIN participants over 50 years of age are in poorer health and report higher prevalence of chronic conditions and diseases (164:2). Overall, 8 of 10 CHAIN participants report being diagnosed with at least one chronic condition such as hypertension or asthma. Recent homelessness is the social variable with the strongest negative impact on treatment success (180:7). The EMA's Minority AIDS Initiative, which targets persons of color who are either not already in care or who are at risk of dropping out of care, appears to be effective (152). Persons reached by MAI programs show improvement in health outcomes including adherence to treatment and improved CD4 and viral load measures (149).

Housing Work Group

A July 2002 CHAIN report on exposure to trauma and violence notes that almost 1/3 of persons who reported multiple traumatic events over their lifetime had also experienced one or more recent episodes of homelessness or unstable housing (157:2).

Per a November 2003 CHAIN presentation, the following housing service gaps exist by borough for CHAIN participants (142:19):

- New York City in total: 65%
- Bronx: 64%
- Brooklyn: 47%

- Manhattan: 76%
- Queens: 67%
- Staten Island: 33%

This same presentation revealed that housing service gaps exist by race/ethnicity for CHAIN participants (142:19):

- New York City in total: 64%
- White, non-Hispanic: 84%
- Black, non-Hispanic: 56%
- Hispanic: 73%

A November 2003 presentation on the preliminary results of a survey of people with HIV/AIDS on housing needs stated that PLWHA in appropriate housing are four times more likely to receive ongoing medical care than persons who are homeless or unstably housed. It also noted that at the time, 26,800 persons with HIV/AIDS receive housing assistance from HASA, an increase of about 11.5% over a 2-year period (143:2).

The May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* revealed the following (206:5):

- The new CHAIN cohort was far more likely than the original cohort to have experienced an episode of unstable housing (28% versus 18%) and/or homelessness (18% versus 10%).¹⁵
- Regardless of which cohort is being measured, men were statistically more likely than women to report unstable housing or homelessness.
- In a multivariate analysis, the other factors associated with unstable housing – regardless of which cohort is being considered – are problem drug use and the age group of 20-34 year olds.
- There was a significant increase between the original and the new CHAIN cohorts in the proportion of unstably housed individuals who received housing subsidies, lived in specialized AIDS housing, or who received some other housing services.

Summary and Conclusions

Persons in appropriate housing are 4 times more likely to receive ongoing medical care than persons who are homeless or unstably housed (143:2). Housing and housing-related services remain large unmet needs across the EMA, despite the large number of people living with HIV/AIDS (26,800) who receive housing assistance from HASA, an increase of 11.5% over a 2-year period (143:2). CHAIN documented a relationship

¹⁵ It is possible to attribute some of this variation to the difference between a new “baseline” cohort and to the group who “survived” in the original CHAIN cohort from their initial recruitment in 1994-1995. Over time, in the original CHAIN cohort, respondents who were unstably housed were more likely to be lost to follow-up.

between homelessness/unstable housing and past experience of trauma and violence. Other factors associated with homelessness or unstable housing are being male, problem drug use, and young age (20-34 years) (206:5). The new CHAIN cohort was far more likely than the original cohort to have experienced an episode of unstable housing and/or homelessness (206:5).

Infrastructure Work Group

In the May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* there was one measure of infrastructure development: the proportion of CHAIN participants reporting they delayed or did not get medical or social services because they did not know or were not sure where to go for medical or social services. (206:5). Findings included:

- Overall, there were no statistically significant differences in this measure between the new CHAIN cohort (11%) the original CHAIN cohort (11%).
- One major sub-group difference emerged in that women were more likely than men to have reported delaying or not getting the service they needed because they didn't know where to go for specific medical or social services.

Quality of care data collected by the Title I HIV Quality Management Program suggests providers need capacity building and technical assistance services to support and enhance delivery of quality services. Other factors contributing to low scores on quality of care indicators include gaps in care coordination and communication due to weak infrastructure.

Summary and Conclusions

Information on what medical or social services are available and where they exist affects when persons seek assistance, an important factor in reducing morbidity and mortality. Women are more likely than men to delay or not seek services because they do not have the knowledge or are unsure about where to get help or seek care (206:5).

Mental Health Work Group

In CHAIN study published in July 2002 on trauma and violence among persons living with HIV found extremely high rates of exposure to trauma and violence: over 90% have experienced one or more traumatic events with 39% in last year (which included September 11, 2001) (157:2).

A November 2003 CHAIN presentation document that the following exist by borough for CHAIN participants (142:26):

- New York City in total: 42%
- Bronx: 47%
- Brooklyn: 39%

- Manhattan: 40%
- Queens: 60%
- Staten Island: 13%

According to the same presentation, the following mental health service gaps exist by race/ethnicity for CHAIN participants (142:27):

- New York City in total: 42%
- White, non-Hispanic: 34%
- Black, non-Hispanic: 44%
- Hispanic: 45%

In the May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* mental health was assessed¹⁶ and related to adherence and physical health. The following was revealed (206:6):

- Among individuals with low mental health scores on a standardized scale¹⁷, those in the new CHAIN cohort were almost twice as likely to report good physical health scores than were respondents in the original CHAIN cohort. This finding did not vary based on whether the individuals received mental health services or not.
- The reported receipt of professional mental health services among respondents with low mental health scores did not appreciably raise their physical health scores.
- White respondents with low mental health scores were significantly less likely to be adherent than Latino respondents and less likely to report good physical health than were Black respondents.

According to an April 2004 presentation, the New York State HIV Quality Management Program, selected data from 2002 revealed the following regarding mental health care (201:18):

- A cognitive assessment that included at least one element of the Mini Mental Status Exam was performed 98% of the time during the past year; 13% of the time, an assessment was performed which included all elements.
- 83% of the time, a multi-axis diagnosis including all five axes was performed in the last year.
- Quarterly coordination of care between the mental health care provider and the primary care provider was documented 25% of the time.

¹⁶ Using the Mental Health Component Summary, MCS, of the SF36.

¹⁷ Defined as less than 37.0 on the SF-36 mental component summary scale.

Summary and Conclusions

Mental health needs persist across the EMA. Among CHAIN participants, mental health service gaps are reported in all boroughs (142:26) and across all race groups (142:27). Over 90% of CHAIN participants reported one or more traumatic events in their lifetime (157:2). Newer CHAIN participants with low mental health scores were twice as likely to report good physical health scores (206:6). New York State Quality Management Program data suggests provider adherence to standards of care, although coordination between mental health and primary care was poorly documented (201:18).

Social Services Work Group

A CHAIN communication in August 2002 on the utilization of food and nutrition services reported on use of four food and nutrition services from data collected in 1999 from 508 participants. The study found that:

- overall usage of food and nutrition services is modest,
- patterns of usage differ according to the specific service examined,
- use of food and nutrition services has little relationship to use of other services, except for case management, and
- the key factor associated with use of these services is need for services as measured by access to kitchen facilities and the ability to prepare one's own meals (159:3).

A CHAIN study released in November 2002 on people over 50 years old with HIV/AIDS found that individuals over 50 are more likely to identify provider behaviors and disrespect as barriers to receiving social services. The study also found that social isolation does not increase with age but that those over 60 years expressed more need for social support than younger participants (164:2-3). Per a November 2003 CHAIN presentation, the following case management service gaps exist by borough for CHAIN participants (142:30):

- New York City in total: 20%
- Bronx: 23%
- Brooklyn: 13%
- Manhattan: 20%
- Queens: 30%
- Staten Island: 13%

According to the same presentation, the following case management service gaps exist by race/ethnicity for CHAIN participants (142:31):

- New York City in total: 20%
- White, non-Hispanic: 30%
- Black, non-Hispanic: 19%
- Hispanic: 18%

In the May 2004 CHAIN document *Strategic Plan Progress Indicators: New Cohort Update* social services provided to CHAIN participants were measured in a number of ways. Overall, there were no statistically significant differences in the indicators when the new CHAIN cohort was compared with the original CHAIN cohort. Specifically (206:6):

- The proportion of participants reporting they delayed or did not get medical or social services because staff did not speak their language, were not competent, were disrespectful, didn't understand client's problems or were not good at listening – original cohort 15%; new cohort 13%. (206:33)
- Among those who reported needing help with transportation services or that transportation was a barrier to receiving care in the six months prior to the interview, those who receive transportation services – original cohort 45%; new cohort 38%. (206:35)
- Among those who expressed needing assistance with legal matters, childcare, or food/groceries/meals, those who reported that “no change has occurred” or “the problem has been getting worse” – original cohort 53%; new cohort 58%. (206:37)
- Among those who received help taking medications, those who reported the advice was “very helpful” or “somewhat helpful” – original cohort 91%; new cohort 91%. (206:39)
- Among those who had need for benefits, those who reported being on Medicaid – original cohort 98%; new cohort 96%. (206:41)

The only sub-group difference was among 20-34 year olds, who were more likely to have unresolved problems in legal matters, child care, or food services than were older respondents with similar expressions of need for these services. (206:6)

According to an April 2004 presentation, the New York State HIV Quality Management Program, selected data from 2002 revealed the following regarding case management services (206:20):

- All seven recognized elements of a case management assessment were present 61% of the time within 30 days; at least one element was present 92% of the time within 30 days.
- Quarterly coordination of care was documented 49% of the time.

Summary and Conclusions

New needs assessment data are available for case management, nutrition, and social services for persons over age 50. Case management service gaps exist across all boroughs (142:30) and race groups (142:31). No significant differences emerged in various social service needs reported by the new CHAIN cohort when compared to the earlier cohort, suggesting a general level of stability in met and unmet social service needs. One exception was among 20-34 year olds, who were more likely to have unresolved problems in legal matters, child care, or food services than older CHAIN respondents. Quality management data show that coordination of care was documented less than half the time (201:20). Assuming that an absence of documentation reflects accurately an absence of service coordination, improvements in service coordination, particularly with primary care, are warranted.

Recommendations

Implications and Suggested Action Steps

As stated previously in this document, the data we examined for this assessment are generally consistent with the data available in the 2002 Needs Assessment.

This is not to suggest that changes in Title I priority setting and resource allocations or in service delivery models are unwarranted. Evidence in both documents exists that supports changes and improvements in many areas, as does the EMA's Comprehensive Strategic Plan 2002-2005.

This final section of the Needs Assessment Update presents recommendations from the authors on a range of planning, data application, and related topics.

These recommendations do not necessarily reflect the views of the NYC DOHMH or the Planning Council. They are offered for the purposes of stimulating discussion and improving the overall performance of the Title I program in the NY EMA to effectively serve people living with HIV/AIDS.

Using the Unmet Need Estimation

The HRSA-mandated unmet need estimate is a multi-year process. This Needs Assessment Update summarizes the output of the first cycle of effort around this complex, and new approach by the CARE Act to identifying a population not in care.

As we note elsewhere, caution should be exercised at this time when using this calculation to make changes in the EMA's 2005 priorities and resource allocations. However, as experience with the estimation methodology progresses, and the data inputs become more reliable, the estimation will increasingly become more useful. We recommend continuing to pursue improvements in the data inputs as well as continuing to find additional means to shed more light on the population of persons not in care.

Given these limitations, the relevant question for the Planning Council with respect to the unmet need estimation (both the number and the analysis of who they are) at this time is as follows:

What changes to services are necessary in light of this data?

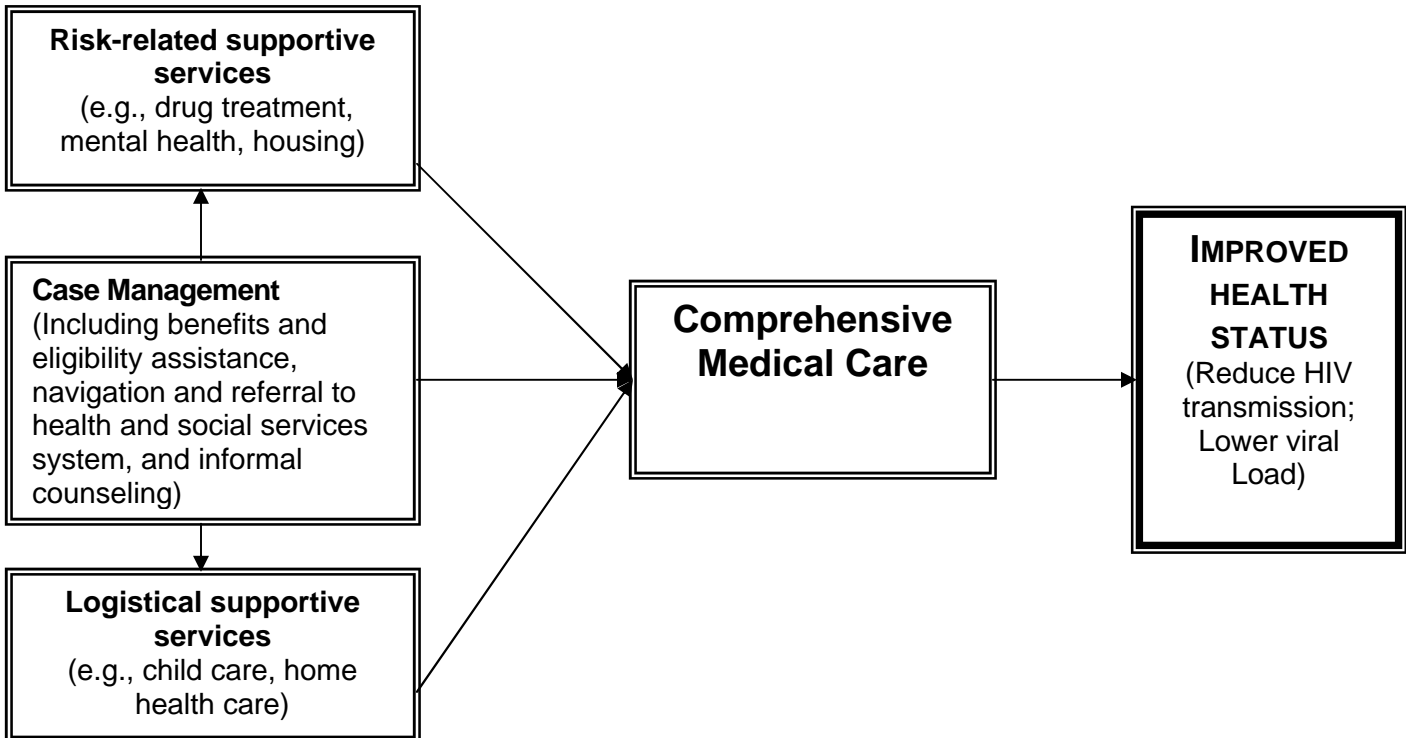
The Planning Council needs to consider ways of addressing the barriers to improve engagement in care and to strengthen the current system of institutional linkages and maintenance in care. Existing priorities would be re-prioritized or enhanced based on best practices and evidence from health services research efforts.

Significantly, it is not the role of the Planning Council to define service models although the Council has a wealth of knowledge about those models. Rather, the grantee performs that function with support from MHRA to assure appropriate implementation of each service model.

Model of HIV Care System

(by David Abramson, Columbia University Center for Applied Public Health, April 2004)

The Planning Council utilizes information garnered from the Comprehensive Care Model for guidance in priority setting and resource allocation (210:3). Illustration embodies an “ideal” model of an HIV care system, one that encompasses both health and social services within a continuum of care. Central to this model HIV care system is comprehensive medical care with the desired end result of improved health status (reduction in HIV transmission and lower viral load). In this model, case management has been shown to assist individuals engage in medical care and maintain continuity, either directly or through risk-reducing supportive services or through logistical services.



Possible Planning Council Actions

The Planning Council may undertake actions that are appropriate to its legislatively mandated duties such as, but not limited to, the following:

- Lead the development of an EMA-wide unified goal for HIV/AIDS prevention interventions, care services, and proactive patient navigation models of care. Such a multi-year unified goal might be, for example, to reduce the number of new infections of HIV by a specific number (to be determined) and reduce the number of AIDS deaths to a specific number (to be determined) by 2008. Flowing from such a goal could be common criteria for prevention and care planning and implementation to:
 - Promote prevention with positives
 - Promote linkage with HIV counseling, testing and referral programs;
 - Ensure more effective linkage to the care continuum upon timely knowledge of serostatus;
 - Improve continuity across the continuum of care;
 - Enhance adherence to treatment: and
 - Manage co-morbidities and other factors that keeps people from behavior change preventing new infections, or that keeps them out of care or that contributes to disconnecting from care.
- Take a position to affirm (or re-affirm) its desire for the EMA's service delivery models to have the capacity to address clients' barriers to improve engagement in care. This position might be particularly geared to the grantee and MHRA in their roles to procure and monitor services, respectively. The position statement should reference specific Strategic Plan goals and objectives.
- Take a position to improve linkages, referrals, and maintenance in care. As above, this emphasis would be geared particularly to encouraging the grantee and MHRA – as well as providers themselves – and it should reference the appropriate specifics in the Strategic Plan.
- Select new Planning and Evaluation initiatives that expand the EMA's knowledge of the effectiveness of service delivery models, that identify the barriers to effective linkage and referral, and that describe strategies to address them.
- Target technical assistance resources to activities that enable providers to adapt and improve their service delivery models to increase retention in care and to improve linkage and referral of clients.

- Assure technical assistance and quality management efforts consistently address coordination between social services and primary care (and vice versa), and also support improvements in perceived provider attitudes that may create barriers to care and other important aspects of care such as treatment adherence and secondary prevention.

Data and Planning

More immediately useful are new data on those persons who delay entry into care, and on delayed HIV testing in general. Policy recommendations flowing from the *Delayed Entry to HIV Care* study include the following (146:27-29):

- Provide more realistic information about treatment, particularly at the time of pre- and post-test counseling;
- Improve the ease, speed and convenience of HIV testing;
- Assure better linkages to medical care for people who test positive;
- Expand the availability of culturally sensitive providers;
- Explore regulatory or funding changes to provide medical care at community based organizations (especially Article 28 providers), rather than relying on partnership arrangements;
- Address contextual factors (housing, prior involvement with medical care, social isolation) during testing and counseling; and
- Educate legal and benefits policy makers and service providers on the consequences of an HIV/AIDS diagnosis.

To these we add the recommendation that the EMA adapt service delivery programs and systems to intensify the focus on those specific populations who are known to delay testing, as well as those who are known to delay care seeking. This would be accomplished by reducing known barriers that are within the realm of the health and social services system, such as facilitating entry into care at the point of a positive test result, regardless of type of setting.

In addition to examining data specific to the NY EMA, we advise the Planning Council to review and take into account existing national reports and studies to better meet the challenges of the changing health care environment as well as the changing funding stream. For example, as part of the 2000 Ryan White CARE Act reauthorization legislation, Congress directed the Institute of Medicine to conduct a study to address issues related to the public financing and delivery of HIV services. In May 2004, the Institute of Medicine published *Public Financing and Delivery of HIV/AIDS Care: Securing the Legacy of Ryan White* report. This report examined the current standards of care for HIV patients and assessed the extent the system currently uses for financing and delivering care allows individuals with HIV to actually receive it. To improve the continuity, equity and efficiency of HIV care, the report recommended the establishment of a new federally-funded HIV Comprehensive Care Program for low-income HIV-infected persons that provides early access, continuous coverage, and uniform benefits to best meet the needs of those with HIV/AIDS. The proposed program is designed with a strong focus on

comprehensive primary care, substance abuse, and mental health services to support adherence to HAART.

We note that the 2002 Needs Assessment devotes an entire chapter (Chapter 8, pages 143-146) to data and evaluation gaps. We recognize that a number of those gaps are being addressed through Planning and Evaluation initiatives such as the outcome evaluation initiative, client-level data project, mapping project and a needs assessment of emerging communities.

One important forthcoming document, an Integrated *Epidemiologic Profile for New York City* will be published by NYC DOHMH soon after this Needs Assessment Update is available. That document will provide a wealth of additional information for the purposes of better understanding the HIV/AIDS epidemic in New York.

In closing, continued attention to the data and evaluation gaps discussed in the 2002 Needs Assessment is recommended through the planning process. The initiation of ongoing Data Days over the past year was a major breakthrough in translating complex data for planning purposes, and is a best practice for future needs assessment and priority setting in the New York EMA.

Appendix: Data Sources

A List of the Data and Primary Resources Utilized

This appendix lists all the sources used for developing this update through May 1, 2004. The Office of AIDS Policy Coordination, the New York City Department of Health and Mental Hygiene, CHAIN, and MHRA provided many of the documents.

Every document was given a unique code number beginning with #130 (the 2002 Needs Assessment having listed 129 documents). All documents were studied for their relevance to the needs assessment update and planning process, and an abstract written using a common format to capture relevant and useful information. Key subjects, such as specific populations and service categories, were used to develop this Needs Assessment Update.

Throughout the document, readers will find sources referenced using the unique code number. In addition, where available, the specific page or slide number of that document is cited. This is intended to give the reader the ability to note specific objective evidence for future planning-related decision-making.

For example, “The strongest theme across the five forums was the need to increase the availability of and access to HIV services (186:2)” appears at the beginning of chapter 5. A reader interested in more information would first turn to this section and look up document #186, Community Forum Report, Spring 2004, HIV Health and Human Services Planning Council of New York, April 5, 2004, NYCDOH/OAPC. On page 2 of that document will be found the specific information cited in Chapter 5.

130. Data Day 1 Presentation: An Overview of Unmet Need/July 21, 2003, HRSA
131. List of Unmet Need Resources/July 21, 2003, HRSA
132. Data Day 1 Presentation: Understanding the Epidemiology of AIDS in New York City/August 1, 2003, NYC DOHMH
133. Data Day 1 Presentation: Proposed NYC EMA Client Level Data Collection System/August 1, 2003, MHRA/Data Link
134. Data Day 1 Presentation: NYS Client Level Data Collection/August 1, 2003, NYSDOH
135. Data Day 2 Presentation: New York City Community Health Assessment/November 7, 2003, NYC DOHMH
136. Data Day 2 Presentation: HRSA/CDC Joint Epidemiological Profile Guidelines/November 7, 2003, HRSA/CDC
137. Data Day 2 Presentation: NYC Integrated Epidemiological Profile/November 7, 2003, NYC DOHMH
138. Data Day 2 Presentation: Determining Unmet Need in the NY EMA/November 7, 2003, NYC DOHMH, OAPC
139. Data Day 2 Presentation: New York State Medicaid/ADAP Unmet Needs Project/November 7, 2003, NYSDOH

140. Data Day 2 Presentation: CHAIN Study Contributions to Understanding Unmet Need/November 7, 2003, Columbia
141. Data Day 2 Presentation: Evaluating Access to Care Using HIV/AIDS Surveillance Data/November 7, 2003, NYC DOHMH
142. Data Day 2 Presentation: Analyzing Service Gaps Using the CHAIN Study November 7, 2003, Columbia
143. Data Day 2 Presentation: New York City HIV/AIDS Housing Needs Assessment/ November 7, 2003, Hudson Planning Group
144. Data Day 2 Presentation: Special Populations/November 7, 2003, Michael Isbell
145. A Consumer's Guide to Quality of HIV Care in New York State 2001, NYSDOH
146. Data Day 2 Presentation: Delayed Entry to HIV Care: A Study of Factors Associated with Delayed Care Seeking Among HIV-Infected Individuals in New York City, September 2003, Columbia.
147. HIV-Infected Youth Ages 13-19 Currently Living in NYC/December 2003, NYC DOHMH
148. Data Day 3 Presentation: Using Data from Minority AIDS Initiative Programs to Assess Title I Services, February 6, 2004, Pagnoni & Associates, Inc.
149. Data Day 3 Presentation: Minority AIDS Initiative Evaluation – Access to Care and Maintenance in Care Programs, February 6, 2004, New York Academy of Medicine
150. Data Day 3 Presentation: HIV CARE Services Data and Assessment of the Title I Portfolio, February 6, 2004, MHRA HIV CARE Services
151. Data Day 3 Presentation: Using CHAIN Data to Assess Title I Services, February 6, 2004, Columbia
152. Impact of the Minority AIDS Initiative on Participants in Treatment Education and Adherence Programs, August 2003, Pagnoni & Associates, Inc.
153. HIV/AIDS Surveillance Quarterly Update, October 2003, NYC DOHMH
154. CHAIN Update Report #45, Patterns of Sexual Behaviors and Sexual Risk among HIV Positive People in New York City, February 2003, Columbia
155. CHAIN Update Report #46, Chronic Diseases and Clinical Comorbidities, July 2002, Columbia
156. CHAIN Update Report #47, CHAIN Retrospective (Unmet Need): 1994-2002, January 15, 2003, Columbia
157. CHAIN Brief Communication 2002-1, Exposure to Trauma and Violence Among Persons Living with HIV, July 24, 2002, Columbia
158. CHAIN Brief Communication 2002-2, Drug Holidays Among the CHAIN Cohort, April 16, 2002, Columbia
159. CHAIN Brief Communication 2002-3, Utilization of Food and Nutrition Services among People with HIV in NYC, August 10, 2002, Columbia
160. CHAIN Brief Communication 2002-4, Religion and Spirituality Among Persons Living with HIV, April 16, 2003, Columbia

161. CHAIN Memo 2002-1, Patterns of Medical Care and Substance Use Providers, July 25, 2002, Columbia
162. CHAIN Memo 2002-2, Partner Notification, July 25, 2002, Columbia
163. CHAIN Memo 2002-3, Trends in Medical Care Visits, July 25, 2002, Columbia
164. CHAIN Memo 2002-4, People Over 50 Years Old with HIV/AIDS, November 20, 2002, Columbia
165. CHAIN Tri-County Report 2002-1, The Tri-County Cohort: Demographics and Other Characteristics, April 1, 2003, Columbia
166. CHAIN Tri-County Report 2002-2, Health Status and Health Services Utilization, April 1, 2003, Columbia
167. CHAIN Tri-County Report 2002-3, Stigma and Social Isolation, May 23, 2003, Columbia
168. CHAIN Tri-County Report 2002-4, Field Notes: Recruiting a Longitudinal Cohort, April 1, 2003, Columbia
169. CHAIN Tri-County Report 2002-5, Support Groups, April 1, 2003, Columbia
170. CHAIN Tri-County Report 2002-6, Baseline Needs Assessment of the Tri-County Cohort, April 1, 2003, Columbia
171. CHAIN Tri-County Report 2003-1, Services Gaps and Utilization in the Continuum of Care, April 13, 2004, Columbia
172. CHAIN Tri-County Report 2003-2, Treatment Adherence: Client Characteristics and Agency Factors Associated with Increased Adherence, Columbia
173. CHAIN Tri-County Report 2003-3, A Geographic Display of Health and Social Service Agencies in the Tri-County Region, July 7, 2003, Columbia
174. CHAIN Tri-County Report 2003-4, Partner Notification, April 12, 2004, Columbia
175. CHAIN Tri-County Report 2003-5, Estimating the Number of HIV/AIDS Infected Individuals in the Tri-County Region, in Care and Not in Care, April 9, 2004, Columbia
176. CHAIN Tri-County, Memorandum Regarding Housing Problems, September 29, 2003, Columbia
177. CHAIN Tri-County Report 2003-7, Strategic Plan Benchmark Report, Columbia
178. CHAIN Tri-County Presentation to the Title I Steering Committee, April 14, 2004, Columbia
179. CHAIN Report 2003-1, Strategic Plan Progress Indicators: Baseline Report (Draft), March 19, 2003, Columbia
180. CHAIN Report 2003-3, Validation of Self-Reported Viral Load Levels (Draft), September 24, 2003, Columbia
181. CHAIN Report 2003-4, Social and Demographic Correlates of Self-Reported Viral Load Levels, November 5, 2003, Columbia
182. CHAIN Report 2004-2, Strategic Plan Progress Indicators: New Cohort Update, January 21, 2004, Columbia

183. Presentation: New York State Department of Health, HIV Uninsured Care Programs, Christine A. Rivera, undated, NYSDOH
184. HIV/AIDS Services Administration, City of New York Human Resources Administration, February 2004, HASA
185. Unmet Need Project for NYCDOH, Draft, April 2, 2004, NYSDOH
186. Community Forum Report, Spring 2004, HIV Health and Human Services Planning Council of New York, April 5, 2004, NYCDOH/OAPC
187. The State of HIV/AIDS in New York City, Thomas R. Frieden MD MPH, Commissioner, New York City Department of Health and Mental Hygiene, December 16, 2003, NYCDOH
188. HIV Special Needs Plan Program Update, April 1, 2004, NYSDOH
189. The New York City CHAIN Study: Presentation to the HIV Planning Council, August 1, 2003, Columbia
190. CHAIN Presentation: Service Gaps and Strategic Plan Progress Indicators, Presented to the Planning and Evaluation Work Group, March 12, 2004, Columbia
191. Delayed Entry to HIV Care, Summary: Year 1 Report: A Study of Factors Associated with Delayed Care Seeking Among HIV-Infected Individuals in New York City, September 2003, Columbia
192. NYCDOH/MN Office of AIDS Policy Coordination, Strategic Directions, NYC DOHMH
193. Presentation to the Data Committee: Minority AIDS Initiative Outcome Evaluation, Access to Care and Maintenance in Care Programs – Outcome Evaluation Overview: Opportunities and Limitations, November 21, 2003, NYAM
194. Strengthening the 2005 Planning Process, OAPC Retreat, April 8, 2004, Isbell
195. Data Day 3 Report: Service Utilization/Epidemiology Data, February 6, 2004, MHRA
196. Ryan White Title I Program Monitoring Report to the New York City Department of Health and Mental Hygiene for March 2001-February 2002, March 2003, MHRA
197. Ryan White Title I Program Monitoring Report to the New York City Department of Health and Mental Hygiene for March 2002-February 2003, April 2004, MHRA
198. Table 7a and Table 7b, FY 2004 Title I Application for the New York EMA, October 2003, NYC DOHMH
199. New York EMA FY 2004 Title I Grant Application, October 2003, NYC DOHMH
200. Unmet Need Presentation (Grace Moon) and Persons with Unmet Need in NYC: Who is not in care? (Susan Forlenza), April 16, 2004, NYC DOHMH
201. HIV Quality Management Program Presentation, April 16, 2004, NYSDOH
202. Cost Effectiveness and Title I Planning, April 16, 2004, NYC DOHMH
203. Unit Cost: Calculations and Applications, April 16, 2004, MHRA
204. HIV/AIDS Surveillance Quarterly Update, January, 2004, NYC DOHMH

205. Geographic Distribution of Service Gaps Among the NYC CHAIN Cohort: A Geomapping Analysis, April 21, 2004, CHAIN Report 2003_2, Columbia
206. Strategic Plan Indicators: New Cohort Update, Revised May 19, 2004, CHAIN Report 2004-2, Columbia
207. Pediatric HIV/AIDS Surveillance in New York City: Semiannual Report, December 2003), NYC DOHMH
208. The 2001 Statewide Coordinated Statement of Need, Strategic Resources Associates, Inc.
209. Data Day 4 Presentation: Persons with Unmet Need In NYC: Who is not in care?, April 16, 2004, NYC DOHMH
210. Service Gaps and Utilization in the Continuum of Care In New York City, CHAIN, June 15, 2004