



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

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

Update to the Tri-County
2002 Initial Needs Assessment
New York Eligible Metropolitan Area (2004)

**Prepared by McClain and Associates, Inc
July 26, 2004**

Acknowledgments

This document was made possible by a grant from the U.S. Health Resources and Services Administration (HRSA), under Title I of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, with the support of the HIV Health and Human Services Planning Council of New York, through the New York City Department of Health and Mental Hygiene (NYC DOHMH) and Medical and Health Research Association of New York City, Inc. (MHRA). Its content is solely the responsibility of McClain and Associates, Inc., and does not necessarily represent the official views of the HRSA, the City of New York, or MHRA.

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The authors wish to acknowledge the assistance of the Planning Council and the following organizations and individuals:

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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.

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

Medical and Health Research Association of New York City, Inc.

Mary Ann Chaisson, DrPH, Judy Verdino, Rachel Miller, Gregg Weinberg, Bettina Carroll,
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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 |
| NYCDOHMH | New York City Department of Health and Mental Hygiene |
| EMA | Eligible Metropolitan Area |
| HIV | Human Immunodeficiency Virus |
| HRSA | Health Resources and Services Administration (federal agency) |
| IDU | Injecting drug user |
| MHRA | Medical and Health Research Association of New York City, Inc. |
| MSM | Men who have sex with men |
| NYC | New York City |
| OAPC | Office of AIDS Policy Coordination |
| OI | Opportunistic Infection |
| PLWH/A | Persons Living With HIV/AIDS |
| Ryan White | Ryan White CARE Act |
| WCDOH | Westchester County Department of Health |

This project was supported by grant number #6H89HA00015-13 of the Ryan White CARE Act from the Department of Health and Human Services, Health Resources and Services Administration (HRSA), HIV AIDS Bureau.

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 a needs assessment is to define and describe service needs and gaps in services for people with HIV disease. The results of the needs assessment will set the stage for 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 the Tri-County Region, 2002*. That document was used to develop the *Comprehensive Strategic Plan for HIV/AIDS Service 2002-2005*, which includes specific Tri-County objectives.

The New York Eligible Metropolitan Area (EMA) consists of New York City and the counties of Westchester, Rockland, and Putnam (known as the "Tri-County Region"). Title I funds are granted by the Federal government to EMAs that are disproportionately affected by the HIV/AIDS epidemic. Funding is to support the provision of care and treatment services.

The New York City Department of Health and Mental Hygiene's (NYCDOHMH) Office of AIDS Policy Coordination (OAPC) together with Westchester County Department of Health (WCDOH) support the entire planning process, including this needs assessment. OAPC provides professional and administrative support to the Planning Council as does WCDOH for the Tri-County Steering Committee. The Planning Council along with input from the Steering Committee set priorities and allocates CARE Act Title I funds for the entire EMA.

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 NYCDOHMH 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.

As a sub-region within the New York EMA, the Tri-County Region has its own Title I Steering Committee whose work parallels that of the mandated HIV Health and Human Services Planning Council of New York. The Title I Steering Committee is convened by the WCDOH, which is also responsible for the administration of Title I programs in the region.

The Tri-County Steering Committee and the NY EMA 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 Steering Committee will use this needs assessment as the base of evidence to develop a plan consisting of goals, objectives and mechanisms to monitor the plan. The Steering Committee conducts much of the detailed work of planning through four service subcommittees (Health, Housing, Case Management, Mental Health/Substance Use)¹, a work group (Support Services), and the PWA Advisory Group (Living Together).

Methods

This update was designed to be consistent with the CARE Act Amendments of 2000, Federal guidance as promulgated by the HIV/AIDS Bureau, Health Resources and Services Administration, and local circumstances. The major elements of the needs assessment are:

- An updated epidemiological profile that describes the current status of the epidemic in the Tri-County region, specifically the prevalence of HIV and AIDS among defined sub-populations. The profile also identifies trends.
- Information on persons not in care.
- New information on characteristics of adults living with HIV/AIDS in the region and information on their service needs and gaps and barriers.
- Recommendations from the authors on a range of planning, data application, and related topics.

A 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 and the Steering Committee 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

¹ Two of the service subcommittees are coordinated by the Lower Hudson Region HIV Care Network.

manageable collection of essential needs assessment data. Not every item that resulted from this process easily fit into one of these definitions, so readers may find some overlap.

How to use this document

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 WCDOH, NYCDOHMH, MHRA, and OAPC.

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 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 can describe 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 a specified population.

Updated Epidemiological Data

New population data on the HIV/AIDS epidemic

Methods

This section of the needs assessment update focuses on data available since the 2002 publication of the Initial Needs Assessment for the Tri-County Region, and includes data on HIV infections, reporting of which began on June 1, 2000.

Sociodemographic Characteristics of the General Tri-County Population

This section presents an epidemiological profile of HIV/AIDS in the Tri-County region, highlighting the epidemiology of the disease as it currently exists and emerging trends that will likely shape the epidemic over the coming years. Tables 1 and 2, presented below, are based on the most recent U.S. Census Bureau data.

Table 1: Tri-County Populations by County

| County | Population in 2002 (Number) | Population in 2002 (Percent of Total) | Percent Change from Population in 2000 | Median Household Income in 1999 | Percent Foreign Born | Percent of Persons 25+ with a Bachelor's Degree |
|----------------------|-----------------------------|---------------------------------------|----------------------------------------|---------------------------------|----------------------|-------------------------------------------------|
| Putnam | 98,257 | 7.4 | 2.6 | \$72,279 | 8.8 | 33.9 |
| Rockland | 291,835 | 22.0 | 1.8 | \$67,971 | 19.1 | 37.5 |
| Westchester | 937,279 | 70.6 | 1.5 | \$63,582 | 22.2 | 40.9 |
| Total Tri-County | 1,327,371 | 100.0 | 1.6 | \$65,129 | 20.5 | 39.6 |
| Total New York State | 19,157,532 | 100.0 | 1.0 | \$43,393 | 20.4 | 37.5 |

Source U.S. Census Bureau: State and County (New York) QuickFacts. Data derived from Population 2002 estimates and 2000 Census of Population and Housing.

Table 2: 2000 Tri-County Populations by County and Race/Ethnicity

| Race/ Ethnicity | Putnam | | Rockland | | Westchester | | Total Tri- County | Total New York State |
|----------------------|---------------|--------------|----------------|--------------|----------------|--------------|-------------------------|-------------------------|
| | Number | Percent | Number | Percent | Number | Percent | Percent | Percent |
| White (non-Hispanic) | 85,973 | 89.8 | 205,653 | 71.7 | 591,776 | 64.1 | 67.6 | 67.9 |
| Black (non-Hispanic) | 1,437 | 1.5 | 30,139 | 10.5 | 125,227 | 13.6 | 12.0 | 15.9 |
| Hispanic | 5,976 | 6.2 | 29,182 | 10.2 | 144,124 | 15.6 | 13.7 | 15.1 |
| Other | 2,359 | 2.5 | 21,779 | 7.6 | 62,332 | 6.8 | 6.6 | 1.1 |
| Total | 95,745 | 100.0 | 286,753 | 100.0 | 923,459 | 100.0 | 100.0 | 100.0 |

Source U.S. Census Bureau: State and County (New York) QuickFacts. Data derived from 2000 Census of Population and Housing.

Tri-County Region Population Profile:

- Between 2000 and 2002 the general population in the Tri-County region grew by 1.6%.
- Westchester County is the most heavily populated area in the Tri-County region (representing 70.6% of the population) and Putnam is the least populated (representing 7.4% of the population).
- The average household income in the Tri-County region is higher than that for the State as a whole (\$65,129 for the Tri-County region versus \$43,393 for the State).
- Tri-County demographics are representative of the racial and ethnic characteristics for the state as a whole. However, Putnam County is the least racially/ethnically diverse and has the highest median household income.

HIV/AIDS Epidemic in the Tri-County Region

As of December 31, 2002 a total of 5,760 cumulative adult AIDS cases have been diagnosed in the Tri-County region and of these 2,570 were known to be living with the disease.

The largest proportion of cumulative AIDS cases result from injecting drug use (IDU) (46.5%, n=2678) with an additional 3.4% (n=196) of men who have sex with men (MSM) IDU cases. Of those living with AIDS, 41.1% (n=1027) have a history of IDU with an additional 3% (n=75) MSM/IDU cases.

The AIDS epidemic in the Tri-County region disproportionately affects:

- Males – 72% of cumulative cases and 65% of living AIDS cases.
- People of Color – 66% of cumulative cases and 72% living AIDS cases.
- Westchester County residents – 82% of cumulative cases and 80% living AIDS cases.

PLWH/A demographics for the Tri-County region indicate the following:

Gender: The Tri-County region continues to see an HIV epidemic increasingly affecting women. While 72% of all AIDS cases diagnosed through 2002 have been among men, women now account for 35% of all living AIDS cases and 48% of all living HIV cases (non-AIDS).

Race/Ethnicity: The Tri-County epidemic continues to disproportionately affect communities of color, with blacks in particular feeling the impact. Half of all living HIV and AIDS cases are among blacks and yet they represent about 12% of the general Tri-County population. Hispanics account for 21% of all living HIV and AIDS cases, but only 14% of the general population.

Age: In contrast to NYC, PLWH/A in the Tri-County region are younger with the 30-39 age group representing the largest percentage (41%) of living HIV and AIDS cases in the Tri-County region and 40-49 age group representing the predominant age group of PLWH/A (39%) in NYC (as of March 31, 2003). This difference is also notable among those 50 and older. Whereas in NYC, this group represents 26% of the living HIV/AIDS cases, it only represents 12% of the Tri-County cases.

Risk: IDUs continue to represent the largest risk group for the Tri-County region with this group accounting for 47% of all AIDS cases. While preliminary HIV (non-AIDS) data seem to show this group declining, it is difficult to draw final conclusions given that over one in four HIV (non-AIDS) cases are reported with risk “unknown.” Regardless of this limitation, persons exposed through heterosexual contact are on the rise, representing 33% of all living HIV cases, which is twice the number represented for all cumulative AIDS cases attributed to heterosexual transmission.

Table 3. Summary of Cumulative AIDS and Living HIV/AIDS Cases by Risk, Age, Race/Ethnicity, Sex, and County²

| Risk Group | NUMBER | | | | PERCENT | | | |
|-----------------------|-----------------------|----------------|-----|----------|-----------------------|----------------|--------|----------|
| | Cumulative AIDS Cases | Persons Living | | | Cumulative AIDS Cases | Persons Living | | |
| | | AIDS | HIV | HIV/AIDS | | AIDS | HIV | HIV/AIDS |
| MSM | 1333 | 473 | 124 | 597 | 23.1% | 18.4% | 14.5% | 17.4% |
| IDU | 2678 | 1050 | 214 | 1264 | 46.5% | 40.9% | 25.0% | 36.9% |
| MSM/IDU | 196 | 77 | 11 | 88 | 3.4% | 3.0% | 1.3% | 2.6% |
| Hetero. Contact | 944 | 603 | 279 | 882 | 16.4% | 23.5% | 32.6% | 25.8% |
| Blood Products | 73 | 17 | 4 | 21 | 1.3% | 0.7% | 0.5% | 0.6% |
| Other/Unknown | 536 | 350 | 223 | 573 | 9.3% | 13.6% | 26.1% | 16.7% |
| AGE | | | | | | | | |
| 13-24 | 162 | 81 | 75 | 156 | 2.8% | 3.2% | 8.8% | 4.6% |
| 25-29 | 550 | 233 | 73 | 306 | 9.5% | 9.1% | 8.5% | 8.9% |
| 30-39 | 2404 | 1069 | 325 | 1394 | 41.7% | 41.6% | 38.0% | 40.7% |
| 40-49 | 1906 | 902 | 272 | 1174 | 33.1% | 35.1% | 31.8% | 34.3% |
| 50+ | 738 | 285 | 110 | 395 | 12.8% | 11.1% | 12.9% | 11.5% |
| Race/Ethnicity | | | | | | | | |
| White | 1818 | 618 | 168 | 786 | 31.6% | 24.0% | 19.6% | 22.9% |
| Black | 2774 | 1304 | 426 | 1730 | 48.2% | 50.7% | 49.8% | 50.5% |
| Hispanic | 1050 | 548 | 182 | 730 | 18.2% | 21.3% | 21.3% | 21.3% |
| Other/Unknown | 118 | 100 | 79 | 179 | 2.0% | 3.9% | 9.2% | 5.2% |
| Sex | | | | | | | | |
| Male | 4140 | 1682 | 445 | 2127 | 71.9% | 65.4% | 52.1% | 62.1% |
| Female | 1620 | 888 | 409 | 1297 | 28.1% | 34.6% | 47.9% | 37.9% |
| County | | | | | | | | |
| Putnam | 162 | 69 | 21 | 90 | 2.8% | 2.7% | 2.5% | 2.6% |
| Rockland | 874 | 435 | 97 | 532 | 15.2% | 16.9% | 11.4% | 15.5% |
| Westchester | 4724 | 2066 | 736 | 2802 | 82.0% | 80.4% | 86.2% | 81.8% |
| Total | 5760 | 2570 | 854 | 3424 | 100.0% | 100.0% | 100.0% | 100.0% |

² Table prepared by WCDOH. Reported cases from NYSDOH Bureau of HIV/AIDS Epidemiology through 12/31/2002 with data as of 3/2/2004. Excludes pediatric cases and includes inmates. As of the same date, NYSDOH reports a total of 61 confirmed pediatric (<age13) HIV/AIDS cases: Westchester, 54; Rockland, 6; Putnam, 1.

Information on Persons Not in Care

Information on Persons Not in Care

Individuals who are “not in care” are examined from two related perspectives.

First, HRSA has mandated³ that a single “unmet need” estimate be part of an overall needs assessment which supports comprehensive service planning. This measure is presented and discussed below.

Second, 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 examined in depth in the NYC needs assessment update.

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

Unmet Need Estimate

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

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

Like NYC, Tri-County’s approach to calculating unmet need (200:8-9) involved using combined data from the Medicaid and ADAP claims files from federal fiscal year 2001 – with an adjustment to account for those in care with private insurance, Medicare, or Veterans Administration coverage – to form the numerator of the “unmet need” equation (i.e., those “in care”). NYS Department of Health Bureau of HIV/AIDS Epidemiology data for calendar year 2001 were used to form the denominator of the “unmet need” equation

³ 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)

(i.e., the total number of individuals estimated to be living with a diagnosis of HIV disease). The calculation yielded the following result (200:10):

- Forty-four percent (44%) of those in Tri-County with a diagnosis of HIV disease in 2001 fall in the category of “unmet need,” i.e., had not received a viral load test, CD4 count, or antiretroviral therapy within a 12-month period.

The “unmet need” estimate is currently under review. Limitations to the approach outlined exist in both the numerator⁴ and the denominator⁵, however these are arguably the best data sources currently available for the calculation of “unmet need” (source: personal conversation with the AIDS Institute’s Ira Feldman).

(See the NYC Needs Assessment Update for more information about their unmet need estimate for NYC.)

It is noteworthy that the researchers from the CHAIN study in the Tri-County region used a different methodology, along with a more flexible definition of unmet need (i.e., defined as those individuals with diagnosed HIV disease not found anywhere in the local continuum of health and social services), and found relatively fewer individuals outside the system of care (175). The researchers calculated that only eighteen percent (18%) of those diagnosed with HIV disease in Tri-County in 2001 met the CHAIN criterion for “unmet need” suggesting that the more likely proportion of those not meeting the stricter HRSA definition actually falls well below 44%.

Summary and Conclusions

There are limitations to the two sources of information (CHAIN and NYCDOHMH surveillance data) on delayed entry into care in the EMA. HIV surveillance reporting is relatively new and is still being refined (source: personal discussion with NYCDOHMH’s Dr. Susan Forlenza) and CHAIN involves self-reported data based on a sample of HIV infected individuals, not the entire population. Nonetheless, results on delayed entry into care from these two sources are not inconsistent (146:12).

⁴ 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).

⁵ 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 of the number of people living with HIV resulting in an overestimate of “unmet need” (Source: personal discussion with NYCDOHMH’s Dr. Susan Forlenza).

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.⁶ (141:12). Twenty percent (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 or historic drug users, have mental health difficulties, are homeless or unstably housed, have no regular sources of income, and/or have histories of incarceration.

Delays occur because the perceived costs of HIV care-seeking (concerns about stigma and rejection, 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).

⁶ 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)

General Information Since 2002

CHAIN in Tri-County

In 2001, the EMA initiated a longitudinal projected five year study of Tri-County residents living with HIV/AIDS similar to the CHAIN study that began in NYC in 1994. CHAIN Tri-County enrolled 398 individuals in 2002, which is approximately 25% of all HIV+ adults in the public system of care in Tri-County (171:3). CHAIN assesses the impact of services on the health of the participants and identifies gaps in health and human services (168:1).

Baseline Characteristics

In 2003, CHAIN published baseline characteristics of the Tri-County CHAIN cohort, including the socio-demographics, economic resources, family and household characteristics, HIV diagnosis and early medical care, current health status, and risks, among others (165:1). The sample (cohort) consists of 398 persons living with HIV/AIDS in Westchester, Rockland, and Putnam counties and is representative of persons living with HIV/AIDS in the region.

Needs and Gaps in Services

The CHAIN study identified several areas of need in Tri-County. The study reported on special subjects such as stigma, the role of support groups, partner notification, and housing among others. The following are some of the expressed needs of respondents and apparent gaps in current services.

- The CHAIN study examined the issue of stigma and social isolation among the suburban population in the Tri-County region. The results indicated that the participants experience high levels of 'felt' stigma: 77% scored very high and an additional 18% reported moderate levels. Women were more likely than men to express high levels of perceived stigma (167:2).
- The need for affordable housing is a major concern in the Tri-County region. In 2003, CHAIN studied the needs of respondents for stable and affordable housing (176). Nearly 40% of respondents said they needed help or assistance in finding and obtaining housing in the past 6 months. The study identified two problems: difficulty paying rent (57%) and poor quality of

housing (49%). Of those respondents who expressed a need for housing about half (46%) reported not seeking help due to lack of awareness as to where to go to get help. Most respondents (71%) do not receive any type of rental subsidy or housing, and of those who did the most frequent type of assistance was Section 8-Housing (14%).

- The CHAIN studied identified a need for improved communication between consumers and providers. As reported in April 2004, only 18% of the participants responded that their doctor or other medical provider talked to them about their sexual or needle-sharing partners in the last 6 months. Some of the participants reported discussing sexual issues, however providers rarely brought up the subjects of drug use and needle sharing behaviors. Subgroup differences among the participants showed that whites were less likely than either blacks or Hispanics to have discussed sexual or needle sharing issues with their providers. Persons with a greater than high school education were also less likely to discuss these issues with their doctors. (174:1-2).
- In 2003 CHAIN reported on the health status of the participants in the study (166:1) and found that about 74% of all respondents report being on ARVs, both HAART (46%) and non-HAART (28%). The results identified MSM as more likely to be adherence (87%) than problem drug users (54%), MSM/IDU (53%), or heterosexuals (65%). When compared to NYC's cohort, Tri-County residents with an AIDS diagnosis were significantly less likely to be on HAART, particularly residents of Westchester and Putnam counties. Individuals living in Westchester or Putnam were approximately half as likely, as similar individuals in NYC, to be on HAART, while blacks and Latinos regardless of location were half as likely as white respondents to be on HAART. About 24% reported a recent drug holiday, of which a large majority (70%) did so on their own without consulting their medical provider. These results may indicate a need for services to aid people in obtaining and remaining adherent to medical treatment.
- In general, the CHAIN study identified greater need for financial housing services and transportation services (171:3-4) in the Tri-County region. The most prominent gaps in services were in the areas of comprehensive case management (45%), professional mental health service (55%), and alcohol and drug treatment (76%) (171:4).

Table 4. Inventory of Tri-County HIV/AIDS Service Providers

| Service Category | Sub-services | Number of Agencies Serving the County ⁷ | | |
|-------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------|----------|--------|
| | | Westchester | Rockland | Putnam |
| Case Management | COBRA, Non-COBRA, Home-based | 21 | 9 | 6 |
| Community Advocacy & Planning | Speaker's Bureau, Planning Group, Consumer Advisory Group, Consumer Education and Advocacy | 22 | 9 | 6 |
| Dental Care | Preventive/Palliative, Oral Surgery | 8 | 4 | 3 |
| Financial Assistance | Cash/Emergency Funds | 9 | 7 | 6 |
| Food | Food bank/Pantry, Food Vouchers, Food Stamps, Soup Kitchen/Congregate Meals, Nutritional Counseling, Home-Delivered Meals | 22 | 8 | 6 |
| Health Care | Outpatient Care, Adult Day Health Care, Home Health, Nursing Facility, Clinical Trials, In-patient care, Complementary / Alternative Therapy, Nutritional Counseling | 24 | 13 | 10 |
| Hospice Care | Home-based, Facility-based | 6 | 3 | 4 |
| Housing | Rent assistance, Scattered Site, Transitional, Search/Placement Assistance, Emergency Shelter, Congregate, Utility Assistance | 28 | 8 | 9 |
| Legal | Legal/Court Representation, Discrimination, Eviction Prevention, Permanency Planning | 11 | 6 | 3 |
| Mental Health | Individual Counseling & Therapy, Group Counseling & Therapy | 24 | 10 | 7 |
| Outreach | General Presentations, Case-finding | 18 | 10 | 3 |
| Prevention / Education | HIV Counseling/Testing, Prevention Case Management, Partner Notification, Health Education / Risk Reduction, Hotlines | 27 | 13 | 13 |
| Respite Care | Buddy/Companion, In-Home, Child Care | 6 | 5 | 2 |
| Substance Use Treatment | Outpatient, Syringe/Needle Exchange, Residential, Methadone Maintenance | 17 | 11 | 12 |
| Support Groups / Psychosocial | Pastoral Counseling, Peer Support Groups, Therapeutic Camp, Educational Forums | 25 | 8 | 8 |
| Transportation | Taxi/Van/Car Service, Public Transit Token/Voucher | 10 | 7 | 5 |

⁷ Table prepared by WCDOH. Data for this inventory was received in response to a fall 2003 survey of providers in the region conducted by WCDOH. Ninety-four agencies with 182 separate service sites responded that they were currently offering the service within the Tri-County region and PLWH/A were eligible to access these services.

| Service Category | Sub-services | Number of Agencies Serving the County⁷ | | |
|---------------------------------|----------------------------------------------------------------------------------|----------------------------------------------------------|-----------------|---------------|
| | | Westchester | Rockland | Putnam |
| Treatment Education / Adherence | Treatment Support Groups, Individual Education/Counseling, Educational Forums | 15 | 5 | 3 |
| Vocational Training | Job Search & Placement, Skills Training, Interview Coaching / Resume Development | 16 | 4 | 4 |

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 exist supporting 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 Tri-County Steering Committee and NYEMA Planning Council. They are offered for the purposes of stimulating discussion and improving the overall performance of the Title I program in the Tri-County region to effectively serve people living with HIV/AIDS.

The Tri-County's CHAIN study continues to serve as the primary data source regarding met and unmet service needs for PLWH/A in the region as well as the qualitative experience of care received. With each passing year, CHAIN provides new and challenging layers of information to factor into decision-making and priority-setting. The reports, based on interviews conducted in 2002-2003, together with more complete data furnished by a review of all HIV/AIDS service programs completed for updating the local service directory at the end of 2003, suggest the following specific recommendations as priorities are set for Title I Year 15:

- 1) With an increasing federal, state, and local emphasis on "prevention for positives," the degree to which individual medical as well as social service providers focus on this issue must be assessed, and prevention efforts targeted to those living with HIV must be bolstered.
- 2) Few dedicated treatment adherence staff positions are supported across the region. Treatment adherence counseling, which is not Medicaid-reimbursable, must be adequately strengthened in the Title I continuum of care.

- 3) Trainings should be provided for community-based organizations on how to elicit information from clients on their sex- and needle-sharing partners in order to optimize outreach efforts at identifying those with HIV not in the medical continuum and connecting them to HIV primary care.
- 4) Trainings should be provided to medical personnel on how to better communicate with patients about the more technical aspects of viral load and resistance testing, CD4 counts, antiretroviral therapies, and sex- and needle-sharing risk.
- 5) With case managers continuing to enter and leave the system of care on too regular a basis, ongoing case management trainings about the local network of provider care should be provided as well as trainings on how best to assess and manage clients especially for substance use and mental health issues.
- 6) Stable and affordable housing remains an ever unfulfilled service gap and should remain a top priority in order for PLWH/A to remain adherent to medical appointments and treatment regimens.
- 7) Because of the increasing number of clients participating in the continuum of HIV/AIDS care, transportation services across the huge geographic region, particular in its more rural sectors, should be re-assessed annually to keep up with the growing demand.



Data Sources

A list of the primary resources used

This appendix lists all the sources used for developing this update⁸. 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.

Resources:

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, NYCDOHMH
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, NYCDOHMH
138. Data Day 2 Presentation: Determining Unmet Need in the NY EMA, November 7,

⁸ Through May 1, 2004.

- 2003, NYCDOHMH, 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, NYCDOHMH
 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 (See also #191 for the full report.)
 147. HIV-Infected Youth Ages 13-19 Currently Living in NYC, December 2003, NYCDOHMH
 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, NYCDOHMH
 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, April 20, 2004, 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. NYCDOHMH Office of AIDS Policy Coordination, Strategic Directions, NYCDOHMH
 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, NYCDOHMH
 199. New York EMA FY 2004 Title I Grant Application, October 2003, NYCDOHMH
 200. Unmet Need Presentation (Grace Moon) and Persons with Unmet Need in NYC: Who is not in care? (Susan Forlenza), April 16, 2004, NYCDOHMH
 201. HIV Quality Management Program Presentation, April 16, 2004, NYSDOH
 202. Cost Effectiveness and Title I Planning, April 16, 2004, NYCDOHMH
 203. Unit Cost: Calculations and Applications, April 16, 2004, MHRA
 204. HIV/AIDS Surveillance Quarterly Update, January, 2004, NYCDOHMH
 205. Geographic Distribution of Service Gaps Among the NYC CHAIN Cohort: A Geopmapping 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