

Assessment of Need Among People Living with HIV/AIDS In the Boston EMA

An Update

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Table of Contents

Preface / Executive Summary	1
1. Epidemiology of HIV/AIDS in the EMA	7
Overview of the Epidemic in the EMA	7
Breakdown of the Epidemic by Specific Populations	11
2. Unmet Need	17
How many PLWH Are Currently Not in Care?	18
Why Are PLWH Not in Care?	21
What are the Needs of PLWH Who ARE Not in CARE?	23
3 Poverty, Insurance and Housing	26
Poverty	26
Insurance Status	27
Housing and Homelessness	34
4 Co-morbidities	38
Substance Use	38
Mental Illness	42
Sexually Transmitted Diseases	44
Hepatitis Co-infection	46
Appendix	50
Useful Acronyms and Definitions	50

List of Tables

Table 1A: Estimated AIDS Incidence and Prevalence & HIV and HIV/AIDS Prevalence by Demographic Group: Race/Ethnicity, Gender and Age at Diagnosis, data as of 12/31/03, Boston EMA	9
Table 1B: Estimated AIDS Incidence and Prevalence & HIV and HIV/AIDS Prevalence by Exposure Category: Adult/Adolescent and Pediatric, data as of 12/31/03, Boston EMA	10
Table 2: Using Population and Care Pattern Data to Calculate Unmet Need for HIV Primary Medical Care	20
Table 3: Poverty Status in the Boston EMA	27
Table 4: Insurance Status in the Boston EMA	28
Table 5: Medicaid Coverage in the Boston EMA	29, 30
Table 6: Homelessness in the Boston EMA	36
Table 7: Substance Use Co-morbidity in the Boston EMA	39
Table 8: Severe Mental Illness Co-morbidity In the Boston EMA	43
Table 9: STD Co-morbidity In the Boston EMA	45
Table 10: Hepatitis Co-morbidity in the Boston EMA	47

List of Figures

Figure 1: The Boston Title I Eligible Metropolitan Area (map)	7
Figure 2: AIDS Incidence for the Boston EMA 1994-2003	8
Figure 3: Estimated HIV/AIDS Prevalence by Race/Ethnicity, Boston EMA as of December 31, 2003	11
Figure 4: Population, Estimated HIV/AIDS Prevalence and Crude Rate by Race/Ethnicity, Boston EMA as of December 31, 2003	12
Figure 5: Estimated HIV/AIDS Prevalence by Gender, Boston EMA as of December 31, 2003	13
Figure 6: Reported HIV/AIDS Prevalence by Race/Ethnicity and Gender, Boston EMA as of December 31, 2003	14
Figure 7: Mode of Exposure for Adult Males Reported Living with HIV/AIDS in the Boston EMA as of December 31, 2003	14
Figure 8: Mode of Exposure for Adult Females Reported Living with HIV/AIDS in the Boston EMA as of December 31, 2003	15
Figure 9: Estimated HIV/AIDS Prevalence by Age, Boston EMA as of December 31, 2003	16

Preface

This report contains information about the needs of people living with HIV/AIDS in the Boston Eligible Metropolitan Area (EMA), compiled from data contained in the FY2005 Ryan White CARE Act Title I grant application and from additional research conducted by the Boston AIDS Consortium, including further analysis of current studies done in the EMA and across the country, along with current epidemiological data within the EMA.

It is hoped that this information will help you plan for the needs of all people living with HIV/AIDS in the EMA, including setting priorities and allocating resources for the Ryan White CARE Act Title I services provided in the Boston EMA for fiscal year 2006. This report should be considered in the context of all other data sources you have or will receive. Specific information about the unmet needs of special populations is provided when known. However, this report is not intended to be an exhaustive list of service gaps or of all needs that are met, partially met, or remain unmet across all populations.

This report has been separated into four sections:

1. ***Epidemiology of HIV/AIDS in the EMA*** provides an overview of the current HIV/AIDS epidemic in the EMA, including populations most affected by the epidemic and HIV/AIDS trends.
2. ***Unmet Need*** presents information on individuals who know their HIV infection status, but are not in care, EMA estimates of unmet need and reasons why individuals are not in care.
3. ***Poverty, Insurance and Housing*** examines the significant social and economic factors of poverty, health insurance status, and homelessness in the EMA, describing how these factors can affect people's service needs.
4. ***Co-morbidities*** discusses how conditions that commonly occur with HIV affect the health and needs of people living with HIV/AIDS in the EMA. The co-morbidities in this section include substance abuse/use, mental health issues, sexually transmitted diseases and Hepatitis B and C.

The Health Resources and Services Administration (HRSA), the federal government agency that manages CARE Act funds and programs, has mandated that EMAs demonstrate adequate funding and access to 6 Core Services:

- Case Management
- Dental Care
- Drug Reimbursement
- Mental Health Services
- Primary Medical Care
- Substance Abuse Services

The Planning Committee presented a report on these Core Services to the Planning Council at its January 13, 2005 meeting, including information on the definition of the services, Title I and other funds dedicated to these services, Title I client demographic data, unmet need as found in the 2003 *Voices of Experience* HIV needs assessment report, and committee comments on each of these service categories based on members' experiences as consumers and providers. The Committee also gave input into this report.

When reading this report, please keep in mind these 6 Core Services as well as the other supportive services provided for people living with HIV/AIDS by Title I funds in the Boston EMA:

- Housing
- Food Services
- Transportation
- Peer Support
- Client Advocacy
- Complementary Therapies
- Respite Care
- Day Care
- Adoption Foster Care
- Minority AIDS Initiative

In addition, 4 other service categories relate to the management and support of the Title I program: Evaluation, Planning Council Support, Quality Management, and Administration.

Executive Summary

The Boston EMA contains a large number of independently organized and governed small and large towns and cities within its 6,451 square miles. The Boston EMA comprises more than 350 cities/towns within ten counties covering Massachusetts and New Hampshire. This expansive area includes both urban city centers and rural areas. The Boston EMA AIDS case total ranks 13th among the 51 Title I Eligible Metropolitan Areas in the United States and its territories. As of 12/31/03, there were 16,597 estimated individuals living with HIV/AIDS within the Boston EMA. The Boston EMA has an annual incidence rate of 22.3 cases per 100,000 population. The EMA's Massachusetts counties account for 86% of the total reported AIDS cases for the Commonwealth of Massachusetts. The three New Hampshire counties within the EMA account for 68% of the total cases for that state.

While the number of new AIDS diagnoses has continued to decline over the past ten years, AIDS incidence data for the past two year period indicates that there were significant changes in the increased proportions of AIDS cases among women, people of color and injection drug users. While Blacks account for only 5%, and Hispanics only 6%, of the EMA population, they account for 30.4% and 19.9% of the HIV/AIDS prevalence cases. Combined Blacks and Hispanics account for 50.3% of persons living with HIV/AIDS. Men having sex with Men (MSM) and Injection Drug Users (IDU) account for 41.7% and 31.1% of the estimated HIV/AIDS Prevalence.

The Ryan White CARE Act is a significant funder of health care, medications, and support services for HIV positive individuals in the Boston EMA, most of whom are low-income, uninsured, or underinsured. The CARE Act has greatly expanded access to available services for people otherwise unable to afford these services. However, there still remain a number of people in the Boston EMA not currently in this system of care. Over the past year the Grantee (Boston Public Health Commission) has worked with other funders and stakeholders to plan and implement the Unmet Need Framework within the Boston EMA and the overlapping Title II regions of Massachusetts and New Hampshire. Using existing

data sources, 14,319 people are estimated to be aware and living with HIV/AIDS in the Boston EMA, of which 11,455 (or 80%) received HIV primary medical care during the specified time period, while 3,467 (or 20%) demonstrated unmet need for HIV primary medical care. Among the 7,483 people with AIDS, 1,550 (or 21%) had unmet need, and among the 6,836 people with HIV (non-AIDS), 1,917 (or 28%) had unmet need.

The cost and complexity of care is impacted by disparities in risk, infection rates, mortality, poverty, health insurance status, and access to care among special populations, and the complex interactions among co-morbidities. It is more complicated and costly to provide care to low income PLWH because they tend to have more complex health problems, less access to care, and more need of subsidized services. People with HIV/AIDS in the Boston EMA are poorer than the general population. Approximately 14% of the Massachusetts (MA) population and 8% of the New Hampshire (NH) population lived below 100% of the Federal Poverty Level (FPL) in 2002-2003, while 60% of Title I clients reported living below 100% FPL. Whereas 30% of the MA population and 24% of the NH population lived below 200% FPL in 2002-2003, 74% of the FY2003 Boston EMA Title I clients were below 200% FPL.

Rising unemployment rates, up from 2.6% in July 2000 to 5.3% in July 2004, the MA state budget crisis, and the economic recession have resulted in more people being uninsured. During 2002-2003, 10% of non-elderly adults in both Massachusetts and New Hampshire were uninsured, an increase of 2.3% in Massachusetts and 2% in New Hampshire over 2000 levels. Medicaid is the primary payer for health services for low-income PLWH. Among Title I clients with a known insurance source, about 49% were Medicaid recipients in FY2003, as compared to 12% of the general population in MA and 7% in NH. In Massachusetts, state budget cuts have threatened the Medicaid safety net. Due to eligibility changes in the Massachusetts' MassHealth, the Massachusetts HIV Drug Reimbursement Program client enrollments and costs escalated. Subsequently the MA HDAP began aggressively enrolling eligible Full-pay clients into Comprehensive Health Insurance Program (CHII) to save funds.

The prevalence of homelessness is higher among people living with HIV/AIDS than in the general population. Homelessness is impacted by rental costs. Massachusetts has the highest rents in the nation, and is dealing with a severe long-term housing crisis. In 2001, nearly 40% of all Massachusetts renters were shelter-poor (meaning they could not meet their non-housing expenses after paying their rent). New Hampshire also has a persistent shortage of affordable housing and has the 9th highest rental costs in the nation. Of 14,155 Title I clients served in FY2003, 55% reported being permanently housed, 31% reported being non-permanently housed, institutionalized or other, and for 13% their housing status was unknown or unreported.

Healthcare needs, costs and access to care for people living with HIV/AIDS can be significantly affected by the presence of certain conditions commonly occurring with or resulting from HIV infection (co-morbidities) including substance use/abuse, mental illness, sexually transmitted diseases (STDs) and Hepatitis co-infection. Of the 2003 total admissions to the MDPH Bureau of Substance Abuses Services (BSAS), 20.7% reported being homeless. Of these, 44% reported injection drug use in the past year and 24% reported prior mental health treatment. Cuts in the MDPH BSAS budget in 2003 resulted in a 40% reduction in the number of Boston-area detoxification beds, resulting in 28% fewer treatment admissions, and a loss of 131 state-funded overflow beds in other facilities. These reductions to the service system occurred at a point in time when Emergency Department visits related to Cocaine and Heroin use were 2 to 3 times the national rate.

A Clinical chart review conducted in the Boston EMA from 2000 to 2002 found that 43% of clients had active psychiatric diagnoses. The most common forms of mental illness found among PLWH include depression, mania (bipolar disorder), schizophrenia, anxiety disorders, personality disorders, problems in sleeping and sexual function, and constitutional problems like chronic fatigue, wasting, and pain. Psychiatric symptoms may be due to antiviral medication side effects, in addition to the impact of HIV on the central nervous system and the neurological effects of opportunistic infections.

Beyond substance abuse and mental illness, another co-morbidity that increases the complexity and cost of care for PLWH is STDs. Getting an STD can greatly increase the risk of HIV transmission and can speed up the rate of HIV replication in exposed individuals. STD rates between 1999 and 2003 have increased for the general MA population: by 16.2% for gonorrhea (to 45.1 cases per 100,000) and 250% for primary and secondary syphilis (to 2.1 cases per 100,000). STD rates in NH have increased as well, by 4.3% for gonorrhea (to 9.8 cases per 100,000) and 1400% for primary and secondary syphilis (to 1.5 cases per 100,000). STD rates in both states however, remain lower than the national average for both gonorrhea and syphilis.

Reported early syphilis among MSM accounted for 68% of MA cases in 2001 and 77% of cases in 2003. In 2003, 41% of the MSM syphilis cases were among HIV+ men, while 59% were among those who were not yet infected with or had not yet been tested for HIV. Three of New Hampshire's 14 early syphilis cases for 2003, or 21%, were HIV co-infected.

Hepatitis co-infection is an increasingly serious co-morbidity. In a recent survey of PLWH in the Boston EMS, 18% reported being co-infected with Hepatitis B and 46% with Hepatitis C. Co-infection with HCV leads to a more rapid progression of HIV infection, along with increases in both morbidity and mortality. Hepatitis C medication costs for a full 48-week course of treatment are about \$30,000 per person. While costs are rapidly rising, Hepatitis C funding has been cut by 80% in Massachusetts over the last four years.

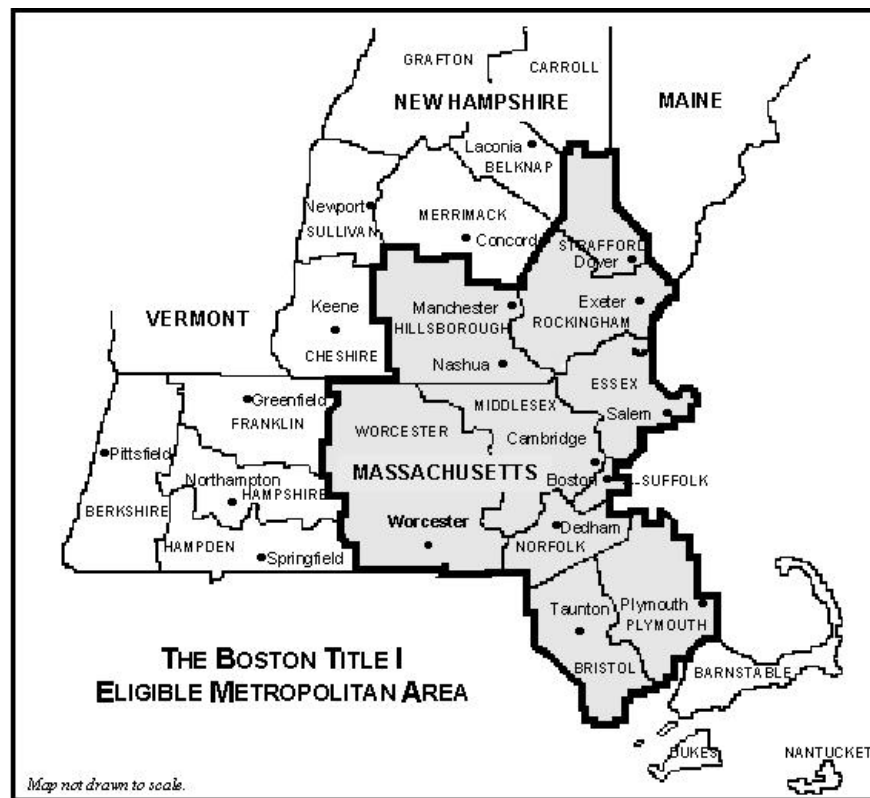
A number of factors create challenges for the ongoing provision of HIV/AIDS medical care and support services for PLWH in the Boston EMA. The number and diversity of PLWH, due to new annual infections and improvements in care and services that keep PLWH alive longer, continues to grow at the same time that the cost of core services and medications also rises. The ability to meet the increasingly complex needs of a growing client base is further complicated by the ongoing impact of state funding reductions, reductions in eligibility for Medicaid services, and reduced federal resources.

1. Epidemiology of HIV/AIDS in the EMA

Overview of the Epidemic In the EMA

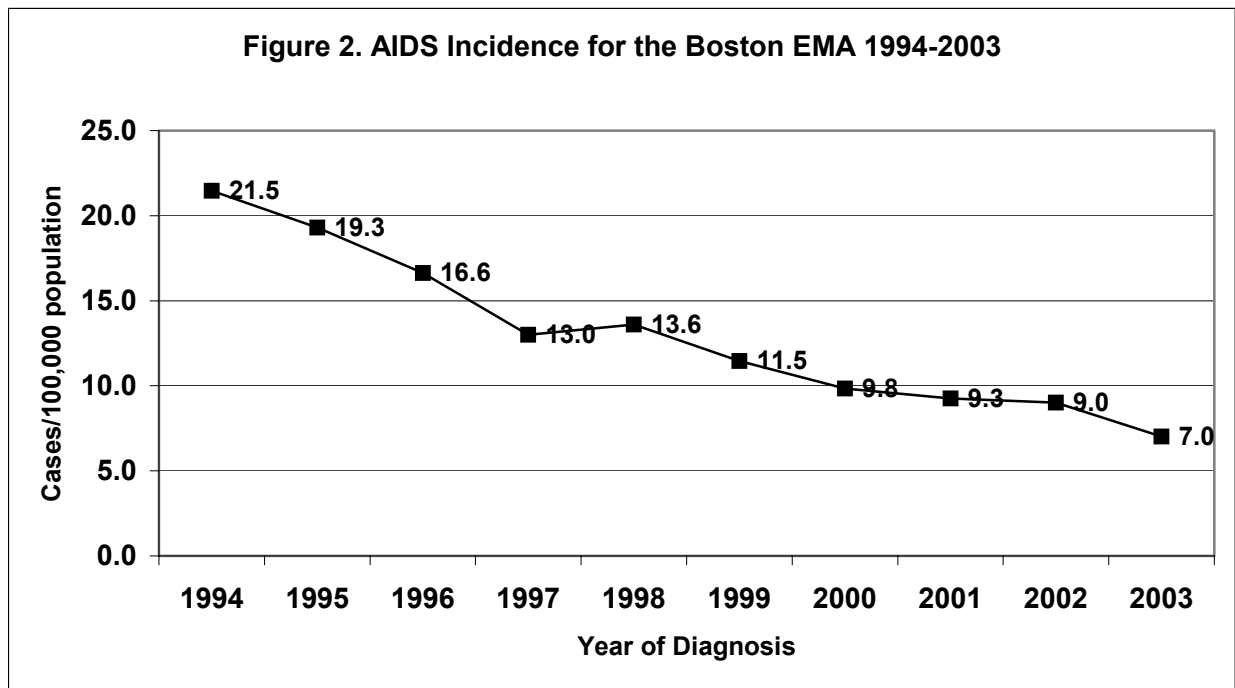
An Eligible Metropolitan Area (EMA) is a geographic area that is highly impacted by HIV/AIDS and eligible to receive Title I CARE Act funds. The Boston EMA includes 7 Massachusetts counties (Suffolk, Norfolk, Essex, Middlesex, Worcester, Plymouth, and Bristol) and 3 New Hampshire counties (Hillsborough, Rockingham, and Strafford).

Figure 1: The Boston Title I Eligible Metropolitan Area (EMA)



As of December 31, 2003, 16,290 cumulative cases of AIDS have been reported to the Centers for Disease Control and Prevention (CDC) among residents of the Boston EMA.¹ The Boston EMA ranks 13th in total reported AIDS cases among all 51 Title I eligible EMAs in the United States.² It accounts for 86% of the total 18,525³ cases in the Commonwealth of Massachusetts and 68% of the State of New Hampshire's 1,023⁴ cases reported through December 31, 2003.

The introduction of highly active antiretroviral treatments (HAART) in 1995 and 1996 resulted in declining AIDS incidence rates in the EMA^{5,6}, as well as AIDS related mortality. As of December 31, 2003, there were an estimated 7,481 people living with AIDS and 9,114 people living with HIV in the Boston EMA, for a combined total of 16,595 people living with HIV or AIDS.⁷



Tables 1A and 1B provide the most recent HIV and AIDS estimates for the Boston EMA as submitted in the Boston EMA FY2005 Title I Grant Application. These data are based on AIDS and HIV surveillance data reported to the CDC and statistically adjusted for reporting delays and for unreported risk.

- **Column 1** provides data on estimated AIDS cases reported in the 2 year period, 2002-2003, allowing the reader to see some of the more recent trends among AIDS cases.
- **Column 2** provides data on estimated living AIDS cases.
- **Column 3** provides data on the estimated number of people living with HIV in the Boston EMA, not including those with AIDS.
- **Column 4** provides data on the estimated number of people living with HIV/AIDS in the Boston EMA. These are the populations for which the Council must plan for care and services.

**TABLE 1A: ESTIMATED AIDS INCIDENCE AND PREVALENCE & HIV AND HIV/AIDS PREVALENCE
BY DEMOGRAPHIC GROUP:
RACE/ETHNICITY, GENDER, AND AGE AT DIAGNOSIS
DATA AS OF 12/31/03
BOSTON ELIGIBLE METROPOLITAN AREA (EMA)**

Demographic Group/ Exposure Category	(1) AIDS INCIDENCE: 01/01/02 TO 12/31/03		(2) AIDS PREVALENCE AS OF 12/31/03		(3) HIV PREVALENCE AS OF 12/31/03		(4) HIV/AIDS PREVALENCE AS OF 12/31/03	
	<i>The number of <u>new</u> AIDS cases reported to the CDC</i>		<i>The number of people living with AIDS</i>		<i>The estimated number of people living with HIV, non- AIDS</i>		<i>The combined estimated number living with HIV/AIDS</i>	
<i>Race/Ethnicity</i>	#	% of Total	#	% of Total	#	% of Total	#	% of Total
White, not Hispanic	481	40.02%	3,531	47.19%	4,368	47.93%	7,899	47.59%
Black, not Hispanic	437	36.36%	2,202	29.43%	2,847	31.24%	5,049	30.42%
Hispanic	262	21.80%	1,624	21.70%	1,670	18.32%	3,294	19.85%
Asian/Pacific Islander	20	1.66%	100	1.34%	124	1.36%	224	1.35%
American Indian/Alaska Native	1	0.08%	11	0.15%	10	0.11%	21	0.13%
Multi-racial/Not Specified	1	0.08%	15	0.20%	94	1.03%	109	0.66%
Total	1,202	100.00%	7,483	100.00%	9,114	100%	16,597	100.00%
<i>Gender</i>	#	% of Total	#	% of Total	#	% of Total	#	% of Total
Male	823	68.36%	5,471	73.14%	6,323	69.38%	11,794	71.08%
Female	381	31.64%	2,009	26.86%	2,791	30.62%	4,800	28.92%
Total	1,204	100.00%	7,480	100.00%	9,114	100.00%	16,594	100.00%
<i>Age at Diagnosis (Years)</i>	#	% of Total	#	% of Total		% of Total		% of Total
<13 years	1	0.08%	37	0.49%	7	0.08%	44	0.27%
13-19 years	11	0.91%	41	0.55%	19	0.21%	60	0.36%
20- 44 years	825	68.58%	4,114	54.99%	5,874	64.45%	9,988	60.19%
45 + years	366	30.42%	3,289	43.96%	3,214	35.26%	6,503	39.18%
Total	1,203	100.00%	7,481	100.00%	9,114	100.00%	16,595	100.00%

**TABLE 1B: ESTIMATED AIDS INCIDENCE AND PREVALENCE & HIV AND HIV/AIDS PREVALENCE
BY EXPOSURE CATEGORY:
ADULT/ADOLESCENT & PEDIATRIC
DATA AS OF 12/31/03
BOSTON ELIGIBLE METROPOLITAN AREA (EMA)**

Demographic Group/ Exposure Category	(1)		(2)		(3)		(4)	
	AIDS INCIDENCE: 01/01/02 TO 12/31/03 <i>The number of new AIDS cases reported to the CDC</i>		AIDS PREVALENCE AS OF 12/31/03 <i>The number of people living with AIDS</i>		HIV PREVALENCE AS OF 12/31/03 <i>The estimated number of people living with HIV, non-AIDS</i>		HIV/AIDS PREVALENCE AS OF 12/31/03 <i>The combined estimated number living with HIV/AIDS</i>	
Adult/Adolescent AIDS Exposure Category	#	% of Total	#	% of Total	#	% of Total	#	% of Total
Men who have sex with men	362	30.14%	2,605	35.15%	4,282	47.02%	6,887	41.70%
Injection drug users	442	36.80%	2,748	37.08%	2,396	26.31%	5,144	31.14%
Men who have sex with men and inject drugs	42	3.50%	295	3.98%	330	3.63%	625	3.78%
Heterosexuals	341	28.39%	1,545	20.85%	1,396	15.33%	2,941	17.81%
Other/hemophilia/blood transfusion	14	1.17%	151	2.04%	53	0.58%	204	1.24%
Risk not reported or identified	0	0.00%	67	0.90%	648	7.12%	715	4.33%
Total	1,201	100.00%	7,411	100.00%	9,106	100.00%	16,517	100.00%
Pediatric AIDS Exposure Categories	#	% of Total	#	% of Total	#	% of Total	#	% of Total
Mother with/at risk for HIV Infection	0	0.00%	71	100.00%	7	100.00%	78	100.00%
Other/hemophilia/blood transfusion	0	0.00%	0	0.00%	0	0.00%	0	0.00%
Risk not reported or identified	0	0.00%	0	0.00%	0	0.00%	0	0.00%
Total	0	0.00%	71	100.00%	7	100.00%	78	100.00%

Breakdown of the Epidemic by Specific Populations

It is useful to breakdown the HIV/AIDS epidemic by specific populations in order to analyze the characteristics of people living with HIV/AIDS to better plan for services to meet their needs. Although there are core needs that may be similar for many or most people living with HIV/AIDS, some needs differ across populations. This section provides data on the race/ethnicity, gender, age, and mode of transmission for people living with HIV/AIDS in the EMA utilizing estimated, as well as actual data reported to the Massachusetts and New Hampshire HIV/AIDS Surveillance Programs.

Race/Ethnicity

Mirroring national trends, AIDS and HIV disproportionately affect people of color in the Boston EMA. While the number of new AIDS cases has continued to decline over the past 10 years, Blacks and Hispanics are disproportionately represented in relation to the proportion of the population these groups make up. As illustrated in Figure 3, Whites account for 48% of the EMA's people living with HIV/AIDS, while Blacks and Hispanics account for 31% and 20% of the prevalent cases respectively

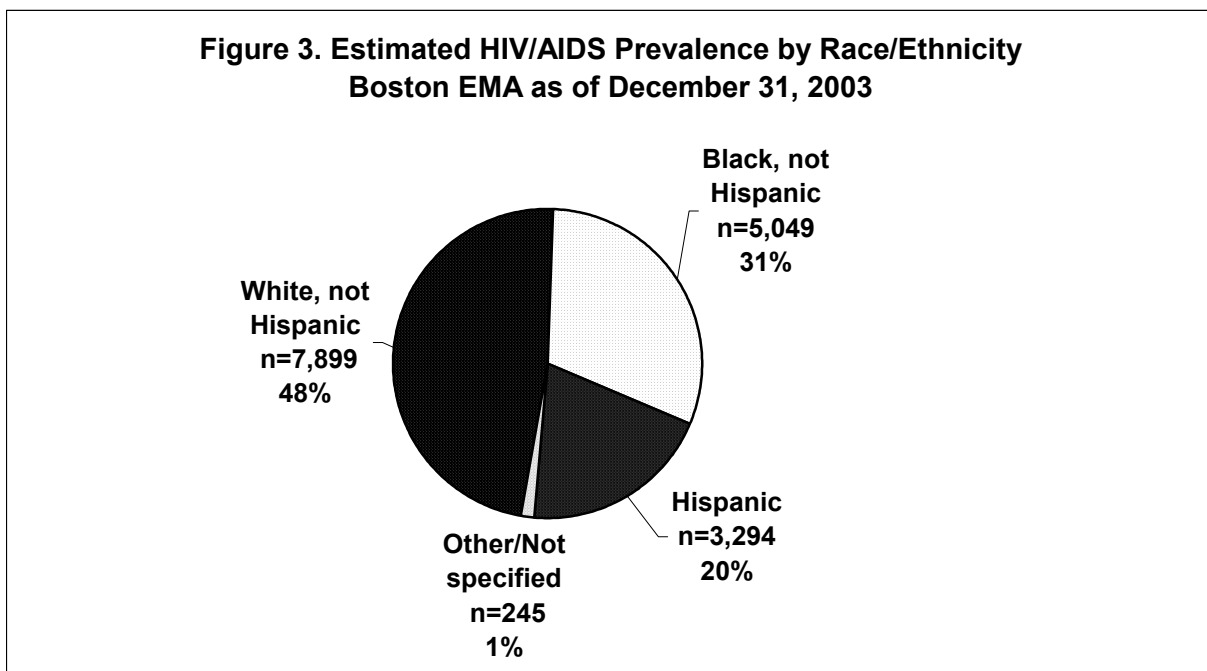
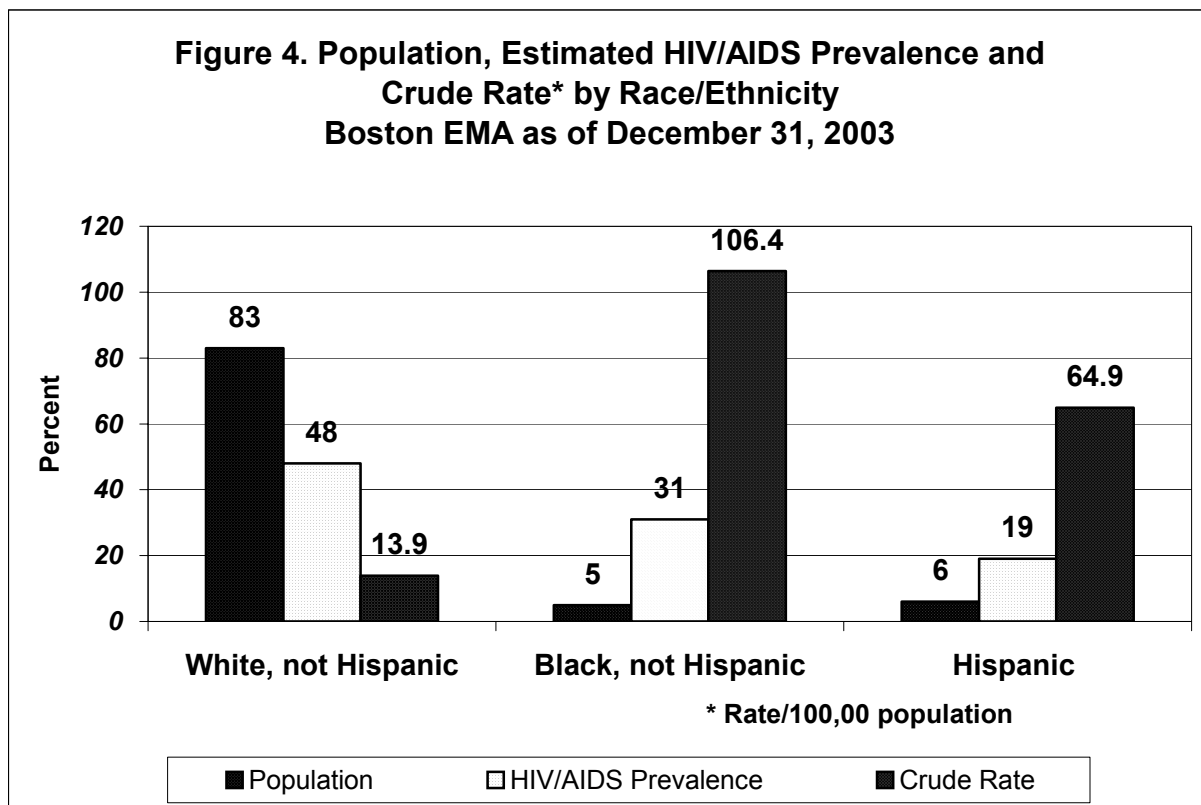


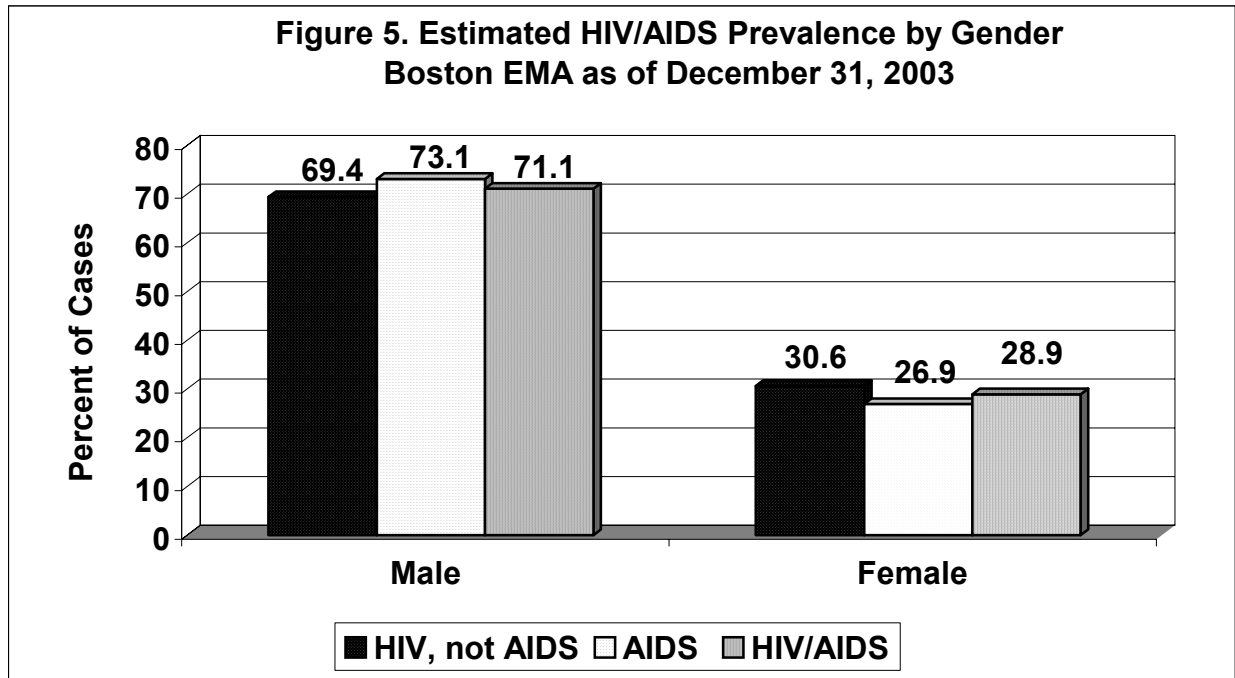
Figure 4 illustrates that, among Blacks and Hispanics, the proportion of HIV and AIDS cases in these populations exceeds their proportion of the general population. (General population percentages are taken from the 2000 US Census). Blacks account for 5% of the Boston EMA population and make up 31% of people living with HIV/AIDS in the region with a crude HIV/AIDS Prevalence Rate of 106.4 per 100,000 population. Hispanics are 6% of the population, yet comprise 19% of HIV/AIDS prevalence in the Boston EMA with a crude HIV/AIDS prevalence rate of 64.9 per 100,000 population. Blacks and Hispanics combined make up 11% of the EMA population, yet account for 50% of persons living with HIV or AIDS in the EMA.



The proportion of AIDS and HIV cases among Whites is lower than the proportion of Whites in the general population. Whites comprise 83% of the EMA population, yet account for 48% of the estimated HIV/AIDS prevalence in the Boston EMA. Because the percentage of HIV and AIDS cases among Asians, Pacific Islanders, and Native Americans is small, information about these populations should be interpreted with caution.

Gender

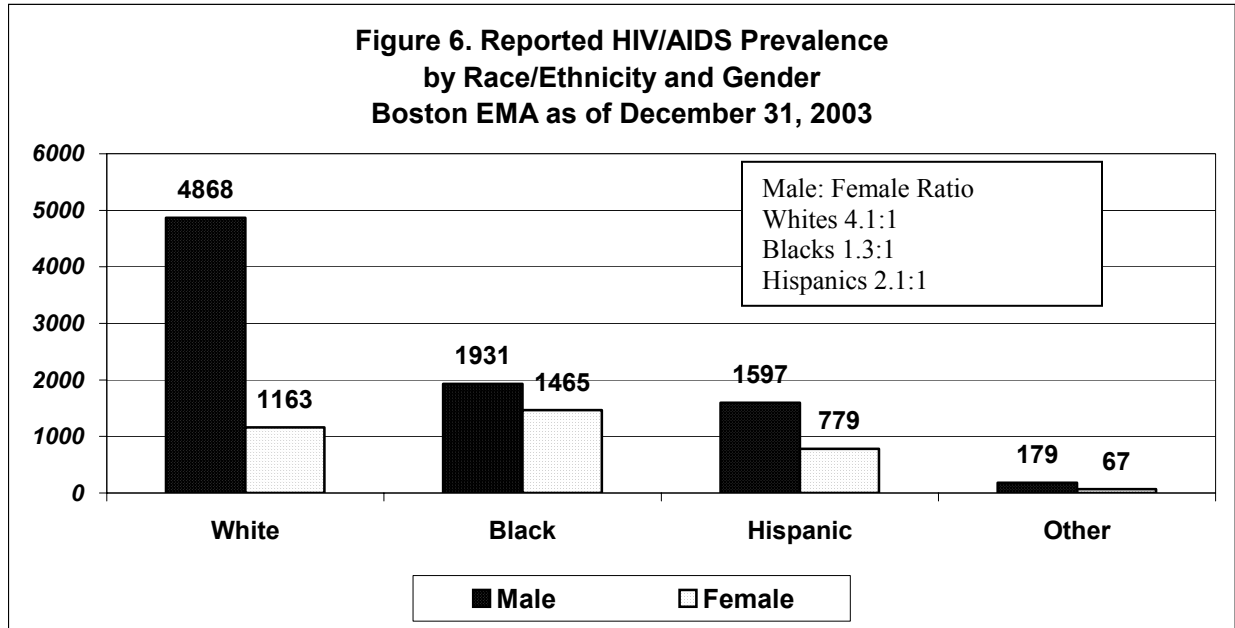
Figure 5 illustrates that in the Boston EMA men represent a greater proportion of HIV and AIDS cases than women. People living with HIV, non-AIDS reflect individuals who were infected more recently than those with AIDS. A higher percentage of women living with HIV than with AIDS suggests that more women proportionally are becoming infected with HIV than in the past.



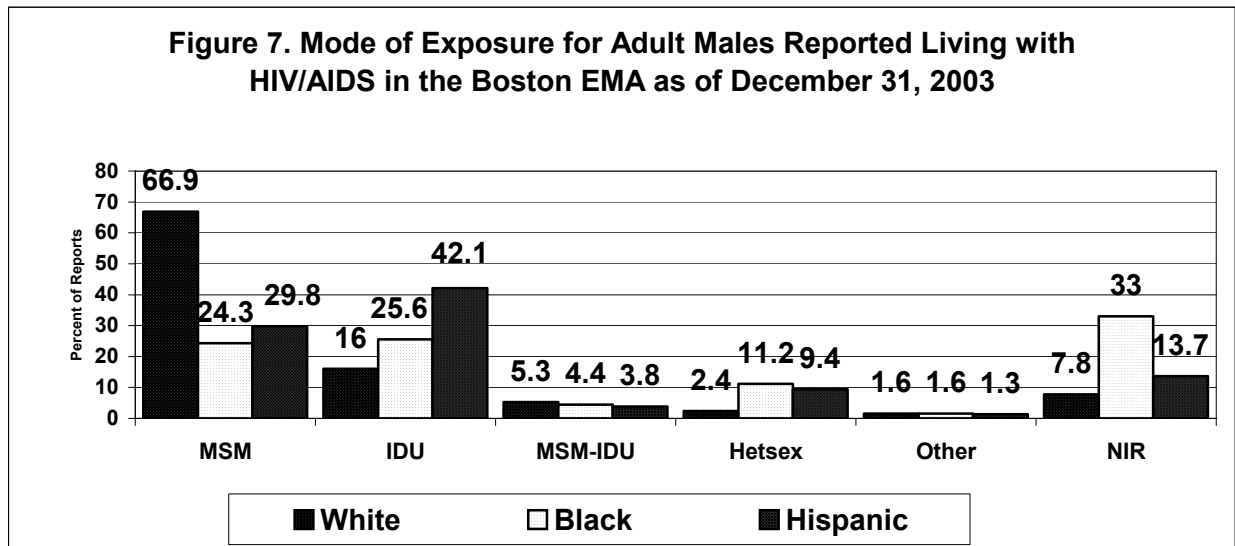
71% of the people living with HIV or AIDS in the EMA are men, and 29% are women. Women account for 29% of HIV/AIDS prevalence in the EMA. Among the 8,575 males living with HIV or AIDS, 53% are white, 25% are Black and 20% are Hispanic. Among the 3,474 Females, 43% are Black, 33% are White and 22% are Hispanic

Figure 6 indicates differing gender impacts of the epidemic when looking at race/ethnicity. Among the 6,031 Whites reported living with HIV or AIDS, 80.7% are male, 29.4% are female. There are 4.2 times as many white males living with HIV or AIDS in the EMA than there are white females. Among the 3,396 Blacks reported living with HIV or AIDS, 56.9% are male, 43.1% are female. Proportionately, there are 1.3 times as many black males

living with HIV or AIDS in the EMA than there are black females. For Hispanics, 67.2% are male, 32.8% are females. Twice as many Hispanic males are living with HIV or AIDS than are Hispanic females.

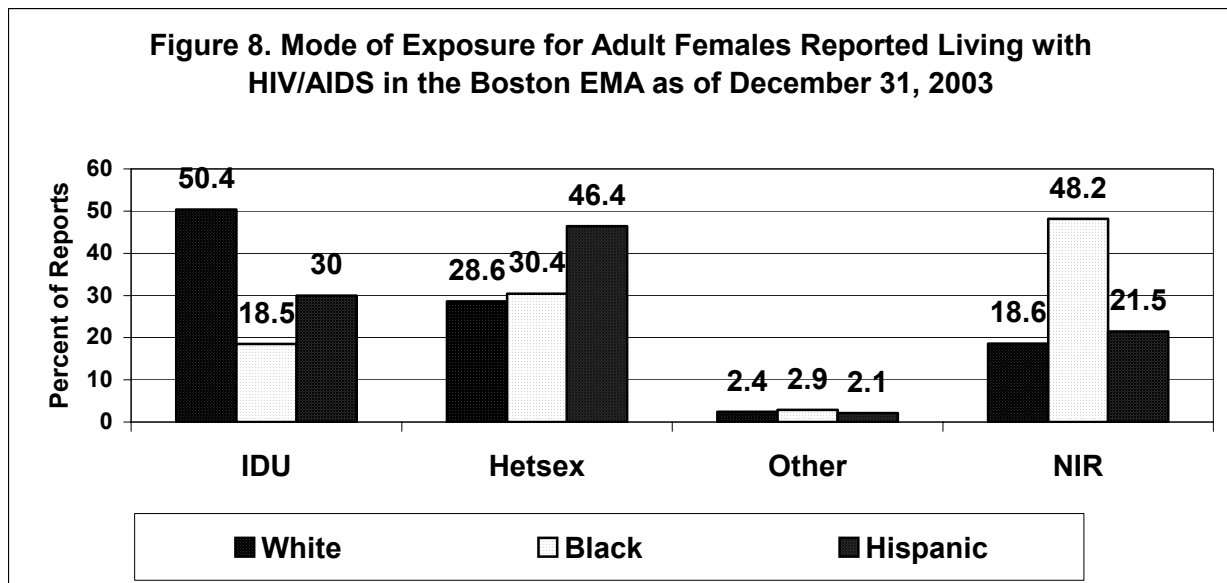


Figures 7 and 8 provide information on the differing proportional impacts by mode of exposure across gender and race/ethnicity.



Of the reported 4,868 White males living with HIV or AIDS in the Boston EMA, 66.9% were men who have sex with men (MSM), 16% were injecting drug users (IDU), 5.3%

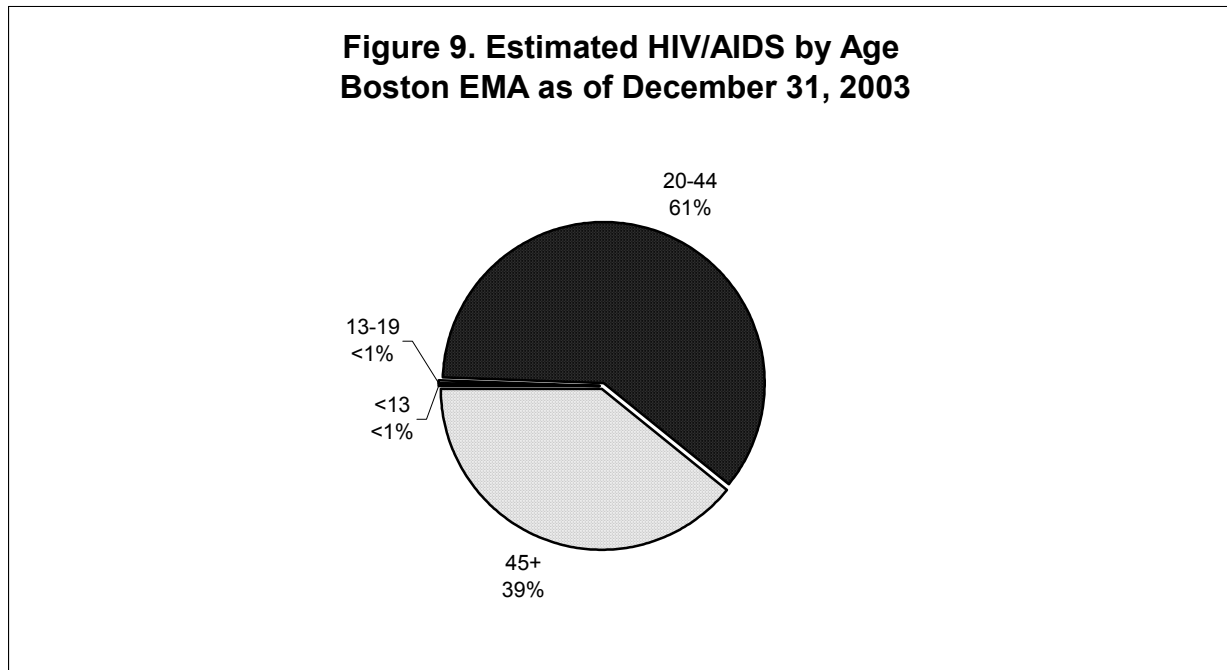
were both MSM and IDU, 2.4% acquired HIV heterosexually (Hetsex) and 7.8% had no identified or reported risk (NIR). Among the reported 1,930 Black males, 24.3% were MSM, 25.6% were IDU, 4.4% were MSM and IDU, 11.2 % acquired HIV heterosexually and 33% had no identified or reported risk. Among the reported 1,595 Hispanic males living with HIV or AIDS in the EMA, 29.8% were MSM, 42.1% were IDU, 3.8% were MSM and IDU, 9.4 % acquired HIV heterosexually and 13.7% had no identified or reported risk.



Of the reported 1,162 White females living with HIV or AIDS in the Boston EMA, 50.4% were IDU, 28.6% acquired HIV heterosexually and 18.6% had no identified or reported risk. Among the reported 1,465 Black females, 28.6% were IDU, 30.4% acquired HIV heterosexually and 48.2% had no identified or reported risk. Among the reported 776 Hispanic females living with HIV or AIDS in the EMA, 30% were IDU, 46.4% acquired HIV heterosexually and 21.5.7% had no identified or reported risk.

Age

Among all age groups, the largest percentage of people living HIV and AIDS is in the 20-44 year old range, and the next largest percentage can be found in the 45 and older group. Together, these two groups account for 99% of all HIV and AIDS cases. Adolescents account for less than 1% of the estimated HIV/AIDS prevalent cases in the EMA.



¹ Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report, 2003* (Volume 15)

² Ibid.

³ Ibid.

⁴ Ibid.

⁵ Massachusetts Department of Public Health, HIV/AIDS Surveillance Program, 01/05 data run by and e-mail correspondence from Betsey John

⁶ New Hampshire Department of Health and Human Services, HIV/AIDS Surveillance Program, 01/05 data run by and e-mail correspondence from Chris Adamski

⁷ Boston Public Health Commission, November 2004. *Boston EMA FY2005 Title I Grant Application*, Table 1

2. Unmet Need

The Ryan White CARE Act is a significant funder of health care, medications, and support services for HIV positive individuals in the Boston EMA, most of whom are low-income, uninsured, or underinsured. As a result, the CARE Act has greatly expanded access to available services for people who would otherwise be unable to afford these services.

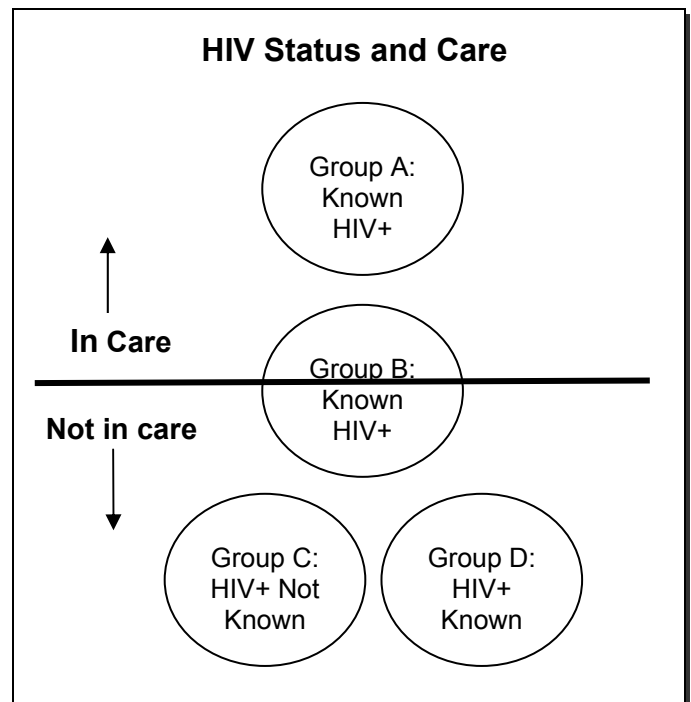
However, there still remain a number of people in the Boston EMA who are not currently in this system of care. A study conducted by the CDC estimates that as many as one third of all HIV-infected people are likely not to be receiving medical care. Additionally, research shows that some populations, especially African Americans, Latinos, women, and the uninsured, are most likely not to be in care.¹ These data are especially troubling, given treatment guidelines that recommend people living with HIV/AIDS (PLWH) enter care as soon as possible, and recent advances in the treatment of HIV and opportunistic infections that have prolonged years of life, improved quality of life, and enhanced the health status for PLWH.

To support expanded access for PLWH not in care, the 2000 CARE Act legislation mandated that EMAs begin to identify and incorporate the needs of this group into the planning for the allocation of Title I funds. Specifically, EMAs must now develop data that better describe who is not currently in care (including factors like geographic location, race and ethnicity, gender, mode of transmission, unmet need^a and service gaps^b.) and the reasons why they are not receiving care. These data are intended to help the Planning Council better plan for and implement appropriate strategies to bring this group into care. This year the Council will be working on a framework for assessing the unmet needs of people with HIV who are not in care.

^a Unmet need: The need for HIV-related health services by individuals with HIV disease who are aware of their HIV status, but are not receiving primary health care.

^b Service Gaps: All service needs of all PLWH, except for the primary care needs of those who know their status but are not in care.

Individuals who are HIV positive may not access available services for several reasons. Some people may not know their serostatus. Others may know their serostatus but choose not to access services; or they may not know the importance of accessing services even while HIV asymptomatic. Some who know their serostatus may have competing priorities that are more important or other issues like homelessness, mental illness, and substance abuse that complicate accessing HIV services; or they may not know about available services and/or their eligibility for these services. Still others may be uninsured or fearful of the stigma associated with being identified as someone with HIV disease. An additional group who know they are HIV-positive may move in and out of care, depending on the severity of their disease or symptoms and other factors. The diagram below shows these different groups and how they intersect.



As defined by HRSA, individuals who are not in care are those who are HIV positive, know their serostatus, and are not currently accessing HIV-related services.² The HRSA definition will be used in this report. This section will describe what is currently known about this subset of individuals.

How Many PLWH Are Currently Not in Care?

It is difficult to accurately state the number of HIV positive people living in the EMA who know their serostatus but are not accessing the Title I system of care. This group is particularly difficult to survey, because they are not currently accessing HIV service providers. However, there are several indirect ways of formulating an estimate for the purposes of report and service prioritization.

Over the past year the Grantee (Boston Public Health Commission) has worked with other funders and stakeholders to plan and implement the Unmet Need Framework within the Boston EMA and the overlapping Title II regions of Massachusetts and New Hampshire. These efforts have built upon existing efforts to collect client profile and utilization data across systems, as well as special studies, which include clinical chart reviews, and a region wide consumer needs assessment project. The Boston EMA estimate of Unmet Need was calculated by utilizing a framework using separate private and public data sources (see Table 2).

- The population of persons living with AIDS in the EMA is based upon the existing data collected by the Massachusetts and New Hampshire HIV/AIDS Surveillance Programs, adjusted for reporting delay.
- The population of persons living with HIV in the EMA is an EMA estimate adjusting for 2001 modeled data as directed by the CDC and the EMA estimated proportion that 75% of currently infected HIV (non-AIDS) are aware of their infection status.
- The percent of PLWH/A who relied on private care in a 12-month period, is based upon percent of Title I FY13 clients with AIDS and non-AIDS where Private Insurance was indicated as the Source of Medical Insurance on the Joint HIV/AIDS Client Form.
- Findings from the 2002 study “HIV Care Quality and Clinical Outcomes in Boston EMA Sites Providing Primary Medical Care 2000” chart review indicated that 85% of clients had a primary care visit in a three month period. This finding was used to estimate the number of PLWA who received “specified primary medical care services” in a 12-month period.
- Findings from the 2002 Boston EMA study “*People Living with HIV/AIDS Who Do Not Use Healthcare Consistently*” indicated that 78% of clients interviewed had not seen a physician in the past 12 months. The lower bound of a 95% Confidence Interval based upon that proportion was used to estimate the number of PLWA who received “specified primary medical care” in that time period.

Table 2. Using Population and Care Pattern Data to Calculate Unmet Need for HIV Primary Medical Care Using Separate Public and Private Data		
Input	Value	Data Source & Calculations
Population Sizes		
A. Number of persons living with AIDS (PLWA), recent time period	7,483	CDC-adjusted MA/NH HIV/AIDS Reporting System Data for the Boston MSA through 12/31/03
B. Number of persons living with HIV (PLWH non-AIDS/aware), recent time period.	6,836	Boston EMA Local Estimate based upon 75% of the 9114 estimated HIV-infected (non-AIDS) individuals living within the Boston EMA are HIV aware.
Care Patterns Among PLWA		
C1. Percent of PLWA who relied on private care in a 12-month period.	8.23%	No. based upon % BPHC FY13 unduplicated PLWA with Private Insurance.
C2. Percent of those in row C1 who received the specified HIV primary medical care services in a 12-month period.	85%	85% of clients with a primary care visit in last 3 months from the 2002 study "HIV Care Quality and Clinical Outcomes in Boston EMA Sites Providing Primary Medical Care."
C3. Number of PLWA who received the specified HIV primary medical care services through <u>private</u> sources in a 12-month period.	523	$A \times C1 \times C2$ or $(7,483 \times 0.823 \times 0.85)$
C4. Number of PLWA who received the specified HIV primary medical care services through <u>public</u> sources in a 12-month period.	5,410	No. based upon Lower Bound of a 95% Confidence Interval where 78% of clients had seen an MD within the past year from the 2002 Boston EMA Study "People Living with HIV/AIDS Who Do Not Use Healthcare Consistently"
C5. Number of PLWA with met need for HIV primary medical care in a 12-month period.	5,933	$C3 + C4$ or $(523 + 5,410)$
Care Patterns Among PLWH (aware, non-AIDS)		
D1. Percent of PLWH (aware, non-AIDS) who relied on private care in a 12-month period.	10.95%	No. based upon % BPHC FY13 unduplicated PLWH with Private Insurance.
D2. Percent of those in row C1 who received the specified HIV primary medical care services in a 12-month period.	85%	85% of clients with a primary care visit in last 3 months from the 2002 study "HIV Care Quality and Clinical Outcomes in Boston EMA Sites Providing Primary Medical Care."
D3. Number of PLWH (aware, non-AIDS) who received the specified HIV primary medical care services through <u>private</u> sources in a 12-month period.	636	$B \times D1 \times D2$ or $(6,836 \times 0.1095 \times 0.85)$
D4. Number of PLWH (aware, non-AIDS) who received the specified HIV primary medical care services through <u>public</u> sources in a 12-month period.	4,283	No. based upon Lower Bound of a 95% Confidence Interval where 78% of clients had seen an MD within the past year from the 2003 Boston EMA Study "People Living with HIV/AIDS Who Do Not Use Healthcare Consistently"
D5. Number of PLWH (aware, non-AIDS) with met need for HIV primary medical care in a 12-month period.	4,919	$D3 + D4$ or $(4,283 + 636)$
Calculated Results		Calculations
E. Number of PLWA who did not receive specified HIV primary medical care services	1,550	$A - C5$ or $(7,483 - 5,933)$
F. Number of PLWH (aware, non-AIDS) who did not receive specified HIV primary medical care services.	1,917	$B - D5$ or $(6,836 - 4,919)$
G. Total HIV+/aware not receiving specified HIV primary medical care services (quantified estimate of unmet need)	3,468	$E + F$ or $1,550 + 1,917$
Of the 14,319 people estimated to be aware and living with HIV/AIDS in the Boston EMA, we estimate that 11,455 (or 80%) received HIV primary medical care during the specified time period, while 3,467 (or 20%) demonstrated unmet need for HIV primary medical care. Among the 7,483 people with AIDS, 1,550 (or 21%) had unmet need, and among the 6836 people with HIV (non-AIDS), 1,917 (or 28%) had unmet need.		

As part of the effort to improve the unmet need framework, as well as the development of an updated epidemiological profile for the area, data matching will be attempted for other systems of care. However, as the varying health services systems use different client coding methods a total unduplicated count of clients in care across all systems is more difficult. The Council has worked to collect client profile data from other funders as part of the funding stream information gathering. The Council has requested that other funders, such as Medicaid include client profile information when presenting funding stream information. As part of the development of the unmet need evaluation, additional commitment will be needed from other funders to provide care pattern data.

Why Are PLWH Not In Care?

Within the Boston EMA, certain populations of PLWH who are not currently in the system of care may face barriers or challenges to accessing services. Generally, PLWH may avoid seeking care because they are asymptomatic, fear being stigmatized for being HIV infected, lack adequate insurance, have competing issues or co-morbidities that make it difficult to prioritize seeking care for their HIV disease, or lack information about available services and eligibility. Complications due to co-morbidities are discussed in the next section.

Certain groups may experience different or heightened barriers. For example, because of the stigmatization and discrimination that men who have sex with men (MSM) may face, some do not identify as gay or bisexual and thus do not perceive themselves to be at risk for HIV infection or fear stigma if they begin to access HIV services. However, within the MSM population, there may be differences that further impact access to services. White MSM living in suburban or semi-rural areas of the EMA tend to be less likely to openly disclose or acknowledge their sexual orientation, perhaps due to the lack of support and community networks in these areas. MSM of color living in suburban or semi-rural areas of the EMA are even less likely to self-identify, perhaps due to the lack of support and community networks in these areas. These individuals may engage in risky behaviors, be unaware of their serostatus, and remain outside the system of care until a much later stage in their HIV disease. In addition, higher rates of alcohol and substance use among some

members of this population can both increase the risk of HIV infection and serve as a major barrier to accessing needed services. These individuals may engage in risky behaviors and remain unaware of their serostatus and outside the system of care until a much later stage in their HIV disease.

Substance users, including injection drug users, may face stigmatization when they seek health care services. Providers may be unwilling or afraid to treat people who present while under the influence of drugs or alcohol. Providers' concerns about poor follow-up and medication adherence may also influence treatment. Furthermore, substance users face an array of needs stemming from multiple problems like unemployment, homelessness, lack of adequate health coverage, psychiatric disorders, histories of past or current physical and sexual abuse, other health problems, and social isolation. These conditions severely affect an individual's ability to seek out care and adhere to a treatment plan.

Youth living with HIV/AIDS are another population of concern, since they are dependents with minimal income and typically lack the autonomy and resources that adults with HIV/AIDS have in making decisions about their health care. Youth may encounter more obstacles to obtaining services, such as the need for parental consent, financial concerns, and legal issues. Also, youth of color and homeless adolescents, populations exhibiting rising rates of HIV infection, may engage in risky behavior, be unaware of their serostatus, and remain outside the system of care until a much later stage in their HIV disease.

Women are the most frequent recipients of federal housing subsidies, food stamps and family-targeted income support, making them potentially vulnerable to reductions in federal assistance resulting from welfare reform or budget reductions. Women with children may also fear losing custody of their children, especially if they also suffer from substance abuse, psychiatric disorders, or partner abuse that may cause others to question the stability of the family situation.

What Are the Needs of PLWH Who Are Not In Care?

The most obvious needs of PLWH not in care are those that are generally needed by all PLWH who initially enter the Title I system of care: primary medical care, appropriate medications, and case management. PLWH who are asymptomatic—both who know and do not know their HIV status—and who are not in care would benefit by receiving information and services (such as case management, peer support, HIV counseling and testing, and client advocacy) that may help them learn they are HIV positive and understand the importance of early entry into medical and support services. PLWH with existing co-morbidities like substance abuse or mental illness or who have competing life-sustaining needs may benefit from the availability of appropriate treatment for non-HIV diseases, mental health services, and housing.

Suffolk University's December 2002 report, based on a study of 203 PLWH and entitled *People Living With HIV/AIDS Who Do Not Use Healthcare Consistently*, found that 22% of them were not in care (defined as not having seen a primary care physician in the past 12 months). The report's authors also discovered that most of the other 78% had either not seen a provider consistently in the past 12 months or had many problems with access to and quality of care. Suffolk's key statistically significant findings were that:

- PLWH report higher CD4 counts and lower viral loads if they have a primary care doctor, have seen another type of provider regularly, and /or have used combination therapy in the past year.
- Homeless PLWH are less likely to have a primary care doctor and less likely to use healthcare consistently.
- PLWH do not use health care consistently because they do not feel ill or feel they don't need help.
- PLWH do not follow medical regimens because they forget to refill prescriptions, the regimens are too complicated, or they prefer alternative therapies.

- PLWH have different experiences with care depending on their race/ethnicity, language, place of residence, and care status (whether they are in or out of care).
 - Hispanic, Black, Spanish-speaking and Haitian-Creole- speaking PLWH were less likely to go to a doctor than those who were White or who spoke English.
 - Hispanic PLWH were less likely to follow their medical regimens.
 - Newly diagnosed PLWH were less likely to see a doctor.
 - People in care were more likely to remain on a consistent medical regimen than those out of care.
 - People in care were more likely than those out of care to know their CD4 count and more likely to have a CD4 count over 501.
 - Worcester PLWH were more likely than those in the greater Boston area to:
 - not go to a provider due to access problems, lack of providers, lack of trust in providers and organizations, cultural barriers, and lack of transportation and
 - not follow medical and drug regimens because of lack of access to medications and pharmacies.

Recommendations from the report's authors are to:

- Target outreach efforts and link into care those with the most difficulty accessing services, including the homeless, those with mental health or substance use problems, non-English speakers, people transitioning out of jail, ER users, undocumented immigrants, migrant workers, those with head injuries, and the deaf and hard of hearing.
- Create a more effective service network with a single point of entry, simpler referral system, and information for consumers about HIV-specific agencies and providers
- Increase housing services
- Educate PLWH about the need for regular medical care
- Provide medication adherence support
- Educate providers about PLWHs needs for emotional support

- Disseminate more information about available dental care services
- Increase transportation services, especially in Central Massachusetts

¹ Department of Health and Human Services, HRSA, HIV/AIDS Bureau, November 2000, *Unmet Need Consultation Report*.

² Department of Health and Human Services, HIV/AIDS Bureau, *Letter to Title I Colleagues from Joseph F. O'Neill, MD, MPH, Associate Administrator "Reauthorization Issues: 1) Needs Assessment, 2) Comprehensive Planning."*

3. Poverty, Insurance and Housing

This section will examine a few major social and economic factors which add to the complexity and cost of providing HIV-related services to people living with HIV/AIDS in the Boston EMA: poverty, insurance status, and homelessness. These factors do not work alone and should be considered with the information presented in the co-morbidities section, especially for PLWH who are also diagnosed with mental health issues and/or substance abuse. The information provided in this section is particularly relevant with regards to primary care, drug reimbursement, and housing services.

Poverty

It is more complicated and costly to provide care to low income PLWH than to the general population with HIV/AIDS because they tend to have more complex health problems, less access to care, and more need of subsidized services. People with HIV/AIDS in the Boston EMA are poorer than the general population. The Kaiser Family Foundation estimates that 14% of the Massachusetts (MA) population and 8% of the New Hampshire (NH) population lived below 100% of the Federal Poverty Level (FPL) in 2002-2003¹, while 60% of Title I clients reported living below 100% FPL². HRSA's HIV/AIDS Bureau (HAB) estimates that 50% of all CARE Act clients nationally live below the Federal poverty level³. Whereas 30% of the MA population and 24% of the NH population lived below 200% FPL in 2002-2003, 74% of the FY2003 Boston EMA Title I clients were below 200% FPL according to data submitted to the Grantee. This data revealed that four out of five (79%) of Title I clients lived below 300% of the FPL, while state poverty data are not collected using a 300% threshold level.

Table 3: Poverty Status in the Boston EMA

Estimated percentage of people in EMA below 100% of the Federal Poverty Level (FPL), 2002-2003	Estimated percentage of PLWH in EMA below 100% of FPL	Data Source
<p>14% of MA population</p> <p>8% of NH population</p>	<p>60% of Title I clients</p> <p>66% of PLWH surveyed for <i>VOE</i></p>	<p>Kaiser Family Foundation, State Health Facts Online, 2002-2003.</p> <p>BPHC, Title I client utilization data, FY2003.</p> <p>Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i>.</p>
Estimated percentage of people in EMA below 200% of FPL, 2002-2003	Estimated percentage of PLWH in EMA below 200% of FPL	Data Source
<p>30% of the MA population</p> <p>23% of the NH population</p>	<p>74% of Title I clients</p>	<p>Kaiser Family Foundation State Health Facts Online, 2002-2003.</p> <p>BPHC, Title I client utilization data, FY2003</p>
Estimated percentage of people in EMA below 300% of FPL, 2002-2003	Estimated percentage of PLWH in EMA below 300% of FPL	Data Source
<p>Not available.</p>	<p>79% of Title I clients</p>	<p>BPHC, Title I client utilization data, FY2003</p>

Note: Each year the federal government develops federal poverty guidelines that are used to determine eligibility for government programs. They are issued each year in the *Federal Register* by the Department of Health and Human Services (HHS) and are based on the size of a family unit. For FY2004, 100% of federal poverty level (FPL) for an individual is \$9,310 and 200% is \$18,620; for a family of two 100% of FPL is \$12,490 and 200% is \$24, 980; for a family of three 100% of FPL is \$15,670 and 200% is \$31, 340. More information may be found at <http://aspe.hhs.gov/poverty/04poverty.htm>.

Insurance Status

Insurance coverage is often closely linked to poverty status. Forms of health insurance coverage include:

- Private insurance (usually through an employer),
- Medicaid (MassHealth in MA and a variety of programs in NH),
- Medicare (for those over 65 years old and the disabled),
- Veterans Administration health coverage (for US veterans) and
- Comprehensive Health Insurance Initiative (CHII, a program for PLWH in Massachusetts) and the NH Care Program’s Insurance Continuation Program.

Insurance for Total Population and Racial/Ethnic Differences

In Massachusetts and New Hampshire the number of uninsured adults is rising. According to Kaiser Family Foundation data, 10% of non-elderly adults in both Massachusetts and New Hampshire were uninsured during 2002-2003⁴, an increase of 2.3% in Massachusetts and 2% in New Hampshire over 2000 levels. Rising unemployment rates, up from 2.6% in July 2000 to 5.3% in July 2004, the MA state budget crisis, and the economic recession are all affecting rates of uninsured people. People of color are disproportionately uninsured. According to Census data, Blacks, Asians, and Hispanics are more likely than Whites to be uninsured. While 10% of White non-elderly MA residents were uninsured in 2002-2003, 23% of the state’s Hispanic residents, 19% of Black residents, and 16% of “other” residents were uninsured.⁵

Table 4: Insurance Status in the Boston EMA

INSURANCE STATUS		
Estimated percentage and number of people in EMA without insurance coverage, including without Medicaid, 2002-2003	Estimated percentage of PLWH in the EMA without insurance coverage, including without Medicaid	Data Source
10% of MA population 662,800 people 10% of NH population 127,740 people	13% of Title I clients	Kaiser Family Foundation State Health Facts Online, 2002-2003. BPHC, Title I client utilization data, FY2003.

Insurance and PLWH

PLWH in the Boston EMA are more likely than the general population to be uninsured. Among Title I clients whose insurance status was known, approximately 13% were uninsured in FY2003⁶. The lack of health insurance has been linked to adverse health outcomes including increased morbidity (illness) and mortality (death). Uninsured people seek out medical care less often, use emergency room care more frequently, and are more likely to be hospitalized for chronic conditions that are exacerbated by delayed entry into care. Studies have shown that uninsured PLWH are both less likely

to be prescribed HAART therapies and to be adherent to their HIV medications over time. For these reasons, low income PLWH are more likely than PLWH with higher incomes to delay care and enter the health care system at a later stage in their illness.

Medicaid

Medicaid, the third largest source of health insurance in the U.S. after employer-sponsored care and Medicare, is the primary payer for health services for low-income PLWH. Medicaid is the single largest payer for primary medical care in the EMA, providing 69% of the primary care funds for PLWH (\$17.6 million) and 80% of the funds for medications in the EMA (over \$56 million in FY03). Medicaid also accounts for 62% of the mental health funds available in the EMA. Massachusetts' Medicaid program (MassHealth) provides about 46% of the total funding available in the Boston EMA for substance abuse services for PLWH⁷. Among Title I clients with a known insurance source, about 49% were Medicaid recipients in FY2003⁸, as compared to 12% of the general population in MA and 7% in NH⁹. Of PLWH surveyed for the 2003 Boston EMA *Voices of Experience (VOE)* HIV/AIDS needs assessment report, MassHealth paid for 82% of their healthcare.

Table 5: Medicaid Coverage in the Boston EMA

Estimated percentage and number of people in EMA with Medicaid coverage	Estimated percentage and number of PLWH in EMA with Medicaid coverage	Data Source
<p>12% in MA 794,590 people</p> <p>7% in NH 88,890 people</p>	<p>49% of Title I clients</p> <p>82% of PLWH surveyed for <i>VOE</i></p> <p>9,040 PLWH (79.3 % of the reported HIV/AIDS Prevalent cases) in the MA part of the Boston EMA were enrolled in MassHealth in FY2004</p> <p>856 average monthly enrollment of PLWH in MA part of the Boston EMA enrolled into MassHealth using HIV waiver in FY2004</p> <p>172 (26.7% of the reported HIV/AIDS prevalent cases) in the NH part of the Boston EMA received assistance through the NH Medicaid program.</p>	<p>Kaiser Family Foundation, State Health Facts Online, 2002-2003.</p> <p>BPHC, Title I client utilization data, FY2003.</p> <p>Suffolk University. <i>Voices of Experience 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i></p> <p>MA Office of Medicaid, December 9, 2004 presentation to the Planning Council.</p> <p>NH HIV/AIDS Prevention Section December 9, 2004 presentation to the Planning Council</p>

Table 5: Medicaid Coverage in the Boston EMA (continued)

Estimated percentage of total funds for care for PLWH in the EMA from Medicaid	Data Source
69% of Primary Care Funds	Boston AIDS Consortium, <i>Funding for HIV/AIDS Care and Services in the Boston EMA, May 2004</i> . Data collected from:
80% of Medication Funds	
62% of Mental Health Funds	
46% of Substance Abuse Funds	
MA Office of Medicaid, MA Department of Public Health, MA Bureau of Substance Abuse Services, NH Department of Health and Human Services, and CARE Act Titles I, II, III, IV providers.	

The MA Office of Medicaid estimates that 9,040 people living with HIV/AIDS in the MA part of the Boston EMA were MassHealth members in FY2004¹⁰. Of these, 51% were Caucasian, 19% were Black (non-Hispanic), 8% were Hispanic, 2% were Asian or Pacific Islander, and 20% were of unknown racial or ethnic origin. Fifty-seven percent were male and 43% female.

Recognizing the importance of early, effective treatments for PLWH in order to reduce or delay the progression to AIDS, MA state officials developed and received federal approval for a waiver program in 2001 to expand Medicaid (Mass Health) coverage to HIV+ people under 65 with incomes up to 200% of the FPL. On average, 856 PLWH in the MA part of the EMA were enrolled monthly into MassHealth using the HIV waiver during FY2004¹¹.

In Massachusetts, state budget cuts are threatening the Medicaid safety net. On January 1, 2003, an \$11 million cut to Medicaid (MassHealth) resulted in 500,000 low-income disabled residents, including those with HIV/AIDS, losing coverage for dentures, eyeglasses, artificial limbs, and other select services. In September 2003, the eligibility level for the HIV waiver was reduced from 200% FPL to 133% of FPL, but it was restored to the original level of 200% FPL in July 2004.

In New Hampshire, PLWH are eligible for 5 types of Medicaid coverage: Medical assistance (Medicaid), Nursing Facility Care, Healthy Kids/Medical Coverage for Pregnant Women, Medicaid for Employed Adults with Disabilities (MEAD), and In and Out Medical Assistance¹². Medicaid eligibility (for the medical assistance program) in New Hampshire is more restrictive than in Massachusetts, requiring disability, and includes both an income limit (75% of FPL) and an assets limit (\$2500). Those with incomes in excess of these limits may be eligible for the In and Out Medical Assistance Program that covers some medical expenses after an individual has spent down to the protected income level. In addition, MEAD is available to disabled individuals who work. The income limit for this program is 450% FPL, with a resource limit of \$20,560. The Healthy Kids program provides Gold coverage for those up to 185% of FPL and Silver coverage for those with an income of between 185% and 300% FPL. Medical Coverage for Pregnant Women is available for those with an income of less than 185% FPL (\$1,436 per month for family of one). While NH has implemented several cost containment actions, such as higher co-pays on doctors' visits, NH Medicaid did not reduce benefits or cut eligibility as of November 2004. In FY03, 218 people living with HIV/AIDS in New Hampshire received Medicaid assistance, a 31% increase from 2002. Females made up 72% of Medicaid recipients. Like Massachusetts, the largest single category of expense for New Hampshire's Medicaid programs was for medications.

HIV Drug Assistance Programs and Insurance Continuation

Because medications are such a vital need of people living with HIV/AIDS, because medications are costly, and because not all PLWH can access medications due to lack of insurance or ineligibility for Medicaid, HIV Drug Assistance Programs (HDAP) have been established in states to assist PLWH in accessing medications by paying for them.

New Hampshire's AIDS Drug Assistance Program, which received over 90% of Title I drug reimbursement funds in FY2003, served 233 people living with HIV in the NH part of the EMA (Hillsborough, Rockingham, and Strafford counties) in calendar year

2004 (CY2004), an increase of 10% over CY2003¹³. Program eligibility is restricted to those with an income below 300% of the Federal Poverty Level, or \$27,930 for an individual, and, as of October 2004, new clients requesting enrollment must have had a past CD4 count under 350. Client demographics for the NH ADAP program for gender are 71% male and 29% female and for race/ethnicity are 72% Caucasian, 12% Hispanic, and 11% African-American. New Hampshire had a restricted ADAP drug formulary in the past due to lack of funds (especially those provided by the New Hampshire state government), but because of Planning Council concerns about having drug access parity across the Boston EMA, New Hampshire now has an open formulary like Massachusetts. People with HIV who are covered by the ADAP program can access all HIV medications and most other needed non-HIV medications, with a few exceptions. Because of its \$20,000 a year price tag, New Hampshire's ADAP program has restricted its coverage for the anti-HIV medication Fuzeon to 2 people, while trying to access pharmacy assistance programs for any other unmet need for the drug¹⁴. New Hampshire also has an insurance continuation program, provided insurance coverage to 94 (28.4%) ADAP clients in CY2004. Using funds to pay for insurance continuation saves money, as programs pay insurance premiums rather than full health care costs. In addition, people tend to have better access to care sooner and stay healthier, which also ultimately reduces health care costs.

Massachusetts' HIV Drug Assistance Program (HDAP) served 3,543 people living with HIV/AIDS in FY2004, an increase of 62% over the previous year¹⁵. Of these, 2,679 PLWH lived in the 7 MA EMA counties. Uninsured or under-insured PLWH with an income of under \$50,000 are eligible for the MA HDAP program, which has 3 components: Full-pay, CHII, and Co-pay. The Full-pay component reimburses pharmacies for their costs at an annual average cost of \$15,600 per person for anti-retroviral therapy and related treatments. Massachusetts has an unrestricted drug formulary. The Comprehensive Health Insurance Initiative (CHII) pays private, non-group health insurance premiums at an average annual cost of \$5,600 per person. Beginning in FY03 HDAP enrollment staff began aggressively enrolling eligible Full-

pay clients into CHII to save funds and in August 2004 MDPH mandated that all eligible Full-pay HDAP clients be shifted to the CHII program component when re-certifying for HDAP¹⁶. MDPH reports that 77% of HDAP enrollees are insured, with 49% having private insurance and 28% being covered by MassHealth. 31% of HDAP clients are insured through CHII. Lastly, the Co-pay component covers a portion of drug costs and insurance premiums not covered by private health insurance, MassHealth, or employment-based health insurance.

MassHealth program changes have impacted insurance coverage for PLWH and costs for the MA HDAP Program. As mentioned above, between September 2003 and July 2004, the eligibility level for the HIV MassHealth waiver was reduced from 200% FPL to 133% of FPL, resulting in affected PLWH losing health coverage. HDAP responded by covering those formerly MassHealth eligible PLWH with incomes of between 133% and 200% FPL. Earlier in April 2003 MassHealth instituted medication co-pay increases and new premiums and premium increases. HDAP responded by enrolling MassHealth clients for co-pay and premium assistance on a time-limited basis. Among its challenges, MDPH staff report increasing program utilization, level funding, MassHealth changes, drug and insurance pricing, Ryan White reauthorization, and the administrative burden of various cost savings measures¹⁷.

Demographics for HDAP clients in the MA part of the EMA are as follows: by gender, 70% male and 30% female; by race/ethnicity, 39% White, 27% Black, 20% Hispanic, 2% Asian, 3% Haitian, 3% Brazilian, 2% Other Portuguese speakers; 1% Native American, and 4% Other/Unknown; and by mode of HIV transmission, 43% Heterosexual Transmission; 34% MSM, 16% IDU and 7% Other/Unknown¹⁸. MDPH staff report that IDUs are under-represented among MA HDAP participants, (16% of HDAP clients vs. 26% of MA portion of the EMA's reported HIV/AIDS prevalence)¹⁹ suggesting that injection drug users may have problems accessing drug reimbursement and insurance continuation programs and therefore may be getting less healthcare than other affected groups of people living with HIV/AIDS.

Housing and Homelessness

According to the Urban Institute approximately 800,000 adults in the U.S. are homeless on any given night.²⁰ For many people, homelessness is a temporary circumstance rather than a permanent condition. Twelve million US adults are estimated to have been homeless at some point in their lives.²¹ Estimates of the number of people who are homeless should be interpreted with caution as differing definitions of homelessness and methodologies are used. The main causes of homelessness are poverty and the lack of affordable housing.

Homelessness is impacted by rental costs. Massachusetts has the highest rents in the nation, and is dealing with a severe long-term housing crisis. A UMass Boston study in 2001 found that nearly 40% of all Massachusetts renters were shelter-poor (meaning they could not meet their non-housing expenses after paying their rent)²². In addition, the number of families using Department of Transitional Assistance and privately-funded homeless shelter services increased by nearly 50% between 1995 and 2000. Median household incomes in MA dropped by 3.2% between 2001-2002 and 2002-2003. The number of individuals on the streets and in shelters during the City of Boston's annual single night census was 6,113 in December 2003, showing a homelessness increase from 2002 levels of 10% among women and 100% among youth. Approximately 28,800 individuals were served by MA emergency shelters in 2003²³. Cuts in the state's operating budget since FY2001 have decreased other housing services, such as housing vouchers and transitional housing subsidies.

New Hampshire also has a persistent shortage of affordable housing and has the 9th highest rental costs in the nation. According to the New Hampshire Housing Finance Authority, only 15% of the state's two-bedroom apartments were affordable to very-low income households in 2003, and the statewide rental vacancy rate was less than 1%. In New Hampshire, 6,553 people received temporary housing and another

17,081 had to be turned away from shelters due to full capacity in FY 2003, an increase of 87% over FY2001 levels²⁴.

Homeless persons use emergency department care more often due to such factors as lack of health insurance, lack of transportation, poor access to primary care, chronic alcohol and drug abuse, and mental illness. Additionally, their limited access to medical care delays the identification of HIV and co-morbidities, and contributes to the higher prevalence of opportunistic infections and other health problems among homeless PLWH.

The prevalence of homelessness is higher among people living with HIV/AIDS than in the general population. One third to one half of PLWH are either homeless or in imminent danger of losing their homes, estimates the MA-based AIDS Housing Corporation²⁵. In a recent national study, 65% of people living with HIV/AIDS cited stable housing as their greatest need after health care²⁶. A 2002 Suffolk University report on health care access for people with HIV/AIDS notes that people with stable housing are more likely to have a primary care doctor and are more likely to see a doctor or health care provider on a regular basis²⁷. Of 14,155 Title I clients, 55% reported being permanently housed, 31% reported being non-permanently housed, institutionalized or other, and for 13% their housing status was unknown or unreported²⁸. Of 466 PLWH surveyed in the 2003 *Voices of Experience* Boston EMA HIV needs assessment, 58% reported living in subsidized housing²⁹. In New Hampshire, Housing Opportunities for People with AIDS (HOPWA) programs assisted 286 PLWH and 191 family members of PLWH in SFY2003, but sheltered only 24 PLWH, a decrease of 300% from the year before³⁰. HOPWA/HUD is the largest payer of housing services for PLWH in the Boston EMA, accounting for 42% of the total funding available for all HIV-related housing services in the EMA³¹.

Table 6: Homelessness in the Boston EMA

Among all people in the EMA	Among PLWH in the EMA	Data Source
<p>Number served by emergency shelters in MA in 2003: 28,800 people</p> <p>Number of individuals on the streets and in shelters in Boston, MA in 12/2003: 6,113 people</p> <p>6,553 people received temporary housing (emergency or transitional) and another 17,081 had to be turned away from shelters due to full capacity in New Hampshire during SFY2003 (an increase of 87% over 2001 levels)</p>	<p>AMONG TITLE I CLIENTS:</p> <ul style="list-style-type: none"> - 55% permanently housed - 31% non-permanently housed or institutionalized - 13% housing status unknown or unreported <p>58% of PLWH surveyed in <i>VOE</i> living in subsidized housing</p> <p>286 PLWH and 191 family members of PLWH assisted by HOPWA programs in New Hampshire in SFY2003</p> <p>24 PLWH sheltered in New Hampshire in SFY2003 (a decrease of 300% from the year before)</p>	<p>The Center for Social Policy, John M. McCormack Graduate School of Policy Studies at UMass Boston, <i>Hard Numbers, Hard Times: Homeless Individuals in Massachusetts Emergency Shelters, 1999-2003</i>.</p> <p>Annual Single Night Census, City of Boston, 12/03</p> <p>NH DHHS, Division of Behavioral Health, Emergency Shelter and Homeless Coordination Commission Annual Report, 7/1/02-6/30/03</p> <p>BPHC, Title I client utilization data, FY2003.</p> <p>Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i>.</p>

¹ Kaiser Family Foundation, State Health Facts, *Distribution of Total Population by Federal Poverty Level, state data 2002-2003, U.S. 2003*, www.statehealthfacts.org, accessed January 18, 2005.

² Boston Public Health Commission, November 2004, *Boston EMA FY2005 Title I Grant Application*.

³ Health Resources and Services Administration (HRSA), HIV/AIDS Bureau. *The AIDS Epidemic and the Ryan White CARE Act. Past successes + future challenges. 2004-2005, Part 1, p.6.*
<http://hab.hrsa.gov/publications/progress05/>

⁴ Kaiser Family Foundation, State Health Facts, *Population Distribution by Insurance Status, state data 2002-03, U.S. 2003*, www.statehealthfacts.org, accessed January 18, 2005.

⁵ Kaiser Family Foundation, State Health Facts, *Rate of Nonelderly Uninsured by Race/Ethnicity, state data 2002-2003, U.S. 2003*, www.statehealthfacts.org, accessed January 18, 2005. Note from Kaiser website: " 'Other' includes Asian-Americans, Pacific Islanders, American Indians, Aleutians, Eskimos and persons of "Two or More Races". These groups have been combined due to their small populations in many states which prevent meaningful statistical analyses of the groups individually."

⁶ Ibid.

⁷ Ibid.

⁸ Ibid.

⁹ Kaiser Family Foundation, State Health Facts, *Population Distribution by Insurance Status, state data 2002-03, U.S. 2003*, www.statehealthfacts.org, accessed January 18, 2005.

¹⁰ Office of Medicaid, December 9, 2004. Presentation to the Planning Council by Alison Kirschgasser, Director of Federal and National Policy Management, Executive Office of Health and Human Services.

¹¹ Ibid.

¹² New Hampshire STD/HIV Prevention Section, December 9, 2004. Presentation to Planning Council by Heather Hauck, Chief.

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Massachusetts Department of Public Health, December 9, 2004. Presentation to Planning Council by Kevin Cranston, Director, HIV/AIDS Bureau.

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ Ibid. HDAP Quarterly Report (includes data from 9/1/04 to 11/30/04).

¹⁹ Massachusetts Department of Public Health, HIV/AIDS Surveillance Program, October 2004.

²⁰ The Boston Foundation, 2002. *The Food and Shelter Initiative Final Report*.

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- ²¹ National Coalition for the Homeless, November 1999. *How Many People Experience Homelessness, Fact Sheet*
Original source: Link, Bruce et al. "Life-time and Five-Year Prevalence of Homelessness in the United States,"
American Journal of Public Health, December 1994.
- ²² UMass Boston, June 2001. *After Welfare Reform: Trends in Poverty and Emergency Service Use in Massachusetts*,
UMass Boston.
- ²³ The Center for Social Policy, John M. McCormack Graduate School of Policy Studies at UMass Boston, *Hard
Numbers, Hard Times: Homeless Individuals in Massachusetts Emergency Shelters, 1999-2003*.
- ²⁴ NH DHHS, Division of Behavioral Health, Emergency Shelter and Homeless Coordination Commission Annual
Report, 7/1/02-6/30/03.
- ²⁵ AIDS Housing Corporation, April 8, 2004. Presentation to the Planning Council by Joe Carleo, Executive Director.
- ²⁶ Ibid.
- ²⁷ Suffolk University, December 8, 2002. *People Living with HIV/AIDS Who Do Not Use Healthcare Consistently: a
Consumer and Provider Survey for the Boston Public Health Commission, AIDS Program, CARE Act Title I
Evaluation Project*.
- ²⁸ Boston Public Health Commission, November 2004. *Boston EMA FY2005 Title I Grant Application*.
- ²⁹ Beinecke, R., Matava S., Rivers, N., Awunti, N., Suffolk University, October 2003. *Voices of Experience 2003
Findings*, presented to the Planning Council November 13, 2003 by Richard Beinecke and Sandy Matava.
- ³⁰ Ibid.
- ³¹ Boston AIDS Consortium, May 2004. *Funding for HIV/AIDS Care and Services in the Boston EMA*.

4. Co-morbidities

Healthcare needs, costs and access to care for people living with HIV/AIDS can be significantly affected by the presence of certain conditions commonly occurring with or resulting from HIV infection (co-morbidities). This section will look at:

- substance use/abuse,
- mental illness,
- sexually transmitted diseases (STDs), and
- Hepatitis B and C

and present information that describes, where known, the specific needs and challenges in meeting the needs of PLWH with these co-morbidities in the Boston EMA. The information provided in this section is particularly relevant with regards to the Core Services of substance abuse services, mental health care, primary care, drug reimbursement, and case management. It is useful to keep in mind that considerable overlap exists among the homeless, mentally ill, and substance abusers - who make up the most vulnerable and costly population - according to a 2003 U.S. Conference of Mayors report.

Substance Abuse

Of total admissions to the MDPH Bureau of Substance Abuses Services (BSAS) in 2003, 20.7% reported being homeless¹. Of these, 44% reported injection drug use in the past year and 24% reported prior mental health treatment². Homeless adults with severe mental illness have much higher rates of HIV prevalence (8.5% - 62%) than the general population, according to a literature review cited in the 2003 Health Care for the Homeless Clinician's Network Report, *Adapting Your Practice: Treatment and Recommendations for Homeless Patients with HIV/AIDS*. A 2001 Boston University report notes that lack of housing options is the leading systemic barrier to accessing health care for HIV+ substance users³. In 2003 there was a 40% reduction in the number of Boston-area detoxification beds, resulting in 28% fewer treatment admissions, and a loss of 131 state-funded overflow beds in other facilities⁴.

Total admissions to substance abuse treatment programs in 2003 numbered 52,202 in Massachusetts and 5,066 in New Hampshire⁵. The most abused substance self-reported in treatment admissions in MA is alcohol, followed by heroin, cocaine, and marijuana. This trend is similar in New Hampshire, with the exception of marijuana, which is the second most cited primary substance in admissions. Between FY1992 and FY2003 past year heroin use reported by substance abuse treatment admissions more than doubled from 20% to about 43% in MA.

Table 7: Substance Use Co-morbidity in the Boston EMA

Prevalence within the general population within the EMA	Prevalence among PLWH in the EMA	Data Source
<p>Total substance abuse admissions to treatment programs in MA in 2003: 52,202</p> <p>Total substance abuse admissions to treatment programs in NH in 2003: 5,066</p> <p>Rank of most abused substance self-reported in treatment admissions in MA in 2003: NH in 2003:</p> <p>1. Alcohol 1. Alcohol 2. Heroin 2. Marijuana 3. Cocaine 3. Heroin 4. Marijuana 4. Cocaine</p> <p>Past year heroin use reported by substance abuse treatment admissions in MA: 43% in FY2003 (up from 20% in FY1992)</p> <p>Cocaine-related Emergency Department (ED) visit rate for the Boston Metropolitan Area* was 156/100,000, twice the national rate</p> <p>Heroin-related ED visit rate for Boston Metropolitan Area* was 111/100,000, three times the national rate.</p>	<p>29% of PLWH surveyed in <i>VOE</i> reported current substance abuse problems</p> <p>Percent of HIV+ women’s reported exposure to HIV through IDU in MA: 34%</p> <p>Percent of HIV+ men’s reported exposure to HIV through IDU in MA: 28%</p>	<p>SAMSHA, Treatment Episode Data Set (TEDS), 2003</p> <p>Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i>.</p> <p>MDPH, <i>HIV/AIDS in Massachusetts: an Epidemiologic Profile FY2005, October 2004</i>.</p> <p>SAMSHA, <i>The Dawn Report – Highlights From Dawn: Boston, 2002. December 2003</i></p>
	Annual Treatment Costs	
	<p>\$12,500 for residential treatment \$3,100 for outpatient treatment</p>	<p>Schneider Institute for Health Policy, <i>Substance Abuse: The Nation’s Number One Health Problem</i> (Princeton, N.J.: Robert Wood Johnson Foundation, 2001)</p>

* The Boston Metropolitan Area for the Drug Abuse Warning Network (DAWN) does not include three counties (Bristol and Worcester Counties of MA, and Hillsborough in NH) contained in the Boston Title I EMA.

Injection Drug Use (IDU)

The incidence and prevalence of HIV/AIDS among IDUs has been increasing steadily, with approximately 35% of alive HIV/AIDS cases in the Boston EMA, as of December 2003, from IDU⁶. According to the MDPH's most recent epidemiologic profile⁷, injection drug use (34%) accounts for HIV+ women's most frequent exposure to HIV. For White women this trend is even higher, with IDU accounting for 52% of HIV exposures. For men living with HIV/AIDS in MA, injection drug use (28%) is the second most common exposure to HIV, after MSM (46%).

Among Hispanic and Black males, IDU is the leading reported risk for HIV infection, accounting for 51% and 31% of exposures, respectively. Urban centers are particularly hard hit by IDU-associated HIV transmission. Cities in the Boston EMA where IDU is the primary mode of HIV exposure include Fall River, Gloucester, New Bedford, and Worcester⁸.

IDUs face an array of needs stemming from multiple problems like unemployment, homelessness, lack of adequate health coverage, psychiatric disorders, histories of physical and sexual abuse, health problems, and social isolation. These conditions severely affect an individual's ability to seek out care and adhere to a treatment plan.

Other Substance Use

While the correlation between injection drug use and HIV infection is well documented, there is also a connection between non-injection drug use and HIV. Clinical chart review data on 544 PLWH in the Boston EMA from 2000 to 2002 found that 25% had an active substance abuse problem⁹. Of 466 PLWH surveyed in the 2003 VOE study, 29% reported current substance abuse problems. Because PLWH who are substance users need primary care, substance abuse treatment, and support services, they require more comprehensive, complex, and costly care. Individual annual substance abuse treatment costs are about

\$12,500 for residential treatment and \$3,100 for outpatient treatment, according to the Institutes of Medicine¹⁰.

Numerous behavioral studies indicate that the use of alcohol and other drugs is a significant factor in sexual HIV transmission. A study in Worcester, MA, the second largest city in the EMA, found that compared to heroin injectors, cocaine injectors had a higher HIV risk because of their injection and sexual practices. Cocaine use was more prevalent among young, African-American males. Crack-cocaine users were more likely to have multiple partners and receive money or drugs for sex¹¹. Another study, which investigated unprotected anal intercourse among men who have sex with men (MSM) in Boston, found that those reporting unprotected anal intercourse were significantly more likely to have a drinking problem, more likely to use poppers (inhalants), more likely to use cocaine, and more likely to have had more sexual partners in the past six months than those who did not report unprotected anal intercourse¹². Recreational use of Viagra in combination with other drugs, like Ecstasy and crystal meth, has been linked to higher rates of STDs, with users having more sexual partners and engaging in more unsafe behaviors. The combination of these drugs may make users less likely to wear condoms and could be leading to an increase in unprotected anal sex and new HIV infections¹³. According to an August 2004 *New York Times* article, doctors report anecdotal evidence that crystal meth use is a factor in 50% to 75% of new HIV cases in New York City. A 2002 San Francisco Department of Public Health study found that gay men who used crystal meth and Viagra together were 6 times as likely as non-users to contract syphilis. There is evidence that abusers of alcohol and other drugs are much less likely than others with HIV to be in care and to remain in care. The period between the time substance abusers learn their serostatus and the time they first seek medical treatment may be especially long. Lastly, a diagnosis with HIV can lead the newly diagnosed to self-medicate with alcohol or other drugs¹⁴.

A growing body of literature describes effective practices and strategies for serving HIV positive substance users, identifying key areas where service delivery systems and practices can be enhanced to meet the needs of this population. These practices and strategies include:

- ❑ Co-located and integrated services;
- ❑ A multidisciplinary team approach to care;
- ❑ Routine substance abuse screening in primary care settings, with subsequent assessment and referral to treatment;
- ❑ A harm reduction approach to service delivery;
- ❑ Adherence support strategies tailored to the lifestyles and needs of substance users;
- ❑ Services that are provided in a culturally sensitive and competent manner;
- ❑ Involving consumers in their own care and using peers as part of the service delivery model; and
- ❑ Providing a holistic array of services that include housing assistance and support services to address peoples' immediate needs as part of their HIV care and substance abuse treatment¹⁵.

Mental Illness.

Self-medication often occurs as a result of untreated mental health problems. According to the National Mental Health Information Center, 5.4% of the non-institutionalized and non-homeless population is living with serious mental illness, equaling 268,081 individuals in Massachusetts and 52,201 in New Hampshire for 2002. Boston emergency rooms are dealing with rising numbers of mental health patients because of budget cuts, such as those at area community health clinics. One hospital ER experienced a 49% increase in psychiatric patients between April 2002 and April 2003. A local community center reports turning away 30 to 40 patients a day seeking care, because it is no longer being reimbursed for treating uninsured psychiatric patients in their outpatient clinic.

Clinical chart review data on 544 PLWH in the Boston EMA from 2000 to 2002 found that 43% had active psychiatric diagnoses¹⁶. The 2003 *VOE* needs assessment supported the findings of the chart reviews and found that 37% of surveyed PLWH reported a diagnosed mental illness and 46% needed mental health treatment¹⁷. The most common forms of mental illness found among PLWH include depression, mania (bipolar disorder),

schizophrenia, anxiety disorders, personality disorders, problems in sleeping and sexual function, and constitutional problems like chronic fatigue, wasting, and pain¹⁸. According to a recent survey of physicians and people with HIV, more than 80% of HIV+ people have symptoms of depression or anxiety. The study found that many psychiatric symptoms were due to antiviral medication side effects, in addition to the “impact of HIV on the central nervous system and the neurological effects of opportunistic infections”¹⁹.

Table 8: Mental Illness Co-morbidity in the Boston EMA

Prevalence within the general population within the EMA	Prevalence among PLWH in the EMA	Data Source
<p>Estimated percentage and number of adults with serious mental illness in 2002: 5.4% of adult population 268,081 individuals in MA 52, 201 individuals in NH</p>	<p>Percent of HIV-infected clients with active psychiatric diagnosis: 43% Percentage of PLWH reporting a diagnosed mental illness in VOE: 37% Percentage of PLWH reporting a need for mental health treatment in VOE: 46%</p>	<p>SAMHSA’s National Mental Health Information Center, 2002. John Snow Institute, Title I Clinical CQI Chart Review, 2000-2002. Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i>.</p>
	Annual Treatment Costs	
	<p>Medical and behavioral health treatment costs per PLWH with serious mental illness: \$13,800</p>	<p><i>Psychiatric Services</i> 54: 1240-1246, September 2003.</p>

Costs for services for PLWH with serious mental illness are 86% greater than for those with HIV/AIDS alone, according to a study of the costs of medical and behavioral health treatment expenditures for Medicaid recipients dealing with HIV and serious mental illness²⁰.

The most effective service models for PLWH with mental illness have been collaborative networks, the formal and informal relationships among service providers and organizations that allow PLWH to more easily know about available services and can ease access to those services. Case management also plays a significant role.

Sexually Transmitted Diseases

Beyond substance abuse and mental illness, another co-morbidity that increases the complexity and cost of care for PLWH is STDs. Studies show that STDs can greatly increase the risk of HIV transmission and can speed up the rate of HIV replication in exposed individuals. Because HIV weakens the immune system, STDs are often harder to treat in HIV+ individuals, causing chronic and drug-resistant infections. According to the MDPH, 1% of MA individuals diagnosed with an STD are HIV positive. Through April 2001, it was estimated that 9.2% of cumulative AIDS cases in MA had a concurrent STD²¹.

STD rates between 1999 and 2003 have increased for the general MA population: by 16.2% for gonorrhea (to 45.1 cases per 100,000), 26.6% for chlamydia (to 175.8 cases per 100,000), and 250% for primary and secondary syphilis (to 2.1 cases per 100,000)²². STD rates in NH have increased as well, by 4.3% for gonorrhea (to 9.8 cases per 100,000) and 1400% for primary and secondary syphilis (to 1.5 cases per 100,000).²³

Reported early syphilis^a among MSM accounted for 68% of MA cases in 2001 and 77% of cases in 2003. This increase is a concern because syphilis not only facilitates HIV transmission, but outbreaks also often serve as precursors to a rise in HIV. In fact, 41% of the 2003 MSM syphilis cases were among HIV+ men, while 59% were among those who were not yet infected with or had not yet been tested for HIV. Three of New Hampshire's 14 early syphilis cases for 2003, or 21%, were HIV co-infected. If left untreated syphilis can cause brain damage, heart disease, arthritis and death. The number of fluoroquinolone-resistant gonorrhea isolates in MA has gone from 3 in 2001 to 54 in 2003, an increase of 1800%, primarily among MSM²⁴. Treatment of these cases requires more expensive medications than those normally used. Gonorrhea and chlamydia complications can lead to chronic pain, infertility and tubal pregnancies. Due to biology, behavior and social factors, adolescents are also disproportionately impacted by STDs, with chlamydia and gonorrhea infection rates consistently 3 or more times the rate for all ages in Massachusetts²⁵.

^a Early syphilis includes primary, secondary and early latent reports.

Table 9: STD Co-morbidity in the Boston EMA

Prevalence within the general population within the EMA	Prevalence among PLWH in the EMA	Data Source
<p>Increase in Primary and Secondary Syphilis rates between 1999 and 2003 in MA: 250% (to 2.1 cases per 100,000 in 2003)</p>		
<p>Increase in Chlamydia rates between 1999 and 2003 in MA: 26.6% (to 175.8 cases per 100,000 in 2003)</p>		<p>Centers for Disease Control and Prevention, <i>2003 STD Surveillance Report</i>, November 15, 2004</p>
<p>Increase in Gonorrhea rates between 1999 and 2003 in MA: 16.2% (to 45.1 cases per 100,000 in 2003)</p>	<p>Percent of cumulative AIDS cases in MA through 4/2001 estimated to have a concurrent STD: 9.2%</p>	<p>Centers for Disease Control and Prevention, <i>Gonococcal Isolate Surveillance Project Annual Report – 2003</i>, November 2004</p>
<p>Increase in Primary and Secondary Syphilis rates between 1999 and 2003 in NH: 1400% (to 1.5 cases per 100,000 in 2003)</p>	<p>Percent of MSM syphilis cases among HIV+ men in 2003 in MA: 41%</p>	
<p>Increase in Chlamydia rates between 1999 and 2003 in NH: 58.6% (to 126.7 cases per 100,000 in 2003)</p>	<p>Percent of early syphilis cases among PLWH in 2003 in NH: 21%</p>	<p>MDPH, Massachusetts Community Health Information Profile, 2000.</p>
<p>Increase in Gonorrhea rates between 1999 and 2003 in MA: 4.3% (to 9.8 cases per 100,000 in 2003)</p>		<p>MDPH, Division of STD Prevention.</p>
<p>Percentage increase in fluoroquinolone-resistant gonorrhea isolates in MA from 2001 to 2003: 2000% (from 3 cases in 2001 to 60 in 2003)</p>		<p>NH DHHS, Office of Community and Public Health, Bureau of Communicable Disease Surveillance, 2003.</p>

Another STD, human papilloma virus (HPV), is the cause of 90% of cervical cancer cases in women. Thirty types of HPV can be sexually transmitted. Data from the CDC-funded HPV Sentinel Surveillance System shows that 24% of MA women surveyed at various primary care and clinic sites in 2003 have high-risk HPV. Recent studies also indicate a high prevalence of HPV among MSM; close to 60% of all MSM are estimated to have HPV, which has been found to increase the incidence of anal cancer among HIV+ men²⁶.

The needs of PLWH who also have STDs are medical in nature. Health care providers should routinely screen their HIV-positive patients, ask about sexual habits and partners, and provide information on how to prevent infection or transmission. *Voices of Experience 2003* reports that very few providers are talking to HIV+ people about their sexual behavior, HIV transmission, or disclosure of HIV status²⁷. Additionally, providers should stay current on the latest treatment and diagnostic methods available, as well as follow the appropriate guidelines for care. Providers should screen male patients who are open about having sex with other men on a regular basis for anal cancer, as early diagnosis increases the treatment success rate²⁸ while decreasing associated medical costs²⁹. The National Coalition of STD Directors estimates that the United States' annual HPV medical costs are \$1.6 billion with 14,000 cases and 5,000 deaths each year. National medical costs for all STDs have been estimated at about \$8.4 billion annually by the Kaiser Family Foundation.

Hepatitis Co-infection

Hepatitis co-infection is an increasingly serious co-morbidity. According to the MDPH, up to 300,000 Massachusetts residents have been or are currently infected with Hepatitis B (HBV) and approximately 110,000 Massachusetts residents are living with Hepatitis C (HCV). In one MDPH study, 10-15% of mental health patients were found to be HCV-infected. Nationally, 20% of people with severe mental illness have HCV infection, compared with less than 2% of the general population. In addition, treatment side effects for Hepatitis C can cause additional mental health problems, such as depression and anxiety. Hepatitis C infection is associated with a history of STDs, IDU and non-IDU drug use, prison stays, and low socio-economic status³⁰.

Shared epidemiological risks, such as unprotected sex and the sharing of syringes and other drug injection paraphernalia, have resulted in higher incidence of both Hepatitis B (HBV) and Hepatitis C (HCV) among PLWH than those uninfected with HIV. Nationally, up to 40% of PLWH are also living with HCV; however, co-infection rates are as high as 90% for some subgroups, including HIV positive intravenous drug users. Of 466 PLWH surveyed for the 2003 *VOE*, 18% were co-infected with Hepatitis B and 46% with Hepatitis C³¹.

According to MDPH surveillance studies, 8,500 MA residents are co-infected with HIV and Hepatitis C. Among them, 70% were exposed through injection drug use, 15% through male-to-male sex, and 15% through heterosexual sex³².

Table 10: Hepatitis Co-morbidity in the Boston EMA

HEPATITIS B		
Prevalence within the general population within the EMA	Prevalence among PLWH in the EMA	Data Source
300,000 in MA Not available - NH	18% of PLWH surveyed for VOE	MDPH, <i>Facts About Hepatitis B Disease and Hepatitis B Vaccine</i> . Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i> .
HEPATITIS C		
Prevalence within the general population within the EMA	Prevalence among PLWH in the EMA	Data Source
110,000 in MA Not reportable in NH	46% of PLWH surveyed for VOE 8,500 in MA	MDPH Suffolk University, <i>Voices of Experience (VOE) 2003: HIV/AIDS Consumer Views on Their Needs for Services in Massachusetts and the Boston Eligible Metropolitan Area (EMA)</i> .
	Annual Treatment Costs	
	Medication costs per person for full 48-week course of treatment: \$30,000	

While the rate of AIDS-related deaths is declining, end-stage liver disease due to HCV has become a leading cause of death for HIV patients in the United States. Co-infection with HCV leads to a more rapid progression of HIV infection, along with increases in both morbidity and mortality³³. HIV co-infection appears to worsen HCV infection, creating more severe fibrosis, a higher frequency of cirrhosis, and increased deaths from liver disease. Access to treatment for HIV and HCV is a significant problem for co-infected injection drug users, who often receive HAART later than non-users. In addition, studies have found that PLWH with chronic HBV or HCV infection have 2.5 to 3 times the risk of

developing a serious liver enzyme elevation after starting an antiretroviral regimen that contains a protease inhibitor than PLWH without hepatitis³⁴. A recent Johns Hopkins study found that men co-infected with Hepatitis B and HIV were 17 times more likely to die from liver disease than men infected with Hepatitis B alone³⁵.

National Hepatitis C costs are \$5 billion annually and the CDC estimates that Hepatitis C-related mortality could triple within the next two decades. Hepatitis C medication costs for a full 48-week course of treatment are about \$30,000 per person. While costs are rapidly rising, Hepatitis C funding has been cut by 80% in Massachusetts over the last four years. Hepatitis B medical costs in the U.S. are estimated at \$700 million annually.

The complexity of co-morbid health issues facing PLWH has increased the complexity and cost of providing comprehensive quality care and support. People newly identified as HIV+ in the Boston EMA are more likely to be further along in the progression of HIV disease, to have complicating mental health and substance abuse issues, to be co-infected with STDs, HBV, and HCV, and be impacted by limited economic resources. The success of the system of care at dramatically reducing the AIDS morbidity and mortality rates has led to a growth in the numbers of PLWH who are in need of health-related support services. These factors will continue to impact the costs and complexity of care, and pose challenges to the care system in the Boston EMA.

¹ Massachusetts Department of Public Health, Bureau of Substance Abuse Services. *Substance Abuse Treatment and Substance Use in Massachusetts – FY '03*.

² Massachusetts Department of Public Health, Bureau of Substance Abuse Services, Office of Statistics and Evaluation. *Substance Abuse Fact Sheet: Adult Homeless Admissions*. Data reported to BSAS Management Information System in FY 2003.

³ Tobias, C., Drainoni, M., Ueda, A., Wood, S., McCree, J., Gerlus, R., Chambers, J., Boston University School of Public Health, Health and Disability Working Group, January 2002. *Performance Standards, Barriers to Care and Innovative Program Models for HIV Positive Substance Users: A Review of the Literature*.

⁴ Massachusetts Department of Public Health, Bureau of Substance Abuse Services, March 11, 2004. Presentation to the Planning Council by Michael Botticelli, Director.

⁵ SAMSHA, Treatment Episode Data Set (TEDS), 2003.

⁶ Boston Public Health Commission, November, 2004. *Boston EMA FY2005 Title I Grant Application*.

⁷ MDPH, *HIV/AIDS in Massachusetts: an Epidemiologic Profile FY2005, October 2004*.

⁸ Ibid.

⁹ John Snow Institute, February 2003. *HIV Care Quality and Clinical Outcomes in Boston EMA Sites Providing Primary Medical Care 2000: Title I Clinical CQI Chart Review Data*.

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- ¹⁰ Schneider Institute for Health Policy, *Substance Abuse: The Nation's Number One Health Problem* (Princeton, N.J.: Robert Wood Johnson Foundation, 2001)
- ¹¹ Hudgins, R., McCusker, J., Stoddard A., (1995) *Cocaine Use and Risky Injection and Sexual Behaviors*, Drug and Alcohol Dependency. January: 37 (1); 7-14.
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**EMA****HRSA****BPHC****BAC****Title I****HDAP**

Useful Acronyms and Definitions

AACTG (Adult AIDS Clinical Trials Group)

Largest HIV clinical trials organization in the world, which plays major role in setting standards of care for HIV infection and opportunistic diseases related to HIV/AIDS in the United States and the developed world. The AACTG is composed of, and directed by, leading clinical scientists in HIV/AIDS therapeutic research.

ACTG (AIDS Clinical Trials Group)

A network of medical centers around the country in which federally funded clinical trials are conducted to test the safety and efficacy of experimental treatments for AIDS and HIV infection. These studies are funded by the NIH National Institute of Allergy and Infectious Diseases (NIAID).

ADAP (AIDS Drug Assistance Program)

Administered by States and authorized under Title II of the CARE Act, provides FDA-approved medications to low-income individuals with HIV disease who have limited or no coverage from private insurance or Medicaid. ADAP funds may also be used to purchase insurance for uninsured CARE Act clients as long as the insurance costs do not exceed the cost of drugs through ADAP and the drugs available through the insurance program at least match those offered through ADAP.

Administrative or Fiscal Agent

Entity that functions to assist the grantee, consortium, or other planning body in carrying out administrative activities (e.g., disbursing program funds, developing reimbursement and accounting systems, developing Requests for Proposals [RFPs], monitoring contracts).

AETC (AIDS Education and Training Center)

Regional centers providing education and training for primary care professionals and other AIDS-related personnel. AETCs are authorized under Part F of the CARE Act and administered by the HRSA HIV/AIDS Bureau's Division of Training and Technical Assistance (DTTA).

AHRQ (Agency for Healthcare Research and Quality)

Federal agency within HHS that supports research designed to improve the outcomes and quality of health care, reduce its costs, address patient safety and medical errors, and broaden access to effective services.

AIDS (Acquired Immunodeficiency Syndrome)

A disease caused by the human immunodeficiency virus.

Antiretroviral

A substance that fights against a retrovirus, such as HIV. (See Retrovirus)

ASO (AIDS service organization)

An organization that provides primary medical care and/or support services to populations infected with and affected by HIV disease.

Asymptomatic

HIV infected but shows no clinical signs of the disease.

BAC

Boston AIDS Consortium

BPHC

Boston Public Health Commission, the city's department of public health.

Capacity

Core competencies that substantially contribute to an organization's ability to deliver effective HIV/AIDS primary medical care and health-related support services. Capacity development activities should increase access to the HIV/AIDS service system and reduce disparities in care among underserved PLWH in the EMA.

CARE Act (Ryan White Comprehensive AIDS Resources Emergency Act)

Federal legislation created to address the unmet health care and service needs of people living with HIV Disease (PLWH) disease and their families. It was enacted in 1990 and reauthorized in 1996 and 2000. Administered by the HHS/Health Resources and Services Administration (HRSA).

CADR (CARE Act Data Report)

A provider-based report generating aggregate client, provider, and service data for all CARE Act programs. Reports information on all clients who receive at least one service during the reporting period. Replaces the Annual Administrative Report (AAR) used for Title I and Title II as well as separate Title III and Title IV data reports.

CBO (community-based organization)

An organization that provides services to locally defined populations, which may or may not include populations infected with or affected by HIV disease.

CDC (Centers for Disease Control and Prevention)

Federal agency within HHS that administers disease prevention programs including HIV/AIDS prevention.

CD4 or CD4+ Cells

Also known as "helper" T-cells, these cells are responsible for coordinating much of the immune response. HIV's preferred targets are cells that have a docking molecule called "cluster designation 4" (CD4) on their surfaces. Cells with this molecule are known as CD4-positive (CD4+) cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4 levels appear to be the best indicator for developing opportunistic infections.

CD4 Cell Count

The number of T-helper lymphocytes per cubic millimeter of blood. The CD4 count is a good predictor of immunity. As CD4 cell count declines, the risk of developing opportunistic infections increases. The normal adult range for CD4 cell counts is 500 to 1500 per cubic millimeter of blood. (The normal range for infants is considerably higher and slowly declines to adult values by age 6 years.) CD4 counts should be rechecked at least every 6 to 12 months if CD4 counts are greater than 500/mm³. If the count is lower, testing every 3 months is advised. (In children with HIV infection, CD4 values should be checked every 3 months.) A CD4 count of 200 or less is an AIDS-defining condition.

Chlamydia

A sexually transmitted disease caused by the bacteria *Chlamydia trachomatis* that infects the genital tract; it is the most frequently reported STD in the country; it is frequently asymptomatic in both men and women; if left untreated, it can cause sterility, tubal pregnancies, and pelvic inflammatory disease in women.

Chief Elected Official (CEO)

The official recipient of Title I or Title II CARE Act funds. For Title I, this is usually a city mayor, county executive, or chair of the county board of supervisors. For Title II, this is usually the governor. The CEO is ultimately responsible for administering all aspects of their title's CARE Act funds and ensuring that all legal requirements are met.

CMS (Centers for Medicare and Medicaid Services)

Formerly known as the Health Care Finance Administration (HCFA). Federal agency within HHS that administers the Medicaid, Medicare, State Child Health Insurance Program (SCHIP), and the Health Insurance Portability and Accountability Act (HIPAA).

Co-morbidity

A disease or condition, such as mental illness or substance abuse, co-existing with HIV disease.

Community Forum or Public Meeting

A small-group method of collecting information from community members in which a community meeting is used to provide a directed but highly interactive discussion. Similar to but less formal than a focus group, it usually includes a larger group; participants are often self-selected (i.e., not randomly selected to attend).

Comprehensive Planning

The process of determining the organization and delivery of HIV services. This strategy is used by planning bodies to improve decision-making about services and maintain a continuum of care for PLWH.

Community Health Centers

Federally-funded by HRSA's Bureau of Primary Health Care, centers provide family-oriented primary and preventive health care services for people living in rural and urban medically underserved communities.

Concurrent

Happening at the same time.

Consortium/HIV Care Consortium

A regional or statewide planning entity established by many State grantees under Title II of the CARE Act to plan and sometimes administer Title II services. An association of health care and support service agencies serving PLWH under Title II of the CARE Act.

Continuous Quality Improvement

An ongoing process that involves organization members in monitoring and evaluating programs to continuously improve service delivery. CQI seeks to prevent problems and to maximize the quality of care by identifying opportunities for improvement.

Continuum of Care

An approach that helps communities plan for and provide a full range of emergency and long-term service resources to address the various needs of PLWH.

CPCRA (Community Programs for Clinical Research on AIDS)

Community-based clinical trials network that obtains evidence to guide clinicians and PLWH on the most appropriate use of available HIV therapies.

Cultural Competence

The knowledge, understanding, and skills to work effectively with individuals from differing cultural backgrounds.

DCBP (Division of Community Based Programs)

The division within HRSA's HIV/AIDS Bureau that is responsible for administering Title III, Title IV, and the HIV/AIDS Dental Reimbursement Program.

Demographic

Data that helps to better understand the characteristics of a population being studied.

DOD

The Department of Defense is a government agency, which, along with the Department of Veteran's Affairs (the VA), provides health care services to service members and veterans of the U.S. uniformed services and their dependents. The DOD and VA also engage in HIV/AIDS prevention and research.

DPH

Department of Public Health

DSS (Division of Service Systems)

The division within HRSA's HIV/AIDS Bureau that administers Title I and Title II of the CARE Act.

DTTA (Division of Training and Technical Assistance)

The division within HRSA's HIV/AIDS Bureau that administers the AIDS Education and Training Centers (AETC) Program and technical assistance and training activities of the HIV/AIDS Bureau.

Early Intervention Services (EIS)

Activities designed to identify individuals who are HIV-positive and get them into care as quickly as possible. As funded through Titles I and II of the CARE Act, includes outreach, counseling and testing, information and referral services. Under Title III of the CARE Act, also includes comprehensive primary medical care for individuals living with HIV/AIDS.

Eligible Metropolitan Area (EMA)

Geographic areas highly-impacted by HIV/AIDS that are eligible to receive Title I CARE Act funds.

EIA (Enzyme-Linked Immunosorbent Assay)

The most common test used to detect the presence of HIV antibodies in the blood, which indicate ongoing HIV infection. A positive ELISA test result must be confirmed by another test called a Western Blot.

Epidemic

A disease that occurs clearly in excess of normal expectation and spreads rapidly through a demographic segment of the human population. Epidemic diseases can be spread from person to person or from a contaminated source such as food or water.

Epidemiologic Profile

A description of the current status, distribution, and impact of an infectious disease or other health-related condition in a specified geographic area.

Epidemiology

The branch of medical science that studies the incidence, distribution, and control of disease in a population.

Exposure Category

In describing HIV/AIDS cases, same as transmission categories; how an individual may have been exposed to HIV, such as injecting drug use, male-to-male sexual contact, and heterosexual contact.

Family Centered Care

A model in which systems of care under Ryan White Title IV are designed to address the needs of PLWH and affected family members as a unit, providing or arranging for a full range of services. Family structures may range from the traditional, biological family unit to non-traditional family units with partners, significant others, and unrelated caregivers.

FDA (Food and Drug Administration)

Federal agency within HHS responsible for ensuring the safety and effectiveness of drugs, biologics, vaccines, and medical devices used (among others) in the diagnosis, treatment, and prevention of HIV infection, AIDS, and AIDS-related opportunistic infections. The FDA also works with the blood banking industry to safeguard the nation's blood supply.

Federal Poverty Level

A scale of individual and family income limits set by the federal government to determine eligibility for certain benefits and entitlements.

Financial Status Report (FSR - Form 269)

A report that is required to be submitted within 90 days after the end of the budget period that serves as documentation of the financial status of grants according to the official accounting records of the grantee organization.

Formula Grant Application

The application used by EMAs and States each year to request an amount of CARE Act funding which is determined by a formula based on the number of reported AIDS cases in their location and other factors. The application responds to guidance from DSS on program requirements and expectations.

Genotypic Assay

A test that analyzes a sample of the HIV virus from the patient's blood to identify actual mutations in the virus that are associated with resistance to specific drugs.

Gonorrhea

A sexually transmitted disease caused by the bacteria *Neisseria Gonorrhoeae*. It is the second most frequently reported STD in the country.

Grantee

The recipient of CARE Act funds responsible for administering the award.

HAART (Highly Active Antiretroviral Therapy)

HIV treatment using multiple antiretroviral drugs to reduce viral load to undetectable levels and maintain/increase CD4 levels.

Harm reduction

A philosophy of drug abuse treatment that attempts to decrease the adverse health, social, and economic consequences of drug use without requiring abstinence but that does not rule out abstinence in the longer term, if this is the client's choice.

HBV

Hepatitis B Virus

HCV

Hepatitis C Virus

Health Professional Shortage Area

Geographic areas, population groups, or health care facilities that inadequate numbers of health professionals who specialize in medical care, mental health, and/or dental care; such areas may receive additional federal funding, for strategies intended to improve access to these health professionals.

Health Insurance Continuity Program (HICP)

A program primarily under Title II of the CARE Act that makes premium payments, co-payments, deductibles, and/or risk pool payments on behalf of a client to purchase/maintain health insurance coverage.

Herpes

A sexually transmitted disease caused by the Herpes Simplex Virus I or II that causes painful sores of the anus or genitals that may lie dormant in nerve tissue; HSV-II is a precursor of some types of cervical cancer.

High-Risk Insurance Pool

A State health insurance program that provides coverage for individuals who are denied coverage due to a pre-existing condition or who have health conditions that would normally prevent them from purchasing coverage in the private market.

HIV/AIDS Bureau (HAB)

The bureau within the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) that is responsible for administering the Ryan White CARE Act.

HIV/AIDS Dental Reimbursement Program

The program within the HRSA HIV/AIDS Bureau's Division of Community Based Programs that assists with uncompensated costs incurred in providing oral health treatment to PLWH.

HIV

Human Immunodeficiency Virus

HIV Disease

Any signs, symptoms, or other adverse health effects due to the human immunodeficiency virus.

Home and Community Based Care

A category of eligible services that States may fund under Title II of the CARE Act.

HOPWA (Housing Opportunities for People With AIDS)

A program administered by the U.S. Department of Housing and Urban Development (HUD) that provides funding to support housing for PLWH and their families.

HPV

Human Papilloma Virus, known to cause genital warts in humans, a sexually transmitted disease.

Health Care for the Homeless Health Center

A grantee funded under section 330(h) of the Public Health Service Act to provide primary health and related services to homeless individuals.

HRSA (Health Resources and Services Administration)

The agency of the U.S. Department of Health and Human Services that administers various primary care programs for the medically underserved, including the Ryan White CARE Act.

HUD (U.S. Department of Housing and Urban Development)

The Federal agency responsible for administering community development, affordable housing, and other programs including Housing Opportunities for People with AIDS (HOPWA).

IDU (Injection Drug User)

IGA (Intergovernmental Agreement)

A written agreement between a governmental agency and an outside agency that provides HIV services.

Incidence

The number of new cases of a disease that occur during a specified time period.

Incidence Rate

The number of new cases of a disease or condition that occur in a defined population during a specified time period, often expressed per 100,000 persons. AIDS incidence rates are often expressed this way.

Lead Agency

The agency within a Title II consortium that is responsible for contract administration; also called a fiscal agent (an incorporated consortium sometimes serves as the lead agency)

MDR-TB

Multiple drug-resistant form of Tuberculosis that is especially difficult to treat; results from incomplete or unsuccessful treatment of TB that allows the bacteria to mutate in ways that increase its resistant to drugs.

Medicaid

A medical assistance program funded by federal and state funds for low-income people; coverage of and payment for medical services are determined by individual states. Administered by the Centers for Medicare and Medicaid Services (CMS) of HHS.

Medicaid Spend-down

A process whereby an individual who meets the Medicaid medical eligibility criteria, but has income that exceeds the financial eligibility ceiling, may "spend down" to eligibility level. The individual accomplishes spend-down by deducting accrued medically related expenses from countable income. Most State Medicaid programs offer an optional category of eligibility, the "medically needy" eligibility category, for these individuals.

Medicare

A federally funded HHS/CMS administered program financing health care services for certain elderly people and people with disabilities (regardless of income and assets).

Migrant Health Centers

Federally-funded by HRSA's Bureau of Primary Health Care, centers provide a broad array of culturally and linguistically competent medical and support services to migrant and seasonal farmworkers (MSFW) and their families.

MAI (Minority AIDS Initiative)

A national HHS initiative that provides special resources to reduce the spread of HIV/AIDS and improve health outcomes for people living with HIV disease within communities of color. Enacted to address the disproportionate impact of the disease in such communities. Formerly referred to as the Congressional Black Caucus Initiative because of that body's leadership in its development.

Modes of Exposure

A grouping of disease exposure and infection routes; in relation to HIV disease, exposure groupings include, for example, men who have sex with men, injection drug use, heterosexual contact, and perinatal transmission.

Morbidity

The condition of being diseased or sick; also the incidence of disease or rate of sickness in a population.

Mortality

Death by disease; also the incidence or rate of death in a population.

MSM

Men Who Have Sex with Men.

Multiply Diagnosed

A person having multiple morbidities (e.g., substance abuse and HIV infection) (see co-morbidity).

Needs Assessment

A process of collecting information about the needs of PLWH (both those receiving care and those not in care), identifying current resources (CARE Act and other) available to meet those needs, and determining what gaps in care exist.

NIR

No Identified Risk; assigned when the actual exposure category cannot be determined.

NNRTI (Non-Nucleoside Reverse Transcriptase Inhibitor, or " non-nuke ")

A class of antiretroviral agents (e.g., delavirdine, nevirapine, efavirenz) that stops HIV production by binding directly onto an enzyme (reverse transcriptase) in a CD4+ cell and preventing the conversion of HIV's RNA to DNA.

Not In Care

An HIV positive person who is not currently receiving HIV-related services.

Nucleoside Analog (Nucleoside Analog Reverse Transcriptase Inhibitor, NRTI, or "nuke")

The first effective class of antiviral drugs (e.g., AZT or ZDV, ddI, ddC, d4T, ABC). NRTIs act by incorporating themselves into the HIV DNA, thereby stopping the building process. The resulting HIV DNA is incomplete and unable to create new virus.

OMB (Office of Management and Budget)

The office within the executive branch of the Federal government that prepares the President's annual budget, develops the Federal government's fiscal program, oversees administration of the budget, and reviews government regulations.

Opportunistic Infection (OI) or Opportunistic Condition

An infection or cancer that occurs in persons with weak immune systems due to HIV, cancer, or immunosuppressive drugs such as corticosteroids or chemotherapy. Kaposi's Sarcoma (KS), pneumocystis pneumonia (PCP), toxoplasmosis, and cytomegalovirus (CMV) are all examples of opportunistic infections.

OSE (Office of Science and Epidemiology)

The office within HRSA's HIV/AIDS Bureau that administers the SPNS Program, HIV/AIDS evaluation studies, and the Cross-Title Data Report Form.

PACTG (Pediatric AIDS Clinical Trials Group)

Body that evaluates treatments for HIV-infected children and adolescents and develops new approaches for the interruption of mother-to-infant transmission.

Part F

The part of the CARE Act that includes the AETC Program, the SPNS Program, and the HIV/AIDS Dental Reimbursement Program.

PCR (Polymerase Chain Reaction)

A laboratory process that selects a DNA segment from a mixture of DNA chains and rapidly replicates it to create a sample of a piece of DNA. For HIV, this is called RT-PCR, which is a laboratory technique that can detect and quantify the amount of HIV (viral load) in a person's blood or lymph nodes. PCR is also used for the diagnosis of HIV infection in exposed infants.

Phenotypic Assay

A procedure whereby sample DNA of a patient's HIV is tested against various antiretroviral drugs to see if the virus is susceptible or resistant to these drug(s).

PHS (Public Health Service)

An administrative entity of the U.S. Department of Health and Human Services.

Planning Council

A planning body appointed or established by the Chief Elected Official of an EMA whose basic function is to assess needs, establish a plan for the delivery of HIV care in the EMA, and establish priorities for the use of Title I CARE Act funds.

Planning Process

Steps taken and methods used to collect information, analyze and interpret it, set priorities, and prepare a plan for rational decision making.

PLWH (People Living with HIV Disease)

Poppers

Slang for Amyl Nitrite or other chemically similar drugs that cause the blood vessels to open wider; nitrite drugs can be inhaled from little glass capsules that break open with a pop, thus the term “poppers.”

Prevalence

The total number of persons in a defined population living with a specific disease or condition at a given time (compared to incidence, which is the number of new cases).

Prevalence Rate

The proportion of a population living at a given time with a condition or disease (compared to the incidence rate, which refers to new cases).

Priority Setting

The process used to establish priorities among service categories, to ensure consistency with locally identified needs, and to address how best to meet each priority.

Prophylaxis

Treatment to prevent the onset of a particular disease (primary prophylaxis) or recurrence of symptoms in an existing infection that has previously been brought under control (secondary prophylaxis).

Protease

An enzyme that triggers the breakdown of proteins. HIV's protease enzyme breaks apart long strands of viral protein into separate proteins constituting the viral core and the enzymes it contains. HIV protease acts as new virus particles are budding off a cell membrane.

Protease Inhibitor

A drug that binds to and blocks HIV protease from working, thus preventing the production of new functional viral particles.

Quality

The degree to which a health or social service meets or exceeds established professional standards and user expectations.

QA (Quality Assurance)

The process of identifying problems in service delivery, designing activities to overcome these problems, and following up to ensure that no new problems have developed and that corrective actions have been effective. The emphasis is on meeting minimum standards of care.

QI (Quality Improvement)

Also called Continuous Quality Improvement (CQI). An ongoing process of monitoring and evaluating activities and outcomes in order to continuously improve service delivery. CQI seeks to prevent problems and to maximize the quality of care.

Reflectiveness

The extent to which the demographics of the planning body's membership look like the demographics of the epidemic in the service area.

Reliability

The consistency of a measure or question in obtaining very similar or identical results when used repeatedly; for example, if you repeated a blood test three times on the same blood sample, it would be reliable if it generated the same results each time.

Representative

Term used to indicate that a sample is similar to the population from which it was drawn, and therefore can be used to make inferences about that population.

RFP (Request for Proposals)

An open and competitive process for selecting providers of services (sometimes called RFA or Request for Application).

Resource Allocation

The Title I planning council responsibility to assign CARE Act amounts or percentages to established priorities across specific service categories, geographic areas, populations, or subpopulations.

Retrovirus

A type of virus that, when not infecting a cell, stores its genetic information on a single-stranded RNA molecule instead of the more usual double-stranded DNA. HIV is an example of a retrovirus. After a retrovirus penetrates a cell, it constructs a DNA version of its genes using a special enzyme, reverse transcriptase. This DNA then becomes part of the cell's genetic material.

Reverse Transcriptase

A uniquely viral enzyme that constructs DNA from an RNA template, which is an essential step in the life cycle of a retrovirus such as HIV. The RNA-based genes of HIV and other retroviruses must be converted to DNA if they are to integrate into the cellular genome. (See Retrovirus.)

Ricky Ray Hemophilia Relief Fund

A program administered by HHS/HRSA providing compassionate payments of \$100,000 to individuals with a blood-clotting disorder, such as hemophilia, who contracted HIV from contaminated antihemophilic factor between July 1, 1982 and December 31, 1987.

Risk Factor or Risk Behavior

Behavior or other factor that places a person at risk for disease; for HIV/AIDS, this includes such factors as male-to-male sexual contact, injection drug use, and commercial sex work.

RT-PCR (Reverse Transcriptase Polymerase Chain Reaction)

A laboratory technique that can detect and quantify the amount of HIV (viral load) in a person's blood or lymph nodes.

Salvage Therapy

A treatment effort for people who are not responding to, or cannot tolerate the preferred, recommended treatments for a particular condition. In the context of HIV infection, drug treatments that are used or studied in individuals who have failed one or more HIV drug regimens. In this case, failed refers to the inability to achieve or sustain low viral load levels.

SAMHSA (Substance Abuse and Mental Health Services Administration)

Federal agency within HHS that administers programs in substance abuse and mental health.

SCSN (Statewide Coordinated Statement of Need)

A written statement of need for the entire State developed through a process designed to collaboratively identify significant HIV issues and maximize CARE Act program coordination. The SCSN process is convened by the Title II grantee, with equal responsibility and input by all programs.

Section 340B Drug Discount Program

A program administered by the HRSA's Bureau of Primary Care, Office of Pharmacy Affairs established by Section 340B of the Veteran's Health Care Act of 1992, which limits the cost of drugs to Federal purchasers and to certain grantees of Federal agencies.

Seroconversion

The development of detectable antibodies to HIV in the blood as a result of infection. It normally takes several weeks to several months for antibodies to the virus to develop after HIV transmission. When antibodies to HIV appear in the blood, a person will test positive in the standard ELISA test for HIV.

Seroprevalence

The number of persons in a defined population who test HIV-positive based on HIV testing of blood specimens. (Seroprevalence is often presented either as a percent of the total specimens tested or as a rate per 100,000 persons tested.)

Service Gaps

All the service needs of all PLWH except for the need for primary health care for individuals who know their status but are not in care. Service gaps include additional need for primary health care for those already receiving primary medical care ("in care").

Socio-demographic factors

Social issues and demographic qualities that impact on people.

SPNS (Special Projects of National Significance)

A health services demonstration, research, and evaluation program funded under Part F of the CARE Act to identify innovative models of HIV care. SPNS projects are awarded competitively.

SSI

Supplemental Security Income; the SSI program is administered by the federal government (SSA) and provides monthly income to people who have limited income and are either 65 or older or are blind or disabled.

SSDI

Social Security Disability Insurance; a program administered by the Social Security Administration (SSA) to provide cash assistance to certain people who have paid into the Social Security Trust Fund and are unable to work because of a disability.

STD

Sexually Transmitted Diseases

Substance Abuse

A clinical diagnosis that substance use has become a recurrent activity that results in (1) failure to fulfill major role obligations in one's life, (2) placing self or others in hazardous situations, (3) legal problems, or (4) persistent or recurrent or recurrent social or relationship problems.

Substance Use

Any occasional use of a psychoactive substance, including alcohol, that results in an acute (short-term) or chronic (long-term) effect on mood, cognition, and/or behavior.

Symptomatic

Changes in the body or its functions that indicate disease or phases of disease as diagnosed by a clinician.

Syphilis

Primarily a sexual transmitted disease resulting from infection with the spirochete (a bacterium), *Treponema Pallidum*; if left untreated it can cause serious damage to internal organs and death.

Surveillance

An ongoing, systematic process of collecting, analyzing and using data on specific health conditions and diseases (e.g., Centers for Disease Control and Prevention surveillance system for AIDS cases).

Surveillance Report

A report providing information on the number of reported cases of a disease such as AIDS, nationally and for specific sub-populations.

TA (Technical Assistance)

The delivery of practical program and technical support to the CARE Act community. TA is to assist grantees, planning bodies, and affected communities in designing, implementing, and evaluating CARE Act-supported planning and primary care service delivery systems.

Target Population

A population to be reached through some action or intervention; may refer to groups with specific demographic or geographic characteristics.

TB

Tuberculosis, a highly contagious bacterial infection caused by *Mycobacterium Tuberculosis*.

Title I

The part of the CARE Act that provides emergency assistance to localities (EMAs) disproportionately affected by the HIV/AIDS epidemic.

Title II

The part of the CARE Act that provides funds to States and territories for primary health care (including HIV treatments through the AIDS Drug Assistance Program, ADAP) and support services that enhance access to care to PLWH and their families.

Title III

The part of the CARE Act that supports outpatient primary medical care and early intervention services to PLWH through grants to public and private non-profit organizations. Title III also funds capacity development and planning grants to prepare programs to provide EIS services.

Title IV

The part of the CARE Act that supports coordinated services and access to research for children, youth, and women with HIV disease and their families.

Unmet Need

The unmet need for primary health services among individuals who know their HIV status but are not receiving primary health care.

VA

The Veteran's Agency is a government agency, which, along with the Department of Defense (DOD), provides health care services to service members and veterans of the U.S. uniformed services and their dependents. The VA and DOD also engage in HIV/AIDS

prevention and research.

Viral Load

In relation to HIV, the quantity of HIV RNA in the blood. Viral load is used as a predictor of disease progression. Viral load test results are expressed as the number of copies per milliliter of blood plasma.

Viremia

The presence of virus in blood or blood plasma. Plasma viremia is a quantitative measurement of HIV levels similar to viral load but is accomplished by seeing how much of a patient's plasma is required to spark an HIV infection in a laboratory cell culture.

VOE

Voices of Experience study conducted by Suffolk University to understand the issues and needs of HIV-positive people living in the EMA.

Western Blot

A test for detecting the specific antibodies to HIV in a person's blood. It is commonly used to verify positive EIA tests. A Western Blot test is more reliable than the EIA, but it is more difficult and more costly to perform. All positive HIV antibody tests should be confirmed with a Western Blot test.

Wild Type Virus

HIV that has not been exposed to antiviral drugs and therefore has not accumulated mutations conferring drug resistance.

Many of the medical terms included in this glossary were drawn from the glossary of "Treatment Issues", a publication of Gay Men's Health Crisis, Dave Gilden, Editor.