

Assessment of Need

Among People Living with HIV in the Boston EMA

Planning Council

2010



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Acronyms

ADAP	AIDS Drug Assistance Program
AETC	AIDS Education and Training Centers
AHC	AIDS Housing Corporation
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ASO	AIDS Service Organization
BPHC	Boston Public Health Commission
BSAS	Bureau of Substance Abuse Services
EMA	Eligible Metropolitan Area
CDC	Centers for Disease Control & Prevention
EIS	Early Intervention Services
FY	Fiscal Year
IDU	Injection Drug User
HAART	Highly Active Antiretroviral Therapy
HARS	HIV/AIDS Reporting System
HBV	Hepatitis B Virus
HCV	Hepatitis C Virus
HDAP	HIV/AIDS Drug Assistance Program
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for People With AIDS
HUD	Housing and Urban Development
JSI	John Snow, Inc Research and Training Institute
LGBT	Lesbian, Gay, Bisexual, Transgender
PLWH	People Living With HIV
MAI	Minority AIDS Initiative
NH	New Hampshire
NHDHHS	New Hampshire Department of Health & Human Services
MA	Massachusetts
MDPH	Massachusetts Department of Public Health
MSM	Men who have Sex with Men
MTF	Male to Female
PCP	Pneumocystis Prophylaxis
PCS	Planning Council Support
RFP	Request for Proposals
SAMHSA	Substance Abuse and Mental Health Services Administration
SPNS	Special Program of National Significance
STD/STI	Sexually Transmitted Disease/Infection
VOE	Voices of Experience (Needs Assessment/conducted in 1993)

Introduction

The 2010 Needs Assessment is intended to identify the potential service needs and services available to people living with HIV (PLWH) in the Boston Eligible Metropolitan Area (EMA); to examine the capacity of the current service system and the resources available; to assess whether resources are being expended to populations most in need and to emerging populations; and whether PLWH can effectively obtain and maintain HIV health and health-related services in the EMA.

Objective

To provide information on the HIV service system in the Boston EMA, so the Planning Council may make informed decisions related to the prioritization of Ryan White Part A service categories and the Ryan White Part A funding allocations process.

Methods

This Needs Assessment was conducted in several steps. A picture of the HIV epidemic was drawn using surveillance data from Massachusetts (MA), New Hampshire (NH), the Centers for Disease Control and Prevention (CDC), and United States census data. Prevalence and incidence data was used to note trends in the local epidemic, and to identify emerging populations infected and affected by HIV/AIDS over time. Demographic factors such as race, gender, age, and mode of transmission were cross-referenced with payer-provided utilization data and examined to determine if all populations affected were accessing a full range of services.

Provider capacity to serve all PLWH in the Boston EMA was estimated using both consumer and provider-completed surveys. Furthermore, a literature review on HIV-related articles was conducted, and included Part A funded Quality Management and Evaluation reports, in addition to other documents published by the Massachusetts Department of Public Health (MDPH) and other payers in the Boston EMA. The literature review estimated barriers to accessing primary medical care services by examining consumer access to needed services, poverty and insurance, housing, and homelessness.

Limitations

Need assessment reports provide the basis for important decisions, taking into account payer, provider, and consumer perspectives. Relying solely on data from some groups and not others introduces bias to this type of report. This Needs Assessment contains the most recent input available from each of these groups. The validity of this Needs Assessment is weakened by comparing different demographic, funding, utilization, outcomes, and survey information from different years, which include variation in service definitions and demographics from year to year. To mitigate these limitations in the future, additional provider and consumer based input will be collected. Additionally, efforts are being made to encourage all payers and providers to create universal standards for data collection, which would allow cross referencing of data.

Executive Summary

Every two years, an assessment of need among PLWH is conducted within the EMA. This document is produced by the Boston EMA HIV Health Services Planning Council, with assistance from Planning Council Support (PCS), to be an unbiased review of the needs of PLWH and how well these needs are being met. The key components of this review include the HIV/AIDS epidemiological profile of the Boston EMA, a description of the available service resources and their funding streams, and a summary of the barriers to care faced by PLWH in the Boston EMA. These elements paint a picture of the health of the HIV care system, and provide insight on areas of unmet need and barriers to PLWH receiving primary medical care. The conclusions and recommendations that come from this review are used by members of the Planning Council to set service priorities and make funding decisions.

Section I of this Needs Assessment describes the HIV/AIDS epidemiologic profile of the Boston EMA. Within the seven Massachusetts and three New Hampshire counties that make up the Boston EMA, as of December 31, 2008, there were 14,963 PLWH, of which 6,191 of them accessed the Part A system of care in FY08. As of December 31, 2008 the AIDS incidence rate is 10.6 cases per 100,000 individuals. In the two years proceeding December 31, 2008, 622 new AIDS cases and 977 new cases of HIV were reported. In terms of local demographics, the population of the Boston EMA as a whole is disproportionately White (80%) compared to the national population (66%), but Suffolk County (where the City of Boston is located) is more diverse (53% White). With that in mind, HIV/AIDS does not affect all segments of the population equally. People of color, particularly Black and Hispanic groups, are disproportionately affected and infected by HIV. Blacks and Hispanics account for 30% and 21% respectively of HIV/AIDS cases even though they represent 6% and 8% of the population. There are also differences by gender, where women (especially women of color) compose an increasing proportion of PLWH. At <1% of the client base, transgender persons are also affected. Age plays a factor as well; while youth aged 13-19 account for only 1% of PLWH, it is believed that many adult cases can be attributed to risk factors from their youth. The predominant mode of transmission among youths, men who have sex with men (MSM), is also the most prevalent transmission mode (42% of HIV/AIDS cases) among adults. Heterosexual contact and intravenous drug use (IDU) are the two other predominant modes of transmission accounting for 29% and 18% of HIV/AIDS cases respectively.

Section II of the Needs Assessment estimates the total unmet need of PLWH in the Boston EMA. An individual is considered to have unmet need if he/she did not receive a viral load test, a CD4 count, or antiretroviral drugs within a defined 12-month period. Of the 14,963 PLWH in the Boston EMA, an estimated 11.6% (1,736 PLWH) are not accessing primary medical care. This number represents only part of the unmet need within the EMA. Many more individuals may be only partially in care and not accessing the full range of services available to them, particularly vulnerable populations; including Blacks, Hispanics, women, and the uninsured. In FY07, JSI conducted a satisfaction survey of Part A consumers receiving case management, food, and/or peer support services. One goal of this survey was to examine the impact of support services on maintenance of primary medical care, and thereby their role in reducing unmet need among PLWH. The survey found that 84% of case management clients, 79% of food clients, and 78% of peer support clients consider these services extremely or very important in helping them keep regular primary medical care appointments. Since higher CD4 counts, lower viral loads and improved adherence to antiretroviral regimens are reported when consumers have access to primary care services, it is important this unmet need is addressed.

Section III of the Needs Assessment describes the barriers that PLWH face in accessing resources in the Boston EMA, in addition to the co-morbidities that complicate a consumer's ability to stay in care. Part A funded services are part of a broad continuum of care that provides services to the range of PLWH in the Boston EMA. However, over 11% of PLWH in the Boston EMA are not accessing services, which stresses the importance of understanding why consumers are not in care in order to reduce or eliminate those barriers. Socio-demographic factors impact the complexity of providing care. For example, youth lack the autonomy and resources of adults, and often do not access care until a late stage of the disease. Women are often more affected by federal funding and as primary caretakers may fear losing their children if they receive a mental health, substance abuse or HIV diagnosis. Transgender populations face stigma, discrimination and report a lack of culturally appropriate care and sensitivity on the part of providers. Insurance coverage is closely tied to poverty status, and in turn affects, access to care. With over 90% of Part A clients falling below 300% of the Federal Poverty Level (FPL), income is a major factor affecting PLWH access to care in the Boston EMA. Homelessness also limits access to medical care and therefore may delay a diagnosis of HIV and other co-morbidities. Homeless PLWH are also often affected by a higher prevalence of opportunistic infections. Substance abuse and mental illness complicate diagnosis, treatment and adherence. Hepatitis, as well as incarceration, has been shown to complicate treatment and access to care. Individually, these barriers may not prevent consumers from accessing or staying in care, but when multiple barriers or co-morbidities exist, the complexity of providing care and treatment increases dramatically.

Section IV outlines the EMA's continuum of care which is an effective and flexible service system that spans prevention efforts, early intervention services, medical care, and health-related support services. Through the efforts of the HIV Services Planning Council and the BPHC HIV/AIDS Services Division (Grantee), Part A plays a leadership role in the development and maintenance of a comprehensive continuum of HIV treatment, care, and services in the region. The continuum of care is supported by a variety of funding streams including: CDC, MA and NH state general funds, City of Boston, Ryan White Parts A, B, C, D, Dental Reimbursement, SPNS programs, Minority AIDS Initiative funds, HOPWA housing funds, and Medicaid.

Section V of the Needs Assessment focuses on the resources available to PLWH in the Boston EMA. The Boston EMA is host to many services designed for those living with, or affected by HIV including: primary medical care and ob/gyn services, drug reimbursement, substance abuse services, transportation, case management, mental health services, housing, food and nutritional support, client advocacy, peer support, and HIV/AIDS prevention. These services are funded by a variety of payers including: Massachusetts and New Hampshire state and federal Medicaid, MA and NH substance abuse programs, private insurance plans, the national Medicare program, Massachusetts and New Hampshire State Budget AIDS line items, Housing Opportunities for People with AIDS (HOPWA) through the US Department of Housing and Urban Development (HUD), and Federal Ryan White funds through Parts A, B, C, D, and F. In FY08, Part A filled the gaps in services to critically underserved population, accounting for 5% of available funding within the Boston EMA and serving 6,191 consumers. In contrast, it is estimated that 63% of funds for HIV/AIDS services come from Medicaid programs, 12% from the MA state line item, and 7% from MA Part B. All other payers contribute between 1% and 4% to the HIV-health service system in the Boston EMA.

In summary, this document is designed to discuss the total state of the HIV/AIDS epidemic in the Boston EMA. Starting with a discussion of the face of the local consumer, the Needs Assessment moves on to discuss available services followed by an evaluation of the available services to fulfill the needs of all PLWH in the Boston EMA. Reasons why consumers do not access health and health-related services are provided, in addition to a discussion of the unmet need of PLWH in the Boston EMA.

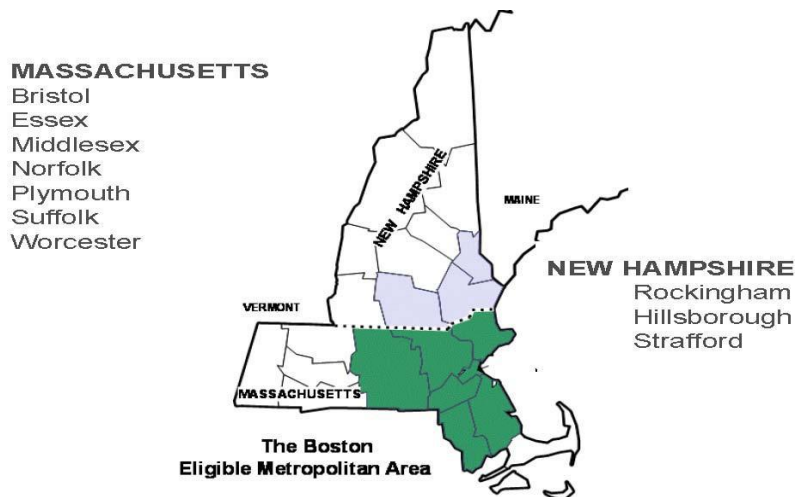
Section I: Epidemiology of HIV/AIDS in the Boston EMA

This section provides information on the incidence and prevalence of HIV and AIDS within the Boston Eligible Metropolitan Area (EMA). In particular, it looks at a number of factors including location, race and ethnicity, gender, age, and mode of exposure.

Overview

An EMA is a geographic area that is highly impacted by HIV/AIDS, and is therefore eligible to receive Ryan White Part A funds. The Boston EMA makes up a ten County region in MA and NH. Figure 1, below, shows the area in further detail.

Figure 1: The Boston Part A Eligible Metropolitan Area (EMA)



The race and ethnicity of the EMA varies, and this must be taken into account when determining the needs of the region. Based on the 2008 census estimates, the population of the Boston EMA is disproportionately White compared to the national population: 80% White (vs. 66% nationally), 5.5% Black (vs. 12% nationally), 7.7% Hispanic (vs. 15% nationally), 5.1% Asian/Pacific Islander (vs. 4.4% nationally), and 0.3% Native American (vs. 1.0%).¹ There are further variations in race/ethnicity when comparisons are made between the counties of the Boston EMA, particularly when looking at urban versus rural areas.

For example, 88% of Bristol County, MA is White compared to 53% of the White population of Suffolk County, MA (includes Boston). Considering minority discrepancies, 1% of the population in NH counties is Black compared to 20% of Suffolk County, MA; 3% of Norfolk County, MA is of Hispanic origin compared to 18% in Suffolk County; and 3% of the population in NH identify as Native American, Asian/Pacific Islander, or other, compared with 9% in Middlesex County, MA.¹ Table 1 demonstrates the demographics of the Boston EMA, MA, and NH.

Table 1: Demographics of the Boston EMA, Massachusetts, and New Hampshire

	EMA	MASSACHUSETTS	NEW HAMPSHIRE
Total Population	6,254,529	6,497,967	1,315,809
White, not Hispanic	80.0%	86.2%	95.5%
Black, not Hispanic	5.5%	7.0%	1.2%
Hispanic	7.7%	7.9%	2.6%
Asian/Pacific Islander	5.1%	5.0%	1.9%
Native American	0.3%	0.3%	0.3%

Source: www.quickfacts.census.gov/qfd/states/25/25005.html accessed 10/30/08

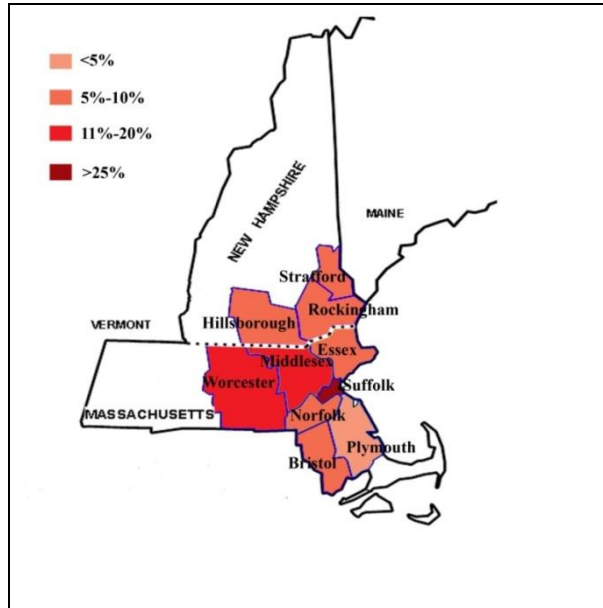
As of December 31, 2008, there were a reported 14,963 PLWH in the Boston EMA, an increase of 543 over the 14,420 cases reported as of December 31, 2007. Table 2 (below) illustrates the proportional representation of HIV/AIDS prevalence by county within the Boston EMA.^{2 3} The Centers for Disease Control and Prevention (CDC) estimates that 21% of PLWH are unaware of their status, and thus there may be an additional 1,767 unreported HIV cases in the EMA (6,647 HIV non-AIDS cases reported).⁴ Further, Figure 2 shows that the majority of HIV and AIDS cases in the Boston EMA are focused around urban centers, particularly in Suffolk, MA, which accounts for more than a third (37%) of all HIV/AIDS cases in the EMA.^{2 3}

Table 2: HIV/AIDS Epidemic in Boston EMA by County

County within the Boston EMA	Percentage of HIV/AIDS Cases in the Boston EMA as of 12/31/2008	Number of HIV/AIDS Cases in Boston EMA as of 12/31/2008
Suffolk, MA	37.8%	5,652
Middlesex, MA	19.2%	2,867
Worcester, MA	10.6%	1,590
Essex, MA	9.5%	1,423
Bristol, MA	7.3%	1,099
NH counties	5.9%	880
Norfolk, MA	5.2%	772
Plymouth, MA	4.5%	680

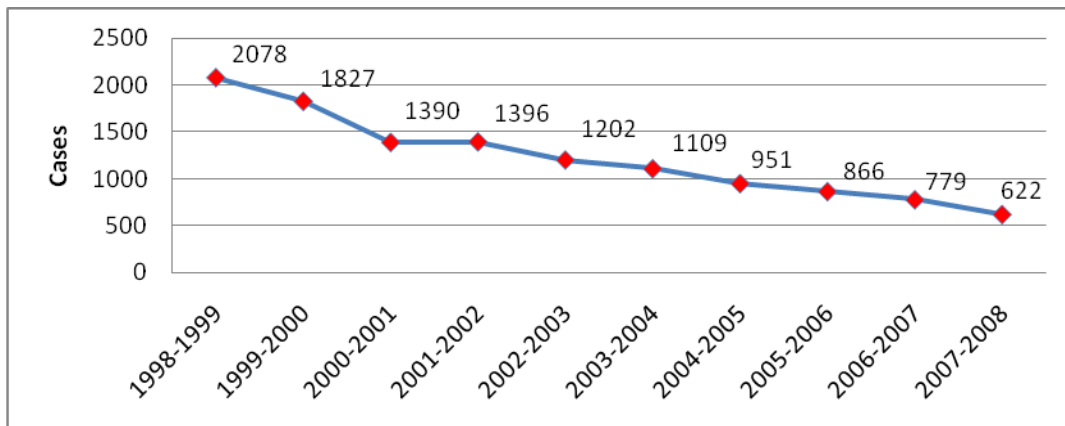
Source: MDPH; NHDHHS.

Figure 2: Percentage of HIV/AIDS Cases in the Boston EMA by County



Looking at the HIV epidemic in the Boston EMA over time, it is evident that AIDS incidence is on the decline. Figure 3 depicts this decline in AIDS incidence from 1999 through 2008. Between January 1, 2007 and December 31, 2008, the EMA had an AIDS incidence rate of 10.6 cases per 100,000 population; there were 622 new AIDS cases reported over the same period.^{1 2} During the past two years, 977 new HIV cases were reported, some of whom were also diagnosed with AIDS during this period. Fifty-three percent of these new cases were reported among Blacks and Hispanics.^{1 2} Due to prolonged reporting delays resulting from changes to the MA HIV reporting regulations, 2007 and 2008 incidence data are considered preliminary and likely represent an undercount of true incidence.²

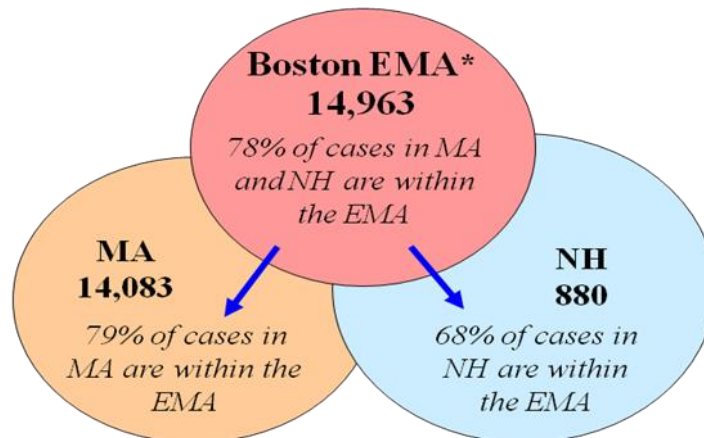
Figure 3: AIDS Incidence in the Boston EMA, 1999-2008



Source: MDPH; NHDHHS.

The Boston EMA accounts for the majority of HIV/AIDS cases in both states, 78% of the total reported number of living HIV/AIDS cases in both MA and NH live in the Boston EMA. The EMA's seven counties in MA represent 79% of the total reported HIV/AIDS cases in the Commonwealth of Massachusetts. The EMA's three counties in NH account for 68% of the total reported cases in NH.³ Figure 4, shows the distribution of cases across regions of the EMA.

Figure 4: HIV/AIDS Prevalence in the Boston EMA, MA, & NH

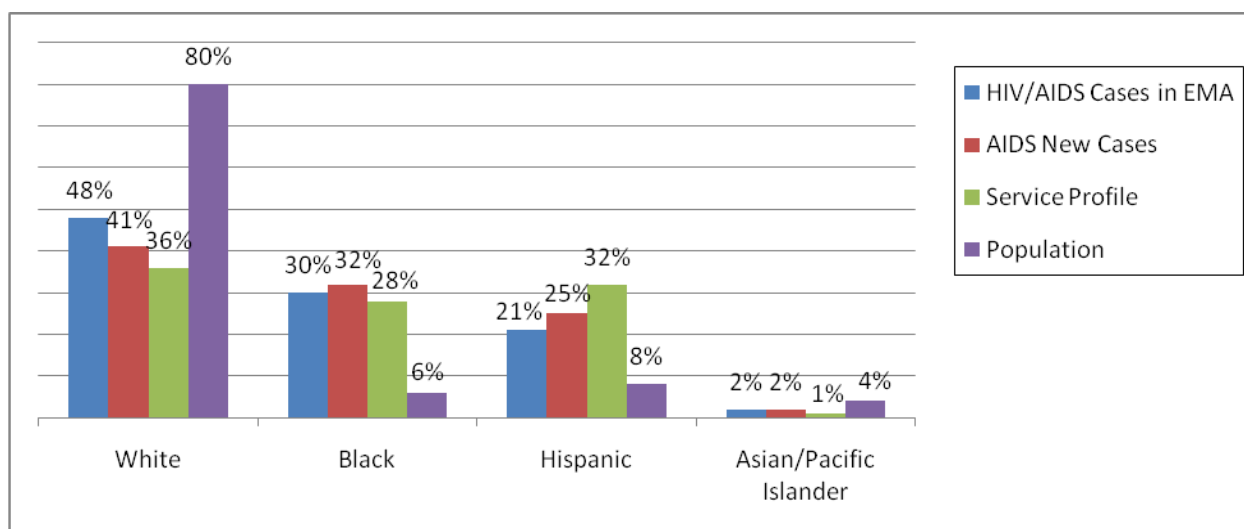


Demographic Groups

Race & Ethnicity

Among those with HIV/AIDS in the EMA, minorities are disproportionately represented. Blacks and Hispanics disproportionately account for a far greater number of cases than would be expected given their smaller share of the total population. In fact, Blacks account for 31% of the AIDS prevalence and 35% of the AIDS incidence yet they represent only 5.5% of the overall population.¹ Similarly, Hispanics account for 21% of the prevalent HIV/AIDS cases in the Boston EMA, yet they represent 7.7% of the EMA population.¹ Combined, in 2008, Blacks and Hispanics comprised 51% of the PLWH in the EMA, and only represent 13% of the population. The proportion of Blacks and Hispanics among new HIV cases increased in recent years (1999 to 2005) compared to the pre-1999 period. On the other hand, 80% of the Boston EMA population is White, yet Whites only account for 48% of the HIV/AIDS cases in the EMA.²

Figure 5: Boston EMA Service Profile by Race/Ethnicity (FY 2008)



Source: MDPH; NHDHHS; BPHC Year 18 Client Services Utilization Report.

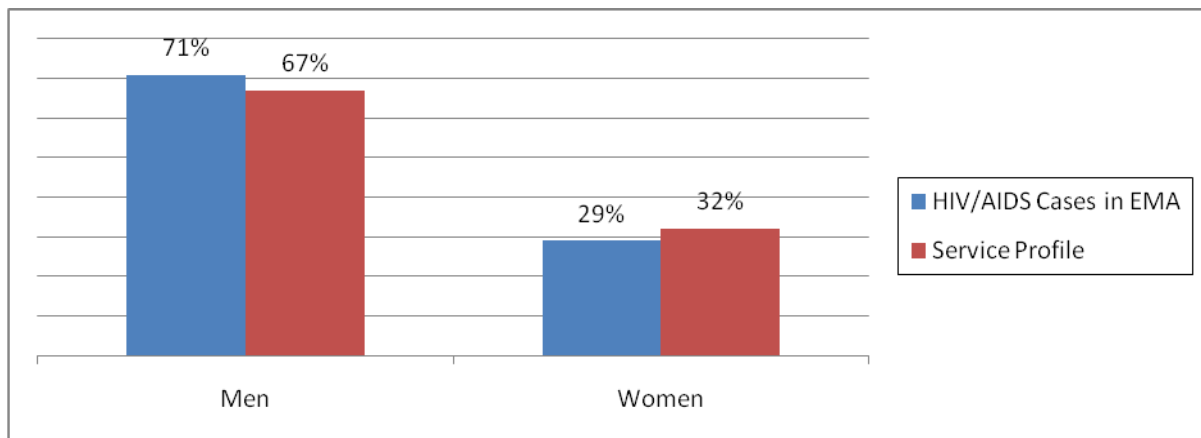
Gender

Males account for 71% of the EMA's reported HIV/AIDS cases compared to 73% of the national cases.⁴ Of male prevalent cases, 52% are attributed to men who have sex with men (MSM). The Massachusetts Department of Public Health reports that MSM are 11 to 25 times more likely to contract HIV than other men.⁶ The Metro Boston region of the EMA has more MSM living with HIV/AIDS than the rest of the regions combined. Across all regions of the EMA, the overwhelming majority of MSM living with HIV/AIDS are White.^{2,3} Among the men diagnosed in the EMA who attribute HIV/AIDS transmission to MSM contact, 26% are from communities of color.^{2,3} Hispanic and Black MSM living with AIDS in the EMA are somewhat younger than White MSM living with AIDS, with 24% of Hispanic and Black MSM living with AIDS under the age of 40 (compared to 15% of White MSM).^{2,3} The percentage of men who acquired HIV/AIDS through reported heterosexual sex (including presumed heterosexual) has increased over time,

and of these men, 51% are Black.^{2 3} Among injection drug users (IDUs) living with AIDS in the EMA, 66% are male.^{2 3}

The number of new HIV/AIDS cases among women in the EMA has also increased over time. Thirty-three percent of the incident AIDS cases and 28% of prevalent AIDS cases in the EMA are women, compared to 23% of the prevalent national cases. The percentages of HIV-infected women of color in the EMA are disproportionately high compared to their representation in the general population. Much of this increase among women of color has particularly affected Black women, representing more of the new HIV cases for females in 2006 than in 1999.⁷ In the Boston EMA, Black women account for 45% of living HIV/AIDS cases among women, while Hispanic women account for 23%. Approximately 60% of AIDS cases among women are related to IDU, either due to a personal history of IDU or that of a sexual partner.² The mode of exposure for reported cases of HIV/AIDS among women differs by race and ethnicity. White women are almost four times as likely as Black and Hispanic women combined to be infected through IDU. The principle mode of transmission for Hispanic women is heterosexual sex (44%, with an additional 21% presumed heterosexual transmission).² Likewise, 31% of cases among Black women were classified as heterosexual transmission (43% presumed heterosexual transmission).²

Figure 6: Boston EMA Service Profile by Gender (as of 12/31/08)



Source: MDPH; NHDHHS; BPHC Year 18 Client Services Utilization Report.

Transgender

Estimated HIV infection rates among specific transgender populations range from 14%-69% nationally. The highest prevalence may be among male-to-female (MTF) transgender sex workers.⁸ The Boston EMA Part A Client Utilization data estimates that 23 transgender individuals received Part A services in FY08, equaling 0.4% of the total client base.⁹

Age

Trends in HIV/AIDS prevalence show that an increasing percentage of PLWH are in the 45+ age group. In 2001, the 20-44 age group comprised the majority of HIV/AIDS prevalence in the

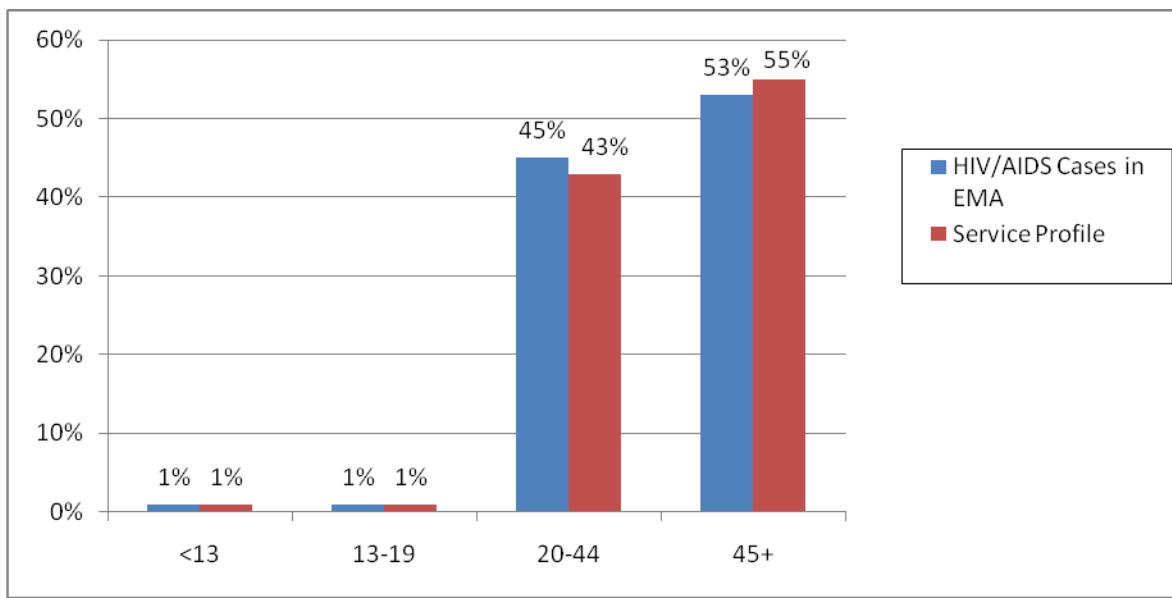
Boston EMA. However, in 2008, more than half (56%) of HIV/AIDS cases in the Boston EMA were among the 45+ age group.^{2,3} This increase of HIV/AIDS cases in the 45+ age group is partly due to the vast increases in survival time among PLWH after the advent of highly active antiretroviral therapies (HAART). Figure 7 shows the number of HIV/AIDS cases in 2008 for different age groups in the Boston EMA.

Trends in AIDS incidence also show that the 45+ age group make up an increasing percentage of the new AIDS diagnoses in the Boston EMA. Between 1999 and 2008, the number of people in the 45+ age group who were newly diagnosed with AIDS increased from 24% to 36%.^{2,3} In contrast, the number of people in the 20-44 age group who were newly diagnosed with AIDS decreased from 75% to 62%.^{2,3}

As of December 31, 2008, there was a total of 425 youth aged 13-24 living with HIV/AIDS in the Boston EMA. Additionally, given the incubation period from initial infection to AIDS diagnosis, many cases diagnosed among adults are the result of behaviors engaged in during adolescence.⁴

Surveillance data show that a disproportionate number of youth are being diagnosed with HIV/AIDS in the Boston EMA through MSM transmission.⁵ Of the 425 HIV/AIDS cases among youth aged 13-24 in the Boston EMA, 20% (84 cases) were among MSM 13-24 years old, and 18% were attributed to heterosexual (37 cases) and presumed heterosexual (38 cases) transmission.^{2,3}

Figure 7: Boston EMA Service Profile by Age (as of 12/31/08)



Source: MDPH; NHDHHS; BPHC Year 18 Client Services Utilization Report.

Mode of Exposure

Injection Drug Use (IDU)

Injection drug users accounted for 15% of the new AIDS cases reported during the last two years, a large decrease from 35% in 2003-2004.^{2,3} Men account for the majority (62%) of PLWH with transmission attributed to IDU, while women account for 38% of IDU cases.^{2,3} People of color are disproportionately represented among cases associated with IDU; Blacks and Hispanics combined account for 56% of living HIV/AIDS cases attributed to IDU.^{2,3} Among IDU HIV/AIDS cases in the Boston EMA and within each racial/ethnic group, men consistently comprise a greater proportion of cases. This fact is most dramatic among Hispanics, where men account for almost three times the number of IDU HIV/AIDS cases than women.^{3,5} In the Central and Northeast regions of the EMA, Hispanic men comprise the single greatest number of IDU AIDS cases. However, there are a higher proportion of White and Black women injection drug users with AIDS in most regions of the EMA, than among Hispanic injection drug users. White men account for the largest number of IDU AIDS cases in the Southeast and Metro West regions of the EMA. Black men account for the greatest number of IDU AIDS cases in the central Boston region. Table 3 demonstrates the percentage of HIV/AIDS cases by mode of transmission for each county in the Boston EMA.

Table 3: Percentage of HIV/AIDS Cases by Mode of Transmission as of 12/31/ 2008

Primary Reported Mode of Exposure	County in MA							NH	BOSTON EMA
	BRISTOL	ESSEX	MIDDLESEX	NORFOLK	PLYMOUTH	SUFFOLK	WORCESTER		
MSM	23%	29%	36%	40%	27%	46%	22%	42%	37%
IDU	38%	24%	16%	16%	21%	16%	34%	18%	21%
MSM/IDU	3%	3%	3%	3%	2%	4%	3%	5%	3%
Heterosexual	19%	16%	13%	12%	16%	12%	18%	19% **	14%
Presumed Heterosexual	9%	17%	22%	14%	21%	15%	17%	N/A *	16%
Pediatric	2%	2%	2%	3%	3%	2%	2%	1%	2%
Other	1%	1%	1%	1%	1%	1%	1%	2%	1%
Unknown	5%	9%	8%	12%	9%	6%	5%	13%	7%

*NH aggregates presumed heterosexual contact with heterosexual contact.

**Includes presumed heterosexual

Source: MDPH; NHDHHS

Men who Have Sex with Men (MSM)

Within the Boston EMA, the MSM population continues to be deeply affected by the HIV/AIDS epidemic. According to MDPH, recent years have shown a rise of MSM in the HIV population. Among all males in MA diagnosed with HIV between 2004-2006, MSM constitutes over 50% of the newly reported cases.⁶ There was also found to be an inequitable rate of infection that is up to 25 times higher for MSM than for men who report only having had sex with women.⁶ Furthermore, in MA HIV/AIDS disproportionately affects MSM; as 4-9% of men (18-64 yrs) report having had sex with men in the past 12 months; yet, MSM accounts for 39% of the HIV population in MA.⁶

The White MSM community was the first and most profoundly affected by the emergence of the HIV/AIDS, 72% of MSM are white, reflecting the demographics of the EMA. MSM continues to be a major mode of transmission for HIV/AIDS in the Boston EMA, accounting for 36% of those living with AIDS, 44% of those living with HIV, and 40% of those living with HIV/AIDS as of December 31, 2008 (including IDU/MSM).^{2,3}

Hispanic and Black MSM living with AIDS in the EMA are somewhat younger than White MSM living with AIDS, with about a quarter of Hispanic and Black MSM living with AIDS under the age of 40.^{2,3} Across all regions of the EMA, the overwhelming majority of MSM living with HIV/AIDS are White; although 27% of the men who attribute HIV/AIDS transmission to MSM contact are from communities of color.^{2,3}

Heterosexual

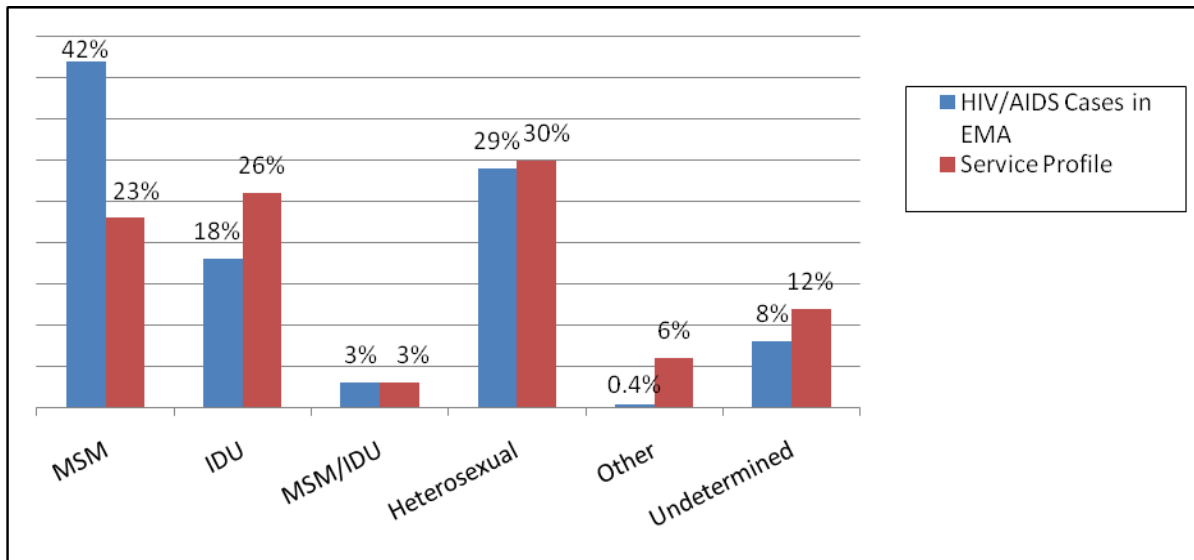
As of December 31, 2008, heterosexual transmission accounts for 36% of new AIDS cases with in the EMA.^{2,3} Today, this percentage exceeds the AIDS incidence rates of all other modes of exposure within in EMA, including, IDU (15%) and MSM (31%).^{2,3} Considering both HIV and AIDS cases, 29% of all PLWH in the EMA were infected via heterosexual transmission (see Figure 8).

Nationally, heterosexual transmission is becoming increasingly prevalent among women of color; making HIV the leading cause of death among black women ages 25-44.¹⁰ The principle mode of transmission for Hispanic women in the Boston EMA is heterosexual sex (44%, with an additional 21% presumed heterosexual transmission). Likewise, 31% of cases in the Boston EMA among Black women were classified as heterosexual transmission (43% presumed heterosexual transmission).^{2,3}

Pediatric

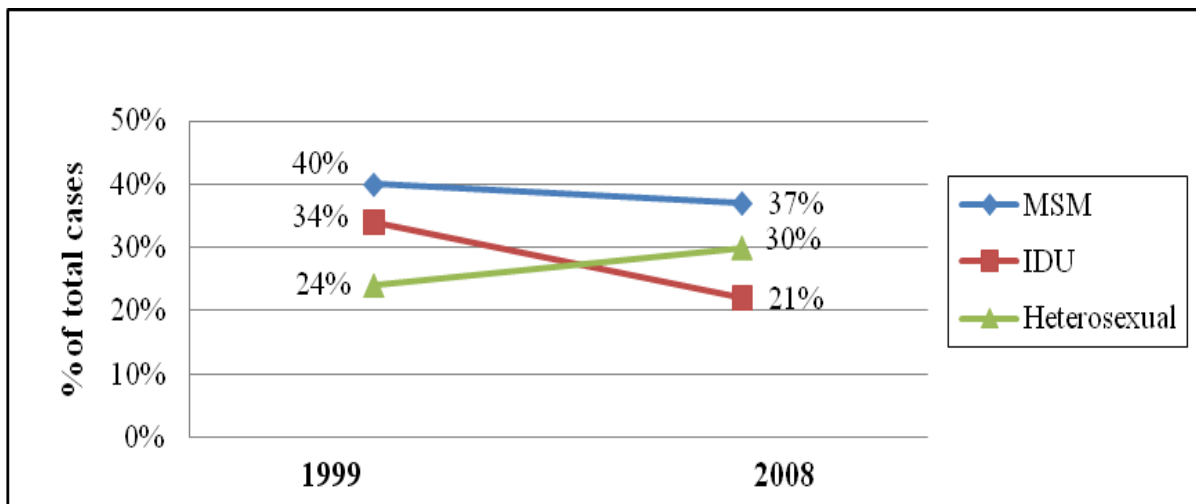
There were 12 new AIDS cases reported in children (<20 years) between January 1, 2007 and December 31, 2008.^{2,3} The changing epidemic in the EMA and preventative measures account for the low numbers of transmission to children.

Figure 8: Boston EMA Service Profile by Mode of Transmission (as of 12/31/2008)



Source: MDPH; NHDHHS; BPHC Year 18 Client Services Utilization Report.

Figure 9: HIV/AIDS Percentage of Cases by Transmission Mode, 1999-2008



Source: MDPH; NHDHHS

Conclusions

In summary, the epidemiological profile of HIV/AIDS in the Part A Boston EMA demonstrates the following changes: 1) continued increases in HIV/AIDS cases across all regions of the EMA; 2) a decrease in HIV/AIDS cases attributed to IDU; 3) an increase in cases attributed to heterosexual sex; and 4) the continued trend of greater representation of women among prevalent cases, reflecting increasing numbers of women who were infected with HIV through sexual contact, principally by IDU partners, and who are now progressing to AIDS. Among racial and ethnic minorities, there continues to be a disproportionate number of Black and Hispanic HIV/AIDS cases relative to their population numbers in the EMA. Of particular note, Blacks and Hispanics make up more than half of HIV/AIDS cases attributable to IDU, and both Black men and women are disproportionately represented among heterosexual cases, which are on the rise. Additionally, AIDS prevalence data shows an aging of the population with a continued increase in the proportion of cases aged 45+.

Section II: Unmet Need

This section will examine the unmet need framework of the Boston EMA, and those PLWH in care compared to those not in care.

The Ryan White Act is a significant funder of health care, medications, and support services for PLWH in the Boston EMA, most of whom are low-income, uninsured, or underinsured. As a result, the Ryan White Act has greatly expanded access to 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 the system of care. A study conducted by the CDC estimates that approximately one third of all PLWH 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.²² These data are especially troubling, given treatment guidelines that recommend 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, now called Part A. 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, and service gaps) 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.

Individuals who are HIV+ may not access available services for several reasons. Some people may not know they are infected. Others may know, but choose not to access services; or they may not know the importance of accessing services while being asymptomatic. Some who know their status 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+ may move in and out of care, depending on the severity of their disease or symptoms and other factors.

Unmet Need Framework

The Grantee has implemented the Health Resources and Services Administration's (HRSA) Unmet Need Framework within the Boston EMA and the overlapping Part B regions of MA and NH. Efforts have recently expanded to incorporate multiple sources of care pattern data, allowing the Grantee and the Council to utilize estimates with increased reliability. Surveillance data indicates that the total number of AIDS cases in the EMA as of December 31, 2008 was 8,316 cases^{3,7}. The total number of HIV cases (aware, non-AIDS) was 6,647. Out of these, 7,359 PLWH and 5,868 PLWH (non-AIDS) received HIV primary medical care during the specified period whereas 957 PLWH and 779 PLWH (non-AIDS) had an unmet need for primary care.²³ Of the combined AIDS and HIV (aware, non-AIDS) cases in the EMA, 1,736 (11.6%)

were not in care during this period.²³ Massachusetts and NH estimates were calculated separately and combined to arrive at the unmet need estimate for the entire EMA.

The Grantee collaborates with MDPH in contracting with John Snow, Inc Research and Training Institute (JSI) to estimate the unmet need for HIV primary care among PLWH who are aware of their status in the Boston EMA. An individual is considered to have unmet need if he/she did not receive one of the following within a defined 12-month time period: 1) a viral load test, 2) a CD4 count, or 3) antiretroviral drugs JSI followed the unmet need framework set forth by HRSA due to the reliability of the framework and availability of multiple data sources. The framework estimates unmet need by calculating the difference between the total population of HIV-positive and aware individuals, and the total number of HIV-positive and aware people who are receiving care as defined above.²⁴

Specifically, JSI was able to utilize state surveillance data on PLWH along with data derived from a data sharing agreement between MDPH and the MA Office of Medicaid (MassHealth), yielding information on publicly funded patients living with HIV/AIDS to be used in the estimate. The MA Division of Health Care Finance and Policy provided hospitalization data in order to calculate the percentage of privately insured patients. In NH, the Department of Health and Human Services (DHHS) provides the Grantee with surveillance data. Estimates of unmet need in NH are prepared through a collaborative effort at the state level through the HIV/AIDS Reporting System (HARS).

In summary, the four main data sources utilized to calculate an unmet need of 11.6% in the Boston EMA for 2008 were: 1) surveillance data; 2) MA hospital discharge data; 3) MA Medicaid data; and 4) HARS data from NH.²³ Population estimates of the number of HIV/AIDS aware individuals were derived from MA and NH surveillance data as of December 31, 2008. Since care patterns may differ based on medical coverage, it was necessary to determine the number of PLWH who were covered by private versus public insurance. Thus, an inpatient discharge database was used with payer information to estimate the distribution of privately and publicly covered PLWH in the Boston EMA. It was estimated that 30% of PLWH in the Boston EMA were covered by private insurance and of this population, 4% had unmet need.²³ The privately insured population's unmet need estimate was derived from the chart review of a large multi-clinic practice. The total number of publicly insured HIV/AIDS aware individuals found to have unmet need was 12.7%.²³ This percentage was derived from MA Medicaid data. Unduplicated numbers of PLWH receiving primary care (based on CD4 count and viral load testing) in NH during calendar year 2006 were generated through a combination of NH CARE Program and HARS data.

The validity of the estimation depends on the accuracy of assumptions made, including the distribution and number of PLWH covered by public and private insurance, and generalizability of the respective unmet need estimates for privately insured PLWH (as represented by limited chart review data) and publicly insured PLWH (derived from Medicaid claims). Despite these potential limitations, the calculated unmet need of 11.6% was the best approximation given the information available at the time of the study.²⁴

Assessment of Unmet Need

Due to improved estimation methodology in recent years, the Grantee has the ability to stratify unmet need findings by gender, race, ethnicity, and diagnosis (HIV non-AIDS and AIDS). Findings from the 2006 analysis of unmet need in MA show that there is no statistically

significant difference in unmet need by any of these stratifications.²⁴ Males were found to have an estimated 9.8% unmet need, while females were found to have an estimated 10.6% unmet need. HIV non-AIDS and AIDS clients both were found to have 10.1% unmet need.²⁴ Findings also show no difference between race with 10.2% of both the White non-Hispanic and Black non-Hispanic populations not connected to medical care. Finally, Hispanics were found to have the lowest unmet need at 8.4%.²⁴ Using these stratified estimates can guide efforts to reach those not in care effectively.

The population of PLWH not accessing medical care is challenging to reach as they are not likely to be connected to other parts of the HIV continuum of care, and may face unique difficulties and barriers accessing care. Providers in the Boston EMA can be useful in reaching those not engaged in medical care. Many programs have targeted outreach programs to attract new clients and have created innovative strategies to bring other HIV-positive peers into care. Information gathered during Grantee site visits also suggests that clients may sometimes access psychosocial support and case management programs before they access primary medical care, giving these providers a unique opportunity to encourage clients to engage in medical care. Recent evaluation studies with Suffolk University Center for Public Management (Suffolk University) and JSI experienced success in using HIV-positive peers as a method to sample those not in care, pointing towards the potential of using peers to engage clients in care in the future.

The Grantee subcontracts multiple special evaluation projects each fiscal year, utilized in concert with other data to supply population-specific information. Clinical chart review evaluations were analyzed in FY 09 specifically to assess factors associated with retention in care among HIV-positive patients in Part A funded primary medical care sites.²⁵ Findings from this report showed that intravenous drug use is a strong predictor of shorter duration of retention.²⁵ Younger clients and males also had a somewhat higher risk of shorter duration of retention over time.²⁵ No difference in retention was found based on race or ethnicity. Though the report findings focused on clients who were, at one point in time over a seven year period, engaged in Primary Medical Care, it assessed predictors of clients who dropped out of care or engaged in care inconsistently. Since this is the population considered to have unmet need, the report provided important information which will aid primary care providers in retaining clients in care. By preventing clients from dropping out of care, in conjunction with identifying those who have never engaged in care, the number of PLWH in the Boston EMA with met need for primary medical care will continue to increase.

Two consumer feedback surveys conducted by subcontractors also provide useful population-specific data on clients who do not consistently access medical care and the role of additional services in connecting to primary medical care. A study by Suffolk University of PLWH not consistently engaged in care identified primary barriers to accessing medical care, which included transportation/distance from home, not knowing where to go for services, difficulty accessing providers/providers not helpful, and embarrassment from family/friends.²⁶ Responses differed slightly based on race and other population specific information is available within the report, including the recently incarcerated, active substance users, immigrants, and those who have additional medical complications. In FY 07, JSI conducted a satisfaction survey of Part A consumers receiving case management, food, and/or peer support services.²⁷ One goal of this survey was to examine the impact of support services on maintenance of primary medical care, and thereby their role in reducing unmet need among PLWH. The survey found that 84% of case management clients, 79% of food clients, and 78% of peer support clients consider these services extremely or very important in helping them keep regular primary medical care appointments.²⁷ Case management clients were also asked about the importance

of this service in helping them access HIV-related medications, and 87% found it extremely or very important.²⁷ Food clients were asked about the importance of food services in helping them take their HIV-related medications, including managing any side effects, and 76% found these services extremely or very important.²⁷

A recent JSI study (*Demographics & Clinical Care & Outcomes in 2006 Among Recently Diagnosed HIV Positive Patients in BPHC Sites Funded Through Ryan White Part A Program*) based on chart review data from Part A clinics gives insight into care patterns of recently diagnosed clients previously not in care. Compared to the cohort of continuing clients, findings showed that recently diagnosed patients were more likely to have regular CD4 counts, with recent CD4 counts above 200, recent viral load of ≤ 400 , be more likely to be on Pneumocystis Prophylaxis (PCP), less likely to be on ART, and often were unaware of their status or were prompted for testing due to clinical symptoms or opportunistic infections.²⁸ The results of the study also highlight that Black non-Hispanics are a growing subpopulation that may need continued assistance in gaining and maintaining access to care.²⁸

Information on those not in care in NH's three EMA counties is important for the Grantee to have a complete understanding of the population of PLWH in the EMA. The NH State Needs Assessment Survey found that Hispanic and Black PLWH were more likely than White PLWH to report going without HIV medical care for 12 months or more.²⁹ Among all PLWH who at some point had a 12 month or greater lapse in medical care, it was found that not having a provider who spoke their language was one of the most notable barriers.²⁹ Also, women were more likely than men to have gone 12 months or more without HIV specific medical care and without HIV medications.²⁹

At the present time, the Grantee has subcontracted with Suffolk University and JSI to conduct two evaluation studies, the results of which will be available in the spring of 2010. These evaluation studies will provide additional insight to the population of HIV-positive and aware individuals and their barriers to accessing care. One study is a MA state-wide/EMA-wide Consumer Needs Assessment, this study is sampling over 2,350 PLWH and will provide EMA and county specific data.³⁰ Those not in care were specifically sampled by utilizing peer support leaders as described above. Survey content includes service gaps and barriers to care in addition to detailed questions concerning care patterns, co-morbidities, stigma, disclosure, positive prevention, aging, and employment. Preliminary findings from the not in care sample show that services rated as the top five "essential" services were regular medical care (92% of respondents), help paying for HIV medication (83% of respondents), help paying rent (83% of respondents), help attaining benefits such as social security (77% of respondents), and help taking medications regularly and dealing with side effects (67% of respondents).³⁰ Services listed as those PLWH "needed but could not get" were food vouchers (50% of respondents), home delivered meals (44% of respondents), and help finding a place to live (43% of respondents). Transportation was listed as a main barrier for not accessing most services.³⁰ Findings from this study will provide the most current and accurate data on PLWH in the EMA, leading to more informed service providers, more targeted outreach, and reconfiguration of an optimal HIV service system for local needs.

Section III: Co-morbidities & Barriers

This section will examine HIV co-morbidities and barriers to care observed within the Boston EMA.

NATIONAL LEVEL

Federal Sources of Funding

Providing healthcare for PLWH ultimately relies on two sources of funding: private insurance and government-provided insurance. The principal source of private insurance is employer-paid health insurance. The advantage of non-governmental health care is that it provides the individual with an array of services. That source of funding is not considered here in discussing barriers to care. Governmental health care funding at the macro level will be examined as it affects health care for PLWH.

Currently, the federal government is the largest provider of health care for those without private insurance. These services are provided through the entitlement programs of Medicare, for the elderly and disabled; the Veterans Affairs Administration health care system, for those who served in the military; and Medicaid, a federal-state partnership designed to provide medical assistance to the poor.

Medicare was established in 1965 and serves people 65 years of age and over, the disabled below 65 years of age, and people living with end-stage renal disease. Persons under 65 years of age and deemed to be disabled may receive benefits after 24 months from the time of the disability determination. Under Parts A and B of Medicare, inpatient and outpatient medical services are available. Some equipment and medical consumables are covered by the program. Most services have co-pay requirements on the part of the beneficiary. The schedule for payments to hospitals and healthcare providers is set annually by the federal government.³¹ Medicare is a major payer of health care benefits to PLWH. In federal fiscal year (FFY) 2009, \$4.8 billion was spent on HIV/AIDS.³² For FFY10, the budget request includes \$5.1 billion to be allocated to Medicare for coverage of PLWH, an increase of 6.3% from FFY09.³²

The continuing increase in annual spending for this program has led to congressional debate over cost containment strategies as the number of retirees increases and the tax base supporting the program decreases. The 24-month gap between a disability determination and coverage, and the intricacies of navigating the Medicare system are initial barriers for PLWH. A larger potential barrier to care for PLWH would be restructuring of the program at the national level to reduce costs by reducing benefits and/or raising premiums and co-pays.

The other federal entitlement program providing care for PLWH is Medicaid. Medicaid is a federal-state partnership program designed to provide healthcare services to the needy as defined by a national standard — the Federal Poverty Level (FPL)—which is adjusted annually. Eligibility for program access is further defined by states. Medicaid has different names in different states; for example MA's name for Medicaid is MassHealth. When combined with state contributions, Medicaid is the largest single source of funding for healthcare services to PLWH. In FY09, \$4.4 billion were spent on the federal side of the federal-state partnership for HIV/AIDS.³² While there are a minimal number of benefits required of states in order to

participate in the program, anything beyond the basic offering is contingent on the state's policies and ability to support a larger array of benefits.

Medicaid benefits available to PLWH in the two states of the Boston EMA vary. Massachusetts has a broader offering of services provided under its MassHealth program, while NH offers fewer and more narrowly focused services. Both programs are subject to funding fluctuations because of the federal-state sharing of costs. Recognizing the importance of early, effective treatments for PLWH, in order to reduce or delay the progression to AIDS and fill the gaps in health care coverage, MA state officials developed and received federal approval for a 1115 waiver program in 2001 to expand Medicaid (MassHealth program) coverage to PLWH under 65 years of age with incomes up to 200% of the FPL.¹⁷ In MA FY09, 1,169 PLWH were enrolled into MassHealth using the MA HIV waiver.¹⁷ Of all PLWH in the MA portion of the EMA enrolled in MassHealth, 43% are White non-Hispanic, 20% are Black non-Hispanic, and 10% are Hispanic, according to the MA Office of Medicaid.¹⁷ However, state budget cuts have threatened the Medicaid safety net. In January 2003, a \$11 million cut to 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 of the same year, the eligibility level for the HIV waiver was reduced from 200% FPL to 133% of FPL, but it was restored to the original level in July 2004.¹⁷ In February 2009, MassHealth pharmacy co-pays for generic medications were increased from \$1 to \$2.¹⁷

New Hampshire has been working towards applying for a Medicaid HIV waiver in order to extend services to PLWH. Due to a number of reasons, NH will not be developing a waiver proposal in FY10-11.¹⁸

The 1115 waiver permits states to design innovative programs and services not a part of the standard plan design. Under the MA waiver, MassHealth covers persons with an HIV diagnosis and a certain level of income. This waiver expands access to MassHealth services to people HIV infected but not having an AIDS diagnosis.

The MA Health Reform Law of 2006 poses unique challenges to PLWH accessing Medicaid in MA. Under the new law it is compulsory for all MA residents to have health insurance. A new entity, the Health Insurance Connector, was instituted to create the rules and procure health-financing services from regional managed care organizations. PLWH with incomes up to 200% FPL remain eligible for MassHealth under the new law. In addition, PLWH who are uninsured and have an income between 200% and 300% FPL, will now have access to health insurance coverage through Commonwealth Care (enrollment in a Managed Care Organization with the premium subsidized by the state). PLWH who are uninsured with income over 300% will now have access to affordable products offered through the Connector.

Medicare Part D

The Medicare *Prescription Drug, Improvement and Modernization Act of 2003* was implemented on January 1, 2006. The Act provides a prescription drug benefit for persons participating in the Medicare program. As part of the program, persons who had been receiving pharmaceuticals through Medicaid prior to January 1, 2006 are now receiving medication through Medicare.

Under Part D, the drug benefit is provided through non-governmental entities. There are pharmaceutical benefit plans in place that provide participants with drug coverage at reduced cost. Many PLWH are "dually eligible" for benefits under both Medicaid and Medicare.

Their participation in Medicaid is determined by their income level while their Medicare participation is determined by their disability determination. The switch of providing medication from Medicaid to Medicare was a significant move. The plans offering pharmaceutical coverage are required to have a number of drugs per pharmaceutical category. In the case of anti-retrovirals, every plan must cover their cost. The transition, however, will further be complicated for dually-eligible PLWH whose treatment regimen requires other medications.

Medicare Part D applies to an estimated 21% of AIDS Drug Assistance Program (ADAP) clients.³¹ MA and NH ADAPs must ensure that eligible clients that apply for this drug reimbursement service meet the payer of last resort criteria. As of December 2009, the Boston EMA consumers accounted for 79% of MA HDAP clients and 73% of NH ADAP clients.^{97,98} However, since Medicare does not recognize the ADAP payments as true out of pocket costs to the consumer, consumers are not eligible for Medicare's catastrophic care. State ADAPs frequently pay the remainder of medications after Part D clients reach the "doughnut hole" or coverage gap.

Navigating the complexities of choosing a plan, determining what each plan covers, and dealing with issues around co-pays has the potential of creating roadblocks to access of needed pharmaceuticals by the most vulnerable of PLWH.

PRIORITY POPULATIONS

At the micro-social and economic levels there are significant barriers to care for people living with HIV/AIDS. Certain populations within the EMA continue to be disproportionately at risk of infection, and often simultaneously face community-specific barriers to care. Adolescents, older individuals, IDUs, White MSM, MSM of color, heterosexual women, and individuals with criminal records all have multiple factors that affect their access to care, which are addressed below.

Youth (13-24)

Persons 13 – 24 years of age present a series of challenges to the HIV service delivery system largely due to the unique circumstances inclusive of HIV that they face during this pivotal stage of human development. Given the sense of invulnerability characteristic of this age group, concern for health issues is usually a low priority, while risky drug use and sexual behaviors are common.

Data from the 2007 Youth Behavioral Risk survey from MA and NH showed nearly three quarters of high school students had drunk alcohol, a little less than half reported marijuana use, and 3-10% reported having tried a more serious illicit drug, including cocaine and methamphetamines.³³

Although teen birth rates have steadily declined over the last 15 years, the rate of certain STIs in youth aged 10-24 indicates the continued presence of sexually risky behavior.^{2,3} Both Chlamydia and gonorrhea rates are higher among individuals aged 15-24 than in other age groups.^{2,3} This evidence of risky sexual behavior is corroborated by self-reported risk. In the most recent Youth Risk Behavior Survey (2007), nearly half of MA and NH high school students reported that they were sexually active, and fewer than 40% reported using a condom in their last episode of sexual intercourse.⁷⁰ Meanwhile, students in the city of Boston and the state of MA were less likely to have received any in-school education about HIV or AIDS than they were

four years ago (the Boston percentage falling from 85% in 2003 to 77% in 2007, and the percentage in NH remained roughly the same at 89%).³³

Risk taking, experimentation, substance use, and unsafe sexual activity put youth 13-24 years of age at risk for HIV infection. For those infected in this age group, the barriers to entering and maintaining care are significant. The majority of youth living with HIV aged 13-17 years are dependents with minimal income and lack the autonomy, privacy, and resources that adults living with HIV/AIDS have in making decisions about their healthcare. They often encounter unique obstacles in seeking health care, including parental consent, extremely limited finances and legal issues. They may access services through parents or guardians, or public programs including Department of Social Services and Department of Youth Services. Adolescents who have left their families may attempt to obtain health services through drop-in or homeless shelters which are designed for chronically homeless adults, not adolescents. Homeless youth and youth of color, two populations experiencing rising rates of HIV infection, are likely to remain outside of the system of care until later stages in their HIV disease than the general population. In addition, many youth struggle with continuity of care, side effects from HIV medications, treatment resistance, and adherence to drug regimens. Agencies working with adolescents infected vertically or through other methods report that many youth in care have difficulty maintaining that care when they reach legal adulthood at 18 and must navigate new programs and new systems.

During FY08 of the Ryan White Program, 87 persons aged 13 to 19 years received Part A funded care.⁹

Aging PLWH

Diseases associated with aging already cause the majority of mortalities among the general populations of NH and MA. In 2006, cancer and cardiac disease each accounted for one quarter of all deaths in both states.³⁴ Evidence suggests that PLWH experience diseases common in older populations at higher rates and younger ages than the general population, adding to the cost and complexity of care. An eight year study of patients at Boston hospitals found that PLWH had nearly twice the rates of acute myocardial infarction (AMI) as their uninfected counterparts, as well as increased risk of hypertension, diabetes and dyslipidemia.³⁵ Women living with HIV had a higher rate of AMI than HIV-negative women, even after controlling for race, age and other known risk factors.³⁵ PLWH have a much higher risk for many non-AIDS-defining cancers; including Hodgkin's disease (15 times more common among PLWH than the general population), vaginal cancer (21 times more common), liver cancer (7 times more common), anal cancer (43 times more common), lung cancer (3.6 times more common), leukemia (2.5 times more common), and colorectal cancer (2.3 times more common).^{36 37} Conditions associated with aging can limit the mobility of PLWH, decrease their ability to work or maintain their housing, and increase the costs and complications associated with managing medical care, especially drug regimens.

A study in Massachusetts that compared all HIV infection diagnoses reported in 2005 through 2007, found that people diagnosed concurrently with HIV and AIDS tend to be older (40-49 years old).⁹¹ This finding has also been shown in international and national studies, which have associated older age with concurrent diagnoses and other indicators of lateness to care.

Injection Drug Users

IDU continues to be a major mode of transmission and represents a large portion of the infected population in the EMA. The use of alcohol and non-injection drugs also influences the local epidemic. This population presents many unique challenges to the service delivery system. People with active substance abuse have an array of needs that stem from problems such as unemployment, homelessness, lack of adequate health coverage, psychiatric disorders, histories of physical and sexual abuse, health problems, and social isolation. Studies have shown that substance abuse is associated with greater risk of unsafe sexual behavior, lower quality of life, and greater difficulty adhering to medications.^{38 39} A recent study done by JSI showed that substance use is a strong predictor of loss-to-care (non-retention) among PLWH in the Boston EMA.²⁵ Non-adherence and loss-to-care are substantial risks for PLWH that use drugs or alcohol, as both are associated with higher risk of disease progression and greater mortality.^{25 40}

Other challenges revolve around the fact that IDU is a key risk factor for the transmission of hepatitis C (HCV), and co-infection with HCV increases both the cost and complexity of providing health care to this group. Many co-infected clients have difficulty tolerating their HIV medications due to liver damage caused by HCV, and HCV treatment is associated with significant psychiatric side effects. These conditions severely affect an individual's ability to seek out care and adhere to an HIV treatment plan, and therefore must be addressed in order to meet this population's HIV/AIDS care needs. Challenges in the funding environment also exist. Funding for MA substance abuse treatment services are projected to receive a \$13 million cut for the upcoming fiscal year.⁴¹

Gaps in service and barriers to care are documented for this population. According to preliminary data from a 2009 EMA-wide consumer needs assessment, IDUs report difficulty accessing services including rental assistance, job search, food assistance, locating and maintaining housing, and help with legal issues.³⁰ Without access to these support services, along with substance abuse treatment and mental health counseling, many HIV-infected substance users will have difficulty adhering to care.

State-funded needle exchange programs are a critical intervention that helps bring IDUs into care and reduce the risk of HIV and hepatitis transmission. These programs are difficult to access as they are located in only two cities in the EMA, Boston and Cambridge, leaving a large geographic area with limited access to needle exchange sites. Access to needle exchange programs may soon increase due to the recent lifting of the national ban on using federal money to fund needle exchange programs. Additionally, until 2006, MA was one of only three states to prohibit the over-the-counter sale of clean needles in pharmacies without a prescription. Legislation since that time has sought to improve access to clean needles, but major stigma issues persist.

Among PLWH in the EMA, as of December 31, 2008, 5,973 report IDU (including MSM/IDU) transmission. The total annual cost of medical care for this population across all funding sources is \$85,150,800 or \$86,414,546, depending on the stage of disease. A total of \$6,764,758 Part A funds would be spent to provide care to this population.⁹

Men Who Have Sex with Men, White

The white MSM community was the first and most profoundly affected by the emergence of the HIV/AIDS epidemic. Within the EMA, the MSM population continues to be deeply affected. Seventy-two percent of MSM in the EMA are white, reflecting the demographics of the EMA.^{2,3} MSM continues to be a major mode of transmission for HIV/AIDS in the EMA, accounting for 36% of those living with AIDS, 44% of those living with HIV, and 40% of those living with HIV/AIDS as of December 31, 2008 (including IDU/MSM).^{2,3}

White MSM are a special population of concern due to ongoing elevated rates of sexually transmitted infections (STIs), which are an indicator of risky behavior. Over the last few years, Boston and the EMA, have experienced a spike in primary/secondary syphilis case incidence. In 2008 across the EMA, 87% of newly reported syphilis cases were self-reported MSM.^{2,3} This coincides with an increase in MA of the proportion of MSM among reported infectious syphilis cases from 2000 to 2008, from 23% to 86% of cases. In 2008, the EMA accounted for 89% of MA's reported syphilis cases.² Between 2000 and 2008 in MA, HIV-positive MSM with reported infectious cases of syphilis increased from 12% to 39%.² In the NH counties of the EMA, a regional community health center experienced a spike in syphilis among white MSM during 2007 and has notified its patients and the community. The ongoing incidence of syphilis cases and other STIs indicates risky sexual behavior. Additionally, many suffer from message fatigue, with risk reduction messages no longer being as effective as they were during earlier phases of the epidemic.

Ongoing societal disapproval of MSM behavior, stigma, recreational drug use, and fears of public exposure of one's lifestyle all hinder access to care for this population. Recreational drug use among White MSM increases risk and complexity of care, while creating barriers to care. Club drugs such as Ecstasy (MDMA), "Special K" (ketamine), and "G" (GHB) are still part of some social gatherings, while use of crystal methamphetamine (crystal meth) has become increasingly prevalent in New England, especially among gay men.^{42,43} In addition to its role in increasing HIV transmission, crystal meth may also cause complications for PLWH users including adherence failures, interactions with protease inhibitors, and increased viral replication.^{42,43}

During FY08, an estimated 1,255 White MSM out of the total MSM client base of 1,597 received care funded under Ryan White Part A. The cost of that care was approximately \$2,410,800.⁹

Men of Color Who Have Sex with Men (MSM of color)

MSM of color represent a growing share of HIV and AIDS cases in the Boston EMA, and face multiple linguistic and cultural barriers to care. Twenty-eight percent (28%) of men who attribute their HIV/AIDS infection to MSM contact are from communities of color, a designation which comprises a wide range of races and ethnicities, including African Americans, Hispanics/Latinos, Portuguese speakers (i.e., Cape Verdeans, Brazilians), Asian-Pacific Islanders, and Sub-Saharan Africans.^{2,3} The issues facing each of these subgroups are similar: sexual identity and expression, stigma of MSM relationships in their specific communities, effects of discrimination based on both sexual orientation and race, and difficulties navigating a complex healthcare system. In order to bring MSM of color into care and maintain their access to the continuum of care, it is required that services be delivered in a culturally and linguistically manner to accommodate the increasingly diverse languages and cultures of MSM of color. Additionally, high rates of depression and substance abuse among MSM of color create barriers

to care. A lack of culturally and linguistically competent substance abuse and mental health counseling represents a service gap for this population.

Many MSM of color perceive the established system of care to be structured by and for gay, white males. The perception is sufficient to cause MSM of color not to seek out care providers who have a deep familiarity with HIV/AIDS treatment. Class differences, underscored by economic factors, also raise barriers to both communication and care. Gaps in cultural competency exacerbate the divide between providers and clients of color. Dual minority status leads to simultaneous open and hidden life styles with different social circles for different situations. For example, a 2007 study found that African-American men who have sex with men and were living with HIV were less comfortable discussing MSM behavior with close friends and family.⁴⁴ Language skills, educational attainment, and economic positioning (lower skilled employment) also create hurdles for navigating the system of care, as well as high rates of depression and substance abuse among MSM.

MSM of color who are also immigrants have another layer of complication in seeking care. The Boston EMA has always had a high rate of new immigrants; MA's overall foreign-born population rate of 12% is driven by the seven counties within the EMA. Their rate combined (13%) is greater than that of the seven other counties of MA (6%).¹ This population is further concentrated in the urban centers of the EMA, where the foreign-born population reaches 17%.¹ The three NH counties part of the Boston EMA have foreign born populations ranging from 3% to 7%, compared to 4% in the state as a whole.¹ Uncertain immigration status among foreign-born residents can become an additional barrier to entering the care network for MSM of color.

Stigma surrounding same-sex relationships in communities of color is pervasive and Black and Hispanic MSM are more likely than White MSM to self report as “down low” MSM.⁴⁵ These individuals often do not identify themselves as homosexual, and are more likely than non-DL MSM to have had unprotected vaginal sex in the prior 30 days. Down low-identified MSM are also less likely to have ever been tested for HIV than non-DL MSM.⁴⁵ Uncertain immigration status and fear of deportation also poses a barrier to entering the care network for MSM of color. In the JSI 2009 Consumer Needs Assessment, both White MSM and MSM of color ranked dental services, rental assistance, food vouchers, and job help support among their top five service gaps.³⁰ High rates of STIs, substance use, and stigma present significant barriers to care. During FY07, approximately 382 MSM of color received care under Part A for an expenditure of \$751,776.⁹⁹

Heterosexual Women

There are over 3.1 million women in the EMA, representing nearly 52% of the total population.¹ Women now account for more than one quarter of all newly diagnosed HIV/AIDS cases, and women of color are disproportionately affected. According to the CDC, HIV was among the top five leading causes of death for Black women of all ages in 2004.⁴⁶ High-risk heterosexual contact is the primary mode of transmission for 80% of the newly diagnosed HIV/AIDS cases among women.⁴⁶ Local surveillance data reveals similar trends: 30% of living HIV/AIDS cases in the Boston EMA are among women (46% Black, 28% White, and 23% Hispanic) and women of color represent nearly 70% of those cases (as of December 31, 2008).^{2,3} Seventy-four percent of Black women and 65% of Hispanic women were infected through heterosexual (including presumed heterosexual) transmission, making it the primary mode of transmission among Black and Hispanic females in the Boston EMA.^{2,3}

Access to, and utilization of, HIV-related health care continues to be a significant challenge for women with HIV/AIDS. There are many different factors that increase this population's risk of contracting HIV, including low socioeconomic status, lack of educational and employment opportunities, competing priorities (ie. food, shelter, childcare), gender/power dynamics, and biological differences.⁴⁷ Women of color often have additional risk factors including low perceived vulnerability, lack of HIV knowledge, low literacy levels, and language barriers.⁸¹⁻⁸³ Negative effects of these barriers are exacerbated for women who are homeless, substance users, single parents, foreign-born, or those afflicted with mental health problems.⁸¹⁻⁸³

The Boston EMA provided Part A funded services to 2,069 women in FY08. The yearly cost for services to women is approximately \$5,223,218.⁹

Transgender

Data on the transgender population is not comprehensive, due mostly to reporting issues. Although, transgender people only made up 0.4% of the Part A client base in FY08, HIV infection among this population ranges from 14%-69%.⁹ Massachusetts reported that transgender persons had worse outcomes with respect to self-reported health disability status, depression, anxiety, suicide ideation, and lifetime violence victimization. In the same study, respondents were asked to report whether they ever had an HIV test. Gay men and lesbians were the most likely to receive an HIV test (72.2%), followed by bisexuals (66.7%), transgender persons (65.4%), and heterosexuals (49.0%).⁹²

Individuals who are Incarcerated

The CDC's electronic HIV/AIDS reporting system surveillance system does not track prevalence or incidence of HIV/AIDS among those recently released from incarceration. In 2006, the HIV/AIDS prevalence among incarcerated persons (1.7%) was 4 times as high as the overall national prevalence.⁴⁸ In NH, the HIV/AIDS prevalence among inmates was 1.4 times higher than the national prevalence at 0.6%, while the rate among inmates in MA was 6 times higher (2.5%).^{4,48,49} Furthermore, MA is tied with New York for the highest percentage of confirmed AIDS cases among inmates (1.3%) in the country, which means additional complications (e.g. opportunistic infections) that will require more medical care⁸. During the first half of 2009, 54 PLWH were released into the community from the Suffolk County House of Correction, one of the EMAs largest correctional facilities.⁵⁰ Between 2001 and 2006, 4% (13/328) of deaths in MA and NH state prisons were attributed to AIDS.⁴⁸

Nationally, a high percentage (70%) of HIV/AIDS cases in prison are attributed to IDU, increasing the likelihood of HCV co-infection.⁴⁸ A local provider, that works with formerly incarcerated PLWH, reports that 58% of its clients are living with both HIV and HCV, while the Suffolk County House of Correction reports that 49% of all PLWH released in 2009 were co-infected with HCV.^{50 51} The structured environment of the prison system enables clinicians to provide complicated therapies for HCV and HIV co-infected patients; however, treatment of HCV is a long term course of therapy with severe side effects and it can take months to determine whether a PLWH should start HCV treatment. In practice, few patients co-infected with HIV and HCV end up being treated for their underlying hepatitis because of severe liver disease, ongoing substance abuse, and depression.⁵²

In 1999, HRSA funded the Transitional Intervention Project through MDPH, to help inmates living with HIV transition to life in the community.⁵³ Six programs, including four in the EMA, saw a total of 884 clients over five years. These clients indicated that their greatest needs were medical care (69%), housing (67%) and drug treatment (58%).⁵³ More than 22% had no health insurance of any kind at the time of their release; 19% had no available housing options; 48% had a history of mental illness and 96% had a history of substance abuse.⁵³ Since minorities comprise a disproportionate number of those incarcerated, services targeted to individuals transitioning out of incarceration must be culturally and linguistically appropriate.² Increased resources are needed to provide services to this transitioning population due to the multiple needs and systemic barriers that prevent access to many programs for formerly incarcerated individuals.

Individuals with Criminal Records

Multiple providers in the Boston EMA have reported that PLWH who have criminal records have difficulty accessing certain services. Individuals who have been charged with a crime in a federal or MA state court have a Criminal Offender Record Information (CORI) in their record, even if the case is dismissed or the person has been found not guilty.⁵⁴ In some cases, CORIs which are very old can continue to cause problems. For example, a client at an EMA agency had proceeded through a year-long housing application process only to have the application dismissed two weeks before a scheduled move because of a CORI dating to the 1970s.³³ Closing a CORI, or sealing the record, requires a legal filing and in some cases a court appearance, even for cases that have been dismissed or in which the client has been found not guilty.

CORIs present a significant barrier to obtaining housing for PLWH. Many local housing programs screen applicants who have a history of involvement with the criminal justice system. Additionally, many employers perform CORI checks during the application and interview process, so PLWH who have findings in a CORI search also face a substantial barrier to obtaining stable work and economic self-sufficiency.

CO-MORBIDITIES

Co-morbidities are common across all populations of PLWH. These co-morbidities, such as STIs and hepatitis impact the health outcomes of individuals and can create barriers to care.

Sexually Transmitted Infections

Case counts increased in the EMA between 2007 and 2008 by 28% for primary and secondary syphilis (with 209 cases reported in 2008; case rate = 3 per 100,000 residents) and 6% for Chlamydia (with 13,240 cases reported in 2008; case rate = 255 cases per 100,000 residents).^{2,3} After a 16% increase last year, cases of gonorrhea fell by 25% in 2008 (with 2,094 cases; case rate = 28 per 100,000).^{2,3} The burden of STIs is not uniformly shared. The case rates for Suffolk County were four times that of the EMA for syphilis and gonorrhea and three times the EMA's rate for Chlamydia.² In 2008, Blacks made up only 5% of the EMA's population; however, they accounted for 19% of Chlamydia cases, 34% of gonorrhea cases, and 16% of syphilis cases.^{2,3} The case rate is more than ten times greater among Blacks than Whites for chlamydia, and 23 times higher for gonorrhea.^{2,3} Likewise, Hispanics accounted for

16% of the chlamydia cases, 12% of the gonorrhea cases, and 17% of the syphilis cases, but represent only 8% of the EMA's population.¹⁻³ Adolescents and young adults continue to be disproportionately impacted by STIs, with Chlamydia and gonorrhea case counts peaking among those ages 15-24.^{2,3} MSM accounted for 87% of reported syphilis cases in the EMA in 2008, an increase from 70% in 2007.^{2,3} Among reported cases of syphilis in the EMA in 2008, 34% were also positive for HIV, while a further 30% did not know or declined to provide their HIV status.^{2,3} Co-infections of gonorrhea and Chlamydia in PLWH are not captured in annual surveillance data.

Human papillomavirus (HPV) is the most common STI in the United States and can cause both cervical and anal cancers. A CDC study found a 19% prevalence of high risk HPV (associated with cancers) among women aged 18-65 visiting primary care, family planning, and STI clinics in MA.⁷³ PLWH are at greater risk for acquisition of HPV, reactivation of latent HPV, persistent HPV infection, and progression toward atypical cells.^{74,75} A 2005 University of California San Francisco study found that 95% of a cohort of HIV infected MSM were also infected with HPV, and 84% had evidence of precancerous cells.⁷⁶

Studies show that STIs increase the risk of HIV transmission and can speed up the rate of HIV replication in exposed individuals.⁷⁷ STIs are often harder to treat in HIV-positive individuals, causing chronic and drug-resistant infections, and increasing the cost of care due to the requirement of additional medical visits and medications.

Hepatitis

In 2008, 19 acute and 188 chronic hepatitis B (HBV) cases were reported in the MA EMA counties, accounting for 85% of all cases in MA, and six acute HBV cases were reported in the NH portion of the EMA (chronic HBV case counts are not available).^{2,3} Chronic HBV cases in MA peaked among adults ages 30-44, with the majority of cases among females (59%).² In the same time period, there were 2,895 cases of chronic HCV confirmed in the MA counties of the EMA, an alarming 29% increase in HCV since 2007.² Case counts peaked among those ages 45-54 and the majority of cases were among males (59%).²

Shared epidemiological risks, such as unprotected sex and sharing of injection drug paraphernalia have resulted in higher incidence of both HBV and HCV among PLWH than those not infected with HIV. In MA, chronic HBV infection affects 3.5% of PLWH, and chronic HCV infection affects 13.3% of PLWH.⁷⁸ Of MA individuals co-infected with HCV and HIV, 73% were exposed to HIV through IDU, as were 40% of those co-infected with HBV and HIV.⁷⁸

End-stage liver disease due to HCV has become a leading cause of death for HIV patients in the US.⁷⁹ A BPHC death certificate analysis shows that HIV/AIDS was a contributing cause of death among 50 out of 691 HCV-infected individuals who died in Boston between 2002-2009.⁸⁰ When compared with people infected with hepatitis alone, PLWH have a higher risk for developing more advanced forms of liver disease such as cirrhosis (scarring), severe fibrosis, and increased deaths from liver disease.⁸¹ PLWH coinfecting with HCV are more likely to develop opportunistic infections and liver related complications upon antiretroviral initiation.^{81,82} Additionally, PLWH co-infected with HBV respond as well to antiretroviral treatment (ART) as individuals with HIV alone, but are more likely to die due to non-AIDS-related causes.⁸¹ HCV therapy is also associated with significant psychiatric side effects, such as depression, difficulty sleeping, and irritability, particularly among patients who have used illicit drugs.⁵² Due to the medical and psychological implications of co-infection, providers must be knowledgeable about both HIV and hepatitis to ensure proper management of both illnesses, as well as underlying

substance abuse. The additional time and specialized medications required to treat these co-infected individuals greatly adds to the cost of their care.

Tuberculosis

The Massachusetts Department of Public Health reported 261 cases of tuberculosis (TB) in the state in 2008, of whom 18 (7%) were also infected with HIV.² A report on co-infected individuals treated at the BPHC's TB Clinic reveals the complexities of care. Treatment of TB involves several different types of medications, some of which cannot be prescribed to clients who are taking antiretrovirals, or who have diminished liver function due to hepatitis. Among PLWH seen at the TB clinic from 2005-2007, 84% were Black, 63% were foreign-born, and 21% were homeless, indicating that co-infection of HIV and TB is further concentrated among populations facing multiple service challenges in the EMA.²

BARRIERS TO CARE

Factors, such as homelessness/housing instability, poverty, mental illness, cost of medications, a systemic weakness of cultural competency, and stigma create barriers to care across many populations.

Housing Instability

According to estimates collected in 2007, the total homeless population for the EMA was approximately 13,700 individuals, or 20 per 100,000 population.⁵⁵ The number of individuals on the streets and in shelters during the City of Boston's annual census was 7,681 in 2008, an 11% increase from 2007.⁵⁶ Since people move in and out of homelessness over time, the number of people estimated to be homeless at some point during the year in MA ranges from 19,000 to 29,000.²⁶ In NH, 5,209 people received shelter services in FY08, and the state census in January 2008 identified 2,019 homeless individuals, of whom 484 were not sheltered.²⁷ Homelessness in MA and NH is driven by some of the highest housing costs in the nation, accompanied by low rental vacancy rates and a large share of renting households paying more than 30% of their income toward rent.^{57,58} According to the Department of Housing and Urban Development (HUD), the average Fair Market Rent for the towns included in the Boston EMA was \$960 for a 1-bedroom apartment, more than 30% higher than the national average of \$584.⁵⁹ Considering that the FPL in 2008 was equal to about \$866 per month in 2008, it would be nearly impossible for PLWH living at the poverty line in to retain housing without assistance.⁶⁰ As a result, many clients seek housing subsidies. However, as the Boston-based AIDS Housing Corporation (AHC) notes, the need for subsidized housing outpaces the availability, and in many areas, the subsidized housing stock is found to be substandard or is located in areas "that consumers consider negative to their well-being".⁶¹ Housing stability has been further threatened by the recent increase in foreclosures. Between 2005 and 2008 the number of foreclosure deeds in MA increased more than 1000%, climbing from 1,032 to 12,430.⁶²

The 2008 Homeless Census found that 2.5% of the chronically homeless individuals of Boston are living with HIV/AIDS, roughly 10 times the prevalence of the general population.⁵⁶ Likewise, the prevalence of homelessness is higher among PLWH than the general population. Grantee

data for FY07 indicate that 12% of Part A clients are homeless, recently evicted, or residing in uninhabitable shelters/living environments, while a further 12% are facing eviction or in need of a housing placement. An additional 26% are stably housed but may need rental or utility assistance.⁶³ AHC estimates that 40-60% of PLWH will experience homelessness at least once in their lifetime.⁶⁴ An AHC survey found that 18% of PLWH in NH had been evicted from housing in the last two years, and 72% had used emergency financial assistance to pay for rent, mortgages, or utilities.⁶⁵ As of December 2008, 257 of the living HIV/AIDS cases in the EMA counties of MA were homeless at the time of diagnosis.²

Homeless PLWH die at a rate five times greater than that of PLWH with stable housing.⁶⁴ Homeless persons also use emergency room care more often than the non-homeless, and experience delays in identification of HIV and co-morbidities, resulting in increased costs associated with treating advanced illnesses. In 2003, AHC reported that homeless PLWH are four times more likely to enter health care systems if they receive housing assistance. If the individual also has a history of mental health and substance abuse, providing housing increases the likelihood of receiving care by ten times.⁶¹ Unfortunately, clients with histories of substance abuse, incarceration, or poor credit are especially difficult to house, and the cost and complexity of their illness and reconnection to care increases in accordance with the length of time they are kept out of stable housing.⁶⁵ In addition, providers of legal services to PLWH have reported a rise in clients seeking help with foreclosures or renegotiating mortgages, requiring additional training for staff to assist or refer these clients. These systemic obstacles, combined with the ongoing housing shortage and high housing costs in the EMA, mean that providing housing services for PLWH is extremely costly; this service category comprised 18% of all direct services funding allocated by the grantee in FY 09 – more than any other category except medical case management.¹⁰⁰

Once in care, homelessness presents a significant barrier to accessing critical services, including antiretroviral therapy.⁶⁶ Limited access to medical care among this growing population delays identification of HIV/AIDS and related diseases, increasing the likelihood of severe disease onset prior to entering care. In addition, many PLWH who are homeless also struggle with mental health issues, substance abuse, or both, simultaneously creating a need for complex, intensive care and face a matrix of barriers to entering and maintaining stable medical care.

Poverty

In 2008, 100% of the FPL was equivalent to an income of \$10,392 per year for an individual or \$21,192 for a family of four.⁶⁰ Nine percent of the EMA population lives at or below this level, 21% live below 200% FPL, and 33% live below 300% FPL.⁶⁷ Due to the high cost of living in MA and NH, federal statistics underestimate the true level of poverty in the EMA. When 2003 federal estimates were adjusted to reflect the high cost of living in MA, the number of MA residents living in poverty increased from 10% to 13%.⁶⁸ During FY 08, 79% of Part A clients reported living at or below 100% FPL, 90% reported living at or below 200% FPL, and 93% lived at or below 300% FPL.⁹ This data indicates that PLWH face greater economic stress than the general population of the EMA. Moreover, the percent of Part A clients living at or below 100% FPL increased from 66% to 79% from 2007 to 2008, while the percentage living at or below 100% in the general population in MA and NH remained stable.^{9 67} PLWH who must choose between care and housing, food, or clothing, and those who cannot afford transportation to medical visits, report low overall access to care and are more likely to seek care in emergency rooms and less likely to receive antiretrovirals.⁶⁹ The complexity of care is increased as

providers must address these tangible needs in order to keep clients in care, and the cost of providing care expands to include assistance in navigating public and private sources of assistance to ensure that gaps in care are covered.

Mental Illness

The Substance Abuse and Mental Health Services Administration (SAMHSA) reported that in 2006 and 2007, 10% of the adult MA population and 11% of the adult NH population experienced Severe Mental Distress.⁶⁶ The CDC found similar rates for Frequent Mental Distress (FMD) in 2007. Ten percent (10%) of adults in both MA and NH experienced FMD, with higher numbers among women, Hispanics, and adults aged 18-34.⁷⁰ Among PLWH in the EMA, a 2006 clinical chart review found that 49% had active psychiatric diagnoses.⁷¹ Part A providers have recently reported high rates of a history of trauma and post-traumatic stress disorder occurring in PLWH within the Boston EMA – one large AIDS Service Organization (ASO) reported that 60% of clients have a history of trauma at intake.⁷¹

Mental health and trauma increase the likelihood of substance use, sexually risky behavior, and homelessness.⁷² Untreated mental illness leads to fluctuations in medical adherence and attendance at medical appointments and may lead to drug resistance or premature disease progression.³⁸ Therefore, failure to treat mental health conditions ultimately increases the cost and complexity of medical care for PLWH. On the other hand, adequate treatment of mental illness increases the cost of care as staff must allocate time to recognizing symptoms of psychosocial distress and making supported referrals. The low number of mental health care providers who specialize in trauma and HIV and accept Medicaid reimbursement further complicates the process of helping clients obtain needed mental health treatments.

Cost of Medications

Antiretroviral therapy has greatly extended the quality and length of life for PLWH, but it has also added considerably to the cost of care. According to a 2006 study published in *Medical Care*, the discounted lifetime cost of medical care for a person entering care with CD4 cell count <350 is \$385,200.⁸³ Seventy-three percent of this cost is antiretroviral medications.⁸³ The addition of newer, more costly drugs to the formulary will continue to increase the costs of care. In addition, as people live longer and new infections continue to occur, the number of people needing ART within the Boston EMA continues to grow. The pharmaceutical needs of Medicare-eligible PLWH can be both confusing and expensive. Meanwhile, decreasing resources, reductions in Medicaid eligibility and increased need have led MA and NH to explore mechanisms for reducing eligibility, creating waiting lists, and/or restricting the ADAP formulary. Currently both states have open formularies for ADAP clients. People living with HIV in MA with incomes up to 500% FPL may access ADAP.⁹⁷ Those living in NH must have incomes below 300% FPL.⁹⁸ Additionally, in order to offset rising costs, NH instituted new medical eligibility requirements for new clients enrolling in the NH ADAP program during and after FY04, that currently requires CD4 <350 for all new clients.

Cultural Competency

A significant barrier to care for PLWH is the issue of lack of cultural competency. Cultural differences between a client and healthcare provider can arise from varying levels in educational background, language, social and economic status, or even reading and understanding social cues. In a study conducted on PLWH not consistently receiving consistent care, Suffolk University researchers found that Hispanics and Blacks were less likely to see a provider than Whites, and those who spoke Spanish or Haitian Creole were less likely to see a provider than their English speaking counterparts.¹⁰¹ Health outcomes disparities are also closely related to cultural differences. Awareness of this barrier to effective care has been identified at the national, state, and local levels. The thrust of these efforts and initiatives is to identify the causes of disparities in health outcomes for minority populations and to address the persistent elements in social structures that contribute to these disparities. The forces behind disparities are both overt and subtle. The minority person living with HIV/AIDS encountering these overt and subtle forces is yet another hurdle to entering and remaining in care.

Stigma

Even as the HIV epidemic moves into a third decade, the problem of stigma remains. The focus and manifestation of stigma have changed over time. In the early days of the epidemic, certain populations were more afflicted by HIV/AIDS (e.g. homosexuals, hemophiliacs) and due to this association were consequently shunned by other members of society. As HIV began to spread into other populations, new assumptions developed concerning the associations of HIV/AIDS with high risk behaviors, including drug use and sexual promiscuity. Stigma, whether coming from an awareness of or from a fear of being stigmatized, can be a significant barrier to seeking care.⁸⁴⁻⁸⁶ Once diagnosed with HIV, individuals concerned about stigma are more likely to delay care and/or not adhere to the appropriate treatment options.⁹⁵ Stigma can also affect HIV testing and counseling seeking behavior.⁹⁶ In a 2002 study conducted by Suffolk University of men and women who did not use care consistently, Blacks ranked 'embarrassment among family and friends' as the second most important reason for not seeking care.¹⁰¹ The degree of actual stigmatization encountered or feared by an individual varies from not seeking local health care to avoiding disclosure to healthcare providers, family and social network.

ADDRESSING BARRIERS TO CARE

The barriers to care identified in this Needs Assessment create challenges to delivering services in the Boston EMA. Together with newly diagnosed infections, advances in treatment and services that enable PLWH to live longer, have led to an increase in the number of PLWH at the same time that the cost of core services and medications is rising. Identifying PLWH who know their HIV status, but are not in care, and serving those with unmet need continues to present a challenge and additional cost to the service system. Further challenges include disparities in risk, infection rates, mortality, poverty, health insurance status, access to care among special populations, and complex interactions among co-morbidities that affect the cost and complexity of care for PLWH. The rising costs of core services, in particular ADAP, and the decreasing funding for supportive services, as well as local factors such as a severe affordable housing crisis and a state fiscal situation that has resulted in unprecedented budget cuts, exacerbate service delivery challenges.

The diversity of the EMA's epidemic increases the range of services needed to bring people into care and keep them healthy. Regional variations in the demographics of the HIV epidemic in the EMA create a need for culturally and linguistically appropriate strategies and services within each area. The standards of care for the Boston EMA require providers to document cultural competency training among employees. Supporting agencies that develop innovative, targeted programs should remain a key goal, along with disseminating best practices in cultural competency, and to foster connections between agencies and providers who offer care to similar communities or communities with similar needs.

The increase in co-morbidities, homelessness, and poverty affecting PLWH has meant that consumers enter care with a much more complicated set of interconnected issues than in earlier years of the epidemic, and with a wide array of service needs. The combination of these factors presents multiple service delivery challenges that require the maintenance of a flexible continuum of care that can meet the varied needs of PLWH.

ART has enabled PLWH to live longer and has reduced AIDS-related deaths. In addition to managing the cost, as discussed above, ART introduces a layer of complexity due to side effects and the need to support clients with adherence issues. Although treating side effects adds to the cost and complexity of care, it is an essential part of ensuring that clients remain on recommended drug regimens.

Another challenge is the need for a myriad of adherence strategies that help PLWH comply with the daily routine of taking numerous medications. Viral resistance, either from ART failure or when a person is infected with a drug resistant strain of HIV, poses another serious challenge that can complicate the cost of care and require more intensive medical planning to assess the range of available options. Recent needs assessments in the Boston EMA continue to highlight the need for tools and strategies to help PLWH maintain their medical regimens. Such strategies must be culturally and linguistically appropriate to be most effective.

In this time of economic hardship, PLWH and the agencies that provide HIV/AIDS services face considerable strain as they attempt to maintain high standards of care. Mid-year reductions to the MA state budget in FY09 reduced MassHealth by more than \$260 million, which resulted in reduced provider payments, capped certain mental health benefits, increased patient co-pays, and a policy change making documented immigrants ineligible for future enrollment in Commonwealth Care. The 31,000 documented immigrants already enrolled were originally cut, but later reinstated to a more limited plan under one time funding, without a clear indication of what will happen in future years.^{41,87} The Massachusetts Department of Public Health budget dropped by 12% between FY09 and FY10, eliminating or reducing programs in the areas of community health centers, family planning, substance abuse, early intervention, and dental health.⁸⁸ The state mental health budget was reduced by 10% between FY09 and FY10, forcing elimination of day rehabilitation programs, layoffs of case managers, and reductions in adolescent services and jail diversion programs.⁸⁹ The state of NH removed \$500,000 from ADAP as part of FY09 cuts.⁹⁰ Providers have reported clients having increasing trouble obtaining food vouchers or meal baskets from both publicly funded sources and private community organizations. The success within the EMA in dramatically increasing access to primary care has also meant that the demand for supportive services has continued to grow. The lack of stability, including changing policies and disruption to access will increase the complexity of navigating medical care for PLWH. As increasing strain is put on external resources for medical care and support, HIV specific funding, including Ryan White Part A, will assume an increasing proportion of the cost of maintaining access to care and positive health outcomes for PLWH.

The EMA's Part A Award has also decreased by approximately \$2 million since 2001 (this estimate includes MAI dollars). While core services for PLWH have been maintained as much as possible, this has required a reallocation of resources from supportive services. The network of supportive services, such as peer support, food services, transportation, and housing support, has played a critical role in helping PLWH gain and maintain their access to medical care, and the EMA continues to face the challenge of balancing the need for both. Reduced funding also creates an incentive to develop economies of scale by supporting larger multi-service organizations. However, the EMA must continue to support smaller community-based organizations, especially those based in communities of color, which have the cultural and linguistic capacity to reach those new to care and those who know their HIV status, but are out of care. With more PLWH being identified and brought into care, the capacity of the services system will continue to be strained.

The Grantee and Council will continue to work with all funders of HIV services to monitor and evaluate the impact of the myriad of challenges to maintaining a full continuum of core medical services, case management services, and the other supportive services that enable PLWH to gain and maintain their access to care, and to extend and improve their lives.

Section IV: Continuum of Care

This section describes the Boston EMA continuum of care. It presents the types of services which make up the continuum and the agencies that provide care.

COMPREHENSIVE SYSTEM OF CARE

The Boston EMA's continuum of care is an effective and flexible service system that spans prevention efforts, early intervention services, medical care, and health-related support services. Through the efforts of the Planning Council and BPHC HIV/AIDS Services Division (Grantee), Part A continues to play a leadership role in the development and maintenance of a comprehensive continuum of HIV treatment, care, and services in the region. The continuum of care is supported by a variety of funding streams including the CDC, MA and NH general funds, City of Boston, Ryan White Parts A, B, C, D, F, MAI (Part A), Dental Reimbursement, Special Projects of National Significance (SPNS) programs, Housing Opportunities for People with AIDS (HOPWA) housing funds, and Medicaid. The EMA's integrated system of care enables PLWH to gain and maintain access to needed medical and health-related support services and is adaptable to changing epidemiological trends and emerging needs. An ongoing challenge will be to preserve access to a full range of services in the continuum, despite a lack of any increase in resources at a time when there are increasing numbers of PLWH in need of service.

GOALS

The goals of this comprehensive approach to care are to: 1) decrease the number of new infections; 2) increase the number of people who know their HIV status; 3) link newly diagnosed people, and those who know their status, but are not in care, to medical care and health-related support services in order to extend and improve their health and quality of life; and 4) preserve and maintain the health of individuals currently in care. The continuum of care has been successful in lowering AIDS-related morbidity and mortality rates for those in care within the EMA over the years. Programs have focused their efforts to reach PLWH who are not engaged in primary medical care, particularly those who know their HIV status and those from disproportionately impacted communities. Prevention services follow a similar model of coordinated outreach, education, and referral services that target high risk groups, encourage people to know their status, provide counseling and testing, and link those who are identified as PLWH into care.

CORE MEDICAL SERVICES

The six core medical services for PLWH in the Boston EMA include: outpatient/ambulatory medical care, ADAP, oral health care, substance abuse services, mental health, and medical case management services. A range of funding streams supports these services, with Medicaid being the primary payer for medical services. Due to the availability of non-Part A resources for medical services and the lack of any waiting lists for medical care, the EMA was granted a Part A waiver to the core medical service requirement by HRSA for FY07, FY08 and again in FY09

Under the legislative requirements of the Ryan White Treatment Extension Act, the Core Medical Services Requirement stipulates that a funded EMA must direct at least 75% of Part A funds towards a set of “core medical services” and no more than 25% towards support services. Within the Boston EMA, this requirement is met and exceeded when all HIV-related funding is considered. State and other federal resources have been invested to develop and maintain a comprehensive system of core medical services. This extensive funding has reduced the need for 75% of Ryan White Part A dollars to be used for core medical services.

The availability of funding for core medical services is also supported by a comprehensive state Medicaid system (MassHealth), which includes an HIV waiver program. The HIV waiver allows PLWH, but not currently diagnosed with AIDS, to qualify for Medicaid coverage. These local factors, which led to the granting of a Core Medical Services waiver, have continued to expand. This is largely due to the landmark passage of the 2006 MA Healthcare Reform Law, which provides near universal health insurance coverage for area residents. As a result, the utilization of Part A funds for primary medical care has decreased as healthcare providers are able to bill to additional third party payers.

The MA requirement to have health insurance has expanded the number of possible payers, which reduces the burden on public programs for core medical services. However, the number of payers for support services has remained unchanged. The lack of funds that cover support services means that programs, such as Ryan White Part A, are increasingly important in providing a complete continuum of care and ensuring that all PLWH in the Boston EMA maintain their level of health. A critical focus of the Planning Council and the EMA is providing these key health-related support services that enable PLWH to access and maintain health care. Current Planning Council allocations for FY09 have allocated 45% of Part A funds to be spent on core medical services and 55% of Part A funds to be spent on health-related support services.

Outpatient/Ambulatory Medical Care

Part A funded primary care programs include a specialized pediatric primary care program, a program targeting homeless HIV infected adolescents and young adults, a clinic focused on the lesbian, gay, bisexual, and transgender (LGBT) community, and programs specifically targeting communities of color. Part A funded primary care programs ensure access for those who are not eligible for any other form of medical coverage. Part A funds seven primary care programs located in both neighborhood community health centers and larger community hospitals. As these sites also provide HIV counseling and testing services, they are able to link clients directly into care. Of those who accessed Part A primary care in FY08, 44% were White, 45% Black, 27% Hispanic, 15% African, 8% Haitian, and 2% Brazilian (noting that some clients declared belonging to multiple ethnic groups).⁹

A more detailed look at the demographic profile of those accessing primary care services under Part A dollars shows an emergence of African immigrants with HIV/AIDS accessing care within the EMA. The proportion of African PLWH accessing primary care has increased 6% in comparison to the last fiscal year. This statistic is not only indicative of the growing number of African immigrants in the community, but the ability of funded case management programs through both Part A and MAI contracts to link this community into the continuum of care.

Primary care was identified as the top met need and most essential service in the preliminary data of the JSI 2009 Consumer Needs Assessment.³⁰ In a Suffolk University outcomes analysis (2002), a significantly higher proportion of clients receiving food and/or peer support services

were reported to have excellent outcome levels for maintenance of primary medical care.⁹³

AIDS Drug Assistance Program

Combined funding streams allow for an open formulary of drug therapies to be available for PLWH in the Boston EMA. Coordinated planning by the EMA and the state governments has guaranteed the equitable availability of funds for ADAP services throughout the region. The potential for decreased resources has led both states to explore mechanisms for reducing eligibility, including the creation of waiting lists, and/or limits to the formulary; however, stable funding has allowed for the continuation of the open formulary without waiting lists. Nonetheless, increasing costs have led to a need for higher Part A contributions to the ADAP program. Of those who accessed ADAP services in FY08 from NH, 57% were White, 32% Black, 23% Hispanic, 15% African, and 2% Brazilian (noting that some clients declared belonging to multiple ethnic groups).⁹⁸ In MA, among those who accessed HDAP in FY08, 34% were White, 15% Black, 24% Hispanic, 8% Haitian, and 4% Brazilian.⁹⁷

Drugs was ranked second out of the five most essential services and met needs listed in the preliminary data of the JSI 2009 Consumer Needs Assessment.³⁰ According to Suffolk University, a significantly higher proportion of clients receiving drug reimbursement services were reported to have poor outcomes levels for the following: 1) CD-4 count; 2) viral load; 3) maintenance of primary medical care; 4) adherence to medical therapies; 5) mental health status; 6) access to psychosocial support; and 6) housing status. The analysis also found that clients receiving NH drug reimbursement services had significantly lower aggregate health outcomes.⁹³

Oral Health Care

A network of dentists and dental practitioners, dentistry school clinics, and teaching hospitals provides dental diagnostic and therapeutic care. In addition to Part F programs, Part A funds an HIV Dental Ombudsperson program which coordinates access to dentists throughout the EMA. Dentists are reimbursed by Part A for clients without any other form of coverage. Thirty-five percent of dental clients served in FY08 were from communities of color (estimate includes clients who identified as unknown/unreported).⁹

Dental services were listed as the fifth most needed and used service and the fourth most essential service in the JSI 2009 Consumer Needs Assessment preliminary data. In this same data, dental services were identified as a service gap and a service with an identified barrier.³⁰ In the Suffolk outcomes analysis (2008), clients receiving dental services had significantly higher outcome scores for CD-4 count and housing status, when compared to people accessing other core and support services. Comparing service categories, clients receiving dental services had significantly higher aggregate health and quality of life outcomes.⁹³

Mental Health Services

Mental health programs provide psychological and psychiatric treatment in individual, group, and family sessions. In FY08, 56% of mental health clients in the Boston EMA receiving services from Part A were from communities of color (estimate includes clients who identified as unknown/unreported).⁹

The Planning Council ranked mental health services fifth in the most recent (FY10) priority setting exercise. Providers and consumers have identified mental health services as essential, but not easily accessible, especially home-based services.⁹⁴

Substance Abuse Services

The continuum of substance abuse treatment modalities provides clinical addiction counseling in several settings, including outpatient counseling, free standing detoxification services, and substance abuse recovery home treatment. The substance abuse programs incorporate a harm reduction and relapse prevention model. Needle exchange programs also operate in Boston and Cambridge with funding from the state of MA. In MA, legislation was passed in 2006 decriminalizing the purchase and possession of hypodermic needles without a prescription. In doing so, the state also charged MDPH and local public health officials with providing education about safe and proper collection and disposal of used needles. In addition, the federal government has recently lifted the ban on using federal funds to pay for needle exchange programs.

Substance abuse services play a critical role in HIV services and treatment by stabilizing patients, allowing them to become eligible for care and remain in treatment, and enabling adherence to treatment regimens. In FY08, 52% of substance abuse clients in Boston's EMA Part A were from communities of color (estimate includes clients who identified as unknown/unreported).⁹

According to Suffolk University, a significantly higher proportion of clients receiving substance abuse services had poor outcome levels for housing status (homeless, recently evicted, or home uninhabitable).⁹³

Medical Case Management

Case management is the core service component that ensures newly infected, recently tested, and underserved individuals gain access to care, while managing the continued care of ongoing clients. Comprehensive case management services in the EMA are an extensive, multi-leveled, coordinated system of care. Services provide a continuum of information and referral, advocacy, client assessments, the development of individualized service care plans, and comprehensive care coordination and adherence support. Many programs typically provide a range of coordinated care, including linking a client to primary medical care as well as health-related support services. Specific medical case management allows the case manager to monitor the course of a client's disease progression, provide treatment adherence support, monitor the side effects of treatment, and coordinate access to specialty care. This approach and integration of care removes barriers to services and provides comprehensive HIV care to those traditionally underserved and disproportionately impacted by the epidemic. The demographic profile for case management services in FY08 was 53% White, 41% Hispanic, 32% Black, 7% Haitian, and 7% African (noting that some clients declared belonging to multiple ethnic groups).⁹

The Part A case management programs are part of a coordinated network of HIV case management programs combining BPHC Part A with Part B dollars from MDPH and state AIDS funding. The collaborative was originally designed to coordinate funding streams in three cities (Boston, Cambridge, and Somerville) located within the EMA. The Case Management

Collaborative has since been expanded to eliminate duplication of Ryan White funded efforts and services between MDPH Part B and BPHC Part A case management programs in the overlapping EMA and MA regions. The collaboration has standardized care across the EMA and culminated with a joint review and procurement of case management services which started in 2005. Case management services and training continue to be jointly managed by the funders.

The Case Management Collaborative has improved the quality of life for PLWH across the EMA. Funding priorities consider service providers that integrate medical and support services for comprehensive care in linguistically and culturally appropriate settings in accordance with the HIV/AIDS Case Management Standards of Care. The ultimate goal of case management is to help clients enter into and remain in primary care. In the process, programs must facilitate each client's progress towards self-sufficiency. Primary case management activities include assessment of the client's needs and personal support systems, development of a comprehensive individualized service plan, coordination of the services required to implement the plan, monitoring of the client's progress to assess the efficacy of the plan, and periodic reevaluation and revision of the plan as the needs of the client change over time. Clients are referred to case management services through a variety of health access points, including primary care, substance abuse facilities, detoxification units, homeless shelters, and emergency rooms.

The case management system is closely linked to counseling and testing providers as well as early intervention providers. For case management programs that do not offer these services on site, agreements and linkages are made within the community and at service centers that target similar populations. Some programs have case managers who work off-site and go directly to the early intervention service sites to reach the clients where they are located. Others travel to primary care sites and provide on-site services at infectious disease clinics. There are several programs that initiate contact with clients who are incarcerated, coordinating service upon the client's release. By providing case management services in a variety of settings, such as community health centers, case managers can assist newly identified consumers, as well as ongoing clients, in accessing primary care and supportive services.

In FY08, the case management collaborative included a total of 29 programs, including 18 case management contracts in the EMA that the Grantee funds. Additionally, the Grantee funds eight case management programs through MAI funding. Programs funded include, but are not limited to, those that target: Blacks/African-Americans, Haitians; Latinos/Hispanics; Portuguese speakers; substance abusers; the deaf and hard of hearing; the homeless; the formerly incarcerated, including those recently released; and MSM.

In a JSI Consumer Satisfaction Survey (2007) about case management, clients reported an exceptionally high level of satisfaction with the quality of services being provided. Respondents also reported (between 84% and 86%) that case management is either "extremely" or "very important" in keeping them healthy and linking them to HIV medical and support services.²⁷

HEALTH-RELATED SUPPORT SERVICES

A spectrum of health-related support services are available assisting PLWH to access, remain in care, and to link those who know their status, but are not in care to the continuum of care. These five support services include housing services, psychosocial support, food bank/home-delivered meals, medical transportation services, and non-medical case management. The goal

of these services is to enhance the ability of new clients, as well as those who have been in care, to remain in treatment, adhere to drug therapy, and cope with activities of daily living.

Housing Services

Housing services include short-term rental assistance, supportive services within housing programs, and housing advocacy/search for transitional and permanent housing. Wrap-around services, including case management and clinical counseling sessions, are part of an integrated, intensive model of care for PLWH. Upon transition to permanent housing settings, clients achieve self-sufficiency to access the same services independently and more consistently due to stable housing. In FY08, the demographic profile of housing services was 49% White, 38% Black, 32% Hispanic, 11% African, 10% Haitian, 6% Cape Verdean, and 4% Brazilian (noting that some clients declared belonging to multiple ethnic groups).⁹

In the preliminary data of the JSI 2009 Consumer Needs Assessment, rent and housing search were identified as two of the top five service gaps. Rent was also identified as a service with an identified barrier.³⁰ In the Suffolk outcomes analysis by service category (2008), clients receiving housing services were reported to have a fair outcome level for impact of side effects and access to psychosocial support. A significantly higher proportion of clients receiving housing services were reported to have excellent outcome levels for mental health status and level of self sufficiency.⁹³

Psychosocial Support

Peer support plays a vital role by having peer leaders assist clients with coping mechanisms and in providing guidance to health services in the continuum, particularly for communities of color. HIV peer support services utilize individuals living with HIV/AIDS to help clients navigate the healthcare system, including primary medical services, prescription drug coverage, and other essential clinical services. At the same time, peer providers engage clients in practical skills building around treatment adherence and side effects management. In FY 08, 48% of people accessing Part A peer support programs were people of color.⁹

Peer support was identified as a service with an identified barrier in the preliminary data of the JSI 2009 Consumer Needs Assessment.³⁰ In a JSI Consumer Satisfaction Survey, 74% to 89% of respondents were either “extremely” or “very” satisfied with the quality of services provided. Between 75% and 84% responded that peer support programs are either “extremely” or “very” important to their overall healthcare.²⁷ A significantly higher proportion of clients receiving peer support services were reported to have excellent outcome levels for CD-4 count, viral load, maintenance of primary medical care, adherence to HIV medications, access to psychosocial support, and level of self sufficiency.⁹³

Food Bank/Home-Delivered Meals

Food programs include culturally appropriate congregate meals, food vouchers, nutritional consultations and supplements, and food pantry services. Home-delivered meals are also provided through various food programs which are based on client need with eligibility determined by a comprehensive medical assessment. In FY08, 48% of Part A food services

were provided to people of color (estimate includes clients who identified as unknown/unreported).⁹

In the preliminary data of the JSI 2009 Consumer Needs Assessment, food vouchers/food bank was named as a service gap, as well as a service with identified barriers. Home-delivered meals and congregate meals were listed as non-essential services.³⁰ According to Suffolk University, a significantly higher proportion of clients accessing food services were reported to have excellent outcome levels for adherence to HIV medications and access to psychosocial support.⁹³ Respondents to the JSI Consumer Satisfaction Survey reported that food services play an important role in their overall health care, with between 76% and 86% reporting that food services are either “extremely” or “very” important in keeping them healthy and linking them to HIV medical and support services.²⁷

Medical Transportation Services

Transportation programs provide taxi vouchers, public transportation, coordination of volunteer transportation, and agency-sponsored vans to transport clients to vital medical and social service appointments. In FY 08, 53% of Part A transportation services were provided to people of color (estimate includes clients who identified as unknown/unreported).⁹

According to Suffolk, a significantly higher proportion of clients receiving transportation services were reported to have excellent outcomes for viral load. At a community forum in Sturbridge, MA, consumers identified transportation as a barrier to care, specifically in rural areas.⁹⁴

Non-Medical Case Management

Client advocacy provides short-term assistance with financial and legal services, such as financial benefits, health insurance, and immigration issues. The emphasis is on targeted service coordination in a limited time span for clients who are chronically homeless or diagnosed with multiple co-morbid conditions. Once clients are stabilized, providers are then able to transition them into ongoing case management services. In FY08, 48% of Part A services were provided to people of color (estimate includes clients who identified as unknown/unreported).⁹

In the preliminary data from the 2009 Consumer Needs Assessment, legal help was identified as a service gap.³⁰ According to Suffolk, a significantly higher proportion of clients receiving client advocacy services were reported to have poor/in crisis levels for maintenance of primary medical care and housing status.⁹³

Minority AIDS Initiative (MAI)

The Boston EMA has a history of contracting with minority community-based providers, many of whom have a greater understanding of the social and cultural issues related to their target communities. Agencies funded under the Part A MAI program offer a combination of services that target PLWH from communities of color who are not currently in care. The MAI programs engage clients through professional and culturally competent case management and peer support groups that assist clients in accessing the full range of medical and health-related

support services. MAI programs located at community health centers in minority neighborhoods have been particularly effective in engaging consumers in care and reducing health disparities.

MONITORING THE CONTINUUM OF SERVICES

The continuum of care available in the EMA has continued to succeed at improving access to care and decreasing healthcare disparities across all services. One goal of the continuum of services is to ensure that the service utilization profile is reflective of the epidemic, and is serving populations who have been disproportionately impacted by HIV and traditionally underserved. FY08 utilization data for Part A services demonstrates the success programs have had in providing access to these hard-to-reach populations in the EMA. Table 2 shows that the service profile closely matches the profile of the epidemic with regard to race/ethnicity.

Table 4: Service Profile by Race/Ethnicity in Boston EMA

Demographic Group	AIDS Incidence 1/1/07 -12/31/08	HIV/AIDS Prevalence as of 12/31/08	Service Profile 3/1/08 – 2/28/09
White, Non-Hispanic	40%	48%	36%
Black, Non-Hispanic	35%	30%	28%
Hispanic	22%	21%	32%
Asian/Pacific Islander	3%	2%	1%
American-Indian/ Alaska Native	<1%	<1%	1%

When awarding contracts, the Grantee is guided by a set of funding principles developed by the Council. These principles mandate that funded programs must provide culturally competent services that are accessible to all PLWH in the EMA. In addition, programs must be linked to the continuum of care in order to assure that clients have barrier-free access to a full range of health-related supportive services. Programs are contractually required to describe their linkages with health access points and document how they follow-up on referrals to ensure that clients remain in care. Documentation of linkages is monitored through site visits. These funding principles have also been incorporated into the ongoing monitoring of programs.

The EMA works to ensure access for underserved populations by contracting with minority agencies as well as those that have a history of successfully targeting and reaching underserved populations. The current group of contracted Part A providers includes those who specialize in providing services to PLWH who are African-American, Latino, Haitian, Portuguese, Brazilian, Cape Verdean, homeless, women, children, adolescents, MSM, those recently released from incarceration, and those with a history of substance abuse.

The Grantee requires that all funded programs, regardless of service category, conduct a complete assessment and service care plan for their clients. At a minimum, this includes assessing the medical, financial, housing, mental health, and substance abuse service needs of the client. For those with unmet needs, programs are responsible for linking clients to appropriate internal or external services. Providers must demonstrate they have appropriate linkages to other services, including primary care and support services, and that they follow-up on referrals to ensure that clients are not lost. All programs are contractually required to ensure that their clients are enrolled in primary care.

Part A funding has maximized resources within the EMA's comprehensive network of medical care and health-related supportive services. The breadth of the continuum of care ensures that the needs of all PLWH, and in particular newly affected populations, are met with high quality and culturally appropriate services.

Section V: Resource Inventory

The Resource Inventory describes the available sources of funding within the Boston Eligible Metropolitan Area (EMA). This chapter discusses general eligibility requirements and benefits packages for each payer, as well as the client utilization of these resources.

Provider Descriptions

Ryan White HIV/AIDS Treatment Extension Act of 2009

Part A – Emergency Assistance to Areas Most Affected by the HIV/AIDS Epidemic (Formerly Title I)

The method for determining eligibility for Part A (formerly called Title I) funds gives priority to urban areas with the highest number of people living with AIDS; metropolitan areas with a cumulative of more than 2,000 cases of AIDS during the most recent five-year period and a population of 50,000. The City of Boston receives Part A funding for the Boston EMA. For FY09, Part A received \$12,451,187 and \$843,100 in Minority AIDS Initiative (MAI) funds.⁹

Part B – Grants to States (Formerly Title II)

Part B provides formula funding to states and territories to improve the quality, availability, and organization of health care and support services for consumers. For FY09, MA received \$19,889,352 and NH \$1,502,980 in Part B funding.¹¹

Part C – Funds to Communities — Early Intervention Services (EIS) (formerly Title III)

Part C supports comprehensive primary health care and other outpatient services for individuals who have been recently diagnosed with HIV. Part C funding has been awarded to five agencies located within the Boston EMA. A total of \$8,162,206 was awarded within the Boston EMA in FY08. Fiscal years for Part C services in the Boston EMA vary typically occurring January to December, and others occurring July to June. Several outliers had fiscal years that did not fall in either of these fiscal year groupings.¹²

Part D - Support services for women, infants, children & youth (Formerly Title IV)

Part D provides funding for comprehensive, community-based, and family-centered outpatient or ambulatory services to children, youth, and women living with HIV and their families. There was \$3,378,489 in Part D funding in the Boston EMA in FY08. Fiscal years for Part D services in the Boston EMA vary with some occurring August to July, and others occurring January to December. Several outliers had fiscal years that did not fall in either of these fiscal year groupings.¹²

Part F – Dental Reimbursement

The dental reimbursement program assists accredited dental schools and post-doctoral dental programs with uncompensated costs incurred in providing oral health care treatment to PLWH. There are five institutions that receive dental reimbursement through the Ryan White Act in the

Boston EMA. There was \$621,825 in Part F Dental Program funding in the Boston EMA in FY08. Most Part F Dental Program fiscal years run from July to June.¹²

Part F – AIDS Education and Training Centers (AETC)

The AETC Program is a network of 11 regional centers and 130 associated sites, which conduct targeted, multi-disciplinary clinical education and training programs for health care providers. In FY08 the NEAETC was allocated \$1,747,474.¹³

Part F – Special Projects of National Significance (SPNS)

The SPNS program is intended to advance knowledge and skills in the delivery of health and support services to underserved PLWH. There are two SPNS projects in the Boston EMA; Part F was awarded \$1,350,000 in FY08.¹⁴

Commonwealth of Massachusetts AIDS Line Item

MA provides funding for HIV/AIDS services through the *Department of Public Health (DPH)* AIDS budget line item (\$37.2 million in FY09).¹⁵

New Hampshire State Funds

In FY05, NH provided state funds for HIV/AIDS services for the first time. In FY 2008, \$500,000 was directed to the NH ADAP. In FY09, the \$500,000 allocated to NH ADAP was cut by the state of NH.¹⁶

Medicaid

Medicaid is the federal health insurance program administered by states; each state sets its own guidelines regarding eligibility and service provision. Medicaid is the primary payer of health services for PLWH in the Boston EMA.¹⁷ In MA, the standard Medicaid benefits package covers comprehensive primary and inpatient health services, including primary care, ob/gyn, substance abuse, mental health, and transportation services.¹⁷ Unlike MassHealth, NH Medicaid does not provide substance abuse services.¹⁸ Eligibility for both MA and NH are based on income levels and disability status. In 2008, 389 PLWH in NH received Medicaid assistance; a total of \$433,871 in expenses.¹⁸ For FY09, Masshealth expended a total of \$160,427,748 for 13,172 Medicaid enrolled PLWH. Lastly, 45% of Part A consumers were Medicaid recipients in FY08, compared to 17% of the general population in MA and 7% of the general population in NH.^{17,18}

Commonwealth Care/Connector

The Health Reform Law of 2006 extends access to medical insurance to all MA residents who are US citizens and qualified aliens. Commonwealth Care is for uninsured citizens or qualified aliens aged nineteen years or older who earn less than 300% FPL (currently \$32,490 for an individual), and do not have access to Medicare, Medicaid, or employer coverage.¹⁷ The Commonwealth Connector also provides nonsubsidized, 'affordable' plans available for

purchase through the Connector Board for those with an income over 300% FPL (currently \$32,490), including uninsured people living with HIV/AIDS.¹⁸ On August 31, 2009, the Massachusetts legislature cut \$130 million in funding for legal immigrants under the five year bar in Commonwealth Care, and allocated \$40 million for a new CommCare Bridge program for these individuals.¹⁷ CommCare Bridge is currently being administered by CeliCare, a private health care company.

Private Insurance

Some PLWH have private medical insurance and are able to receive health services at one of the private hospitals or at a community health center. Of 6,191 unduplicated Part A consumers in FY08, 1,009 were enrolled in private insurance programs, which is an increase from FY07.⁹ This number is expected to increase as the Massachusetts Health Reform Law of 2006 is implemented and more MA consumers are enrolled in private health insurance programs.

Medicare

Medicare is the health insurance program that is administered by the Federal government for people who are at least 65 years old or who are disabled (which includes an AIDS diagnosis). Some people are eligible for both Medicaid and Medicare and are thus considered dually-eligible. People who are dually-eligible typically receive the most support from their Medicaid funded programs, as Medicaid services are usually more comprehensive in scope than Medicare services. As of January 1, 2006 Medicare prescription drug coverage is available to everyone with Medicare (Part D). Private insurance companies provide drug coverage for beneficiaries who enroll and pay premiums. Medicare Part D plans have set prescription benefits that vary from plan to plan and co-payments range from \$0-\$5. Medicare Part D has a complex reimbursement and benefits system involving several stages of individual contribution. AIDS Drug Assistance Program funds assist in covering medication costs throughout these complicated stages. People who are dually-eligible continue to receive their prescription drug benefits through their Medicaid program.

Massachusetts Bureau of Substance Abuse Services (BSAS)

Massachusetts provides funding for substance abuse services through the DPH Substance Abuse Treatment line item. The Massachusetts Bureau of Substance Abuse Services administers these funds, as well as federal funds received from Substance Abuse and Mental Health Services Administration (SAMHSA). While HIV-status of clients is not collected, BSAS provides a range of HIV-related services to injection drug users, HIV-positive consumers, and others at high risk for HIV infection who are prioritized for admission to the services provided by BSAS programs. The Massachusetts Bureau of Substance Abuse Services reported that \$96.7 million will be available for substance abuse treatment services in the EMA in FY10.¹⁹

NH Bureau of Drug and Alcohol Services

The majority of people receive substance abuse treatment services in detox, outpatient, intensive outpatient, short-term residential and low-intensity residential. Although the NH Bureau of Alcohol, Tobacco and Other Drugs does not prioritize PLWH for substance abuse treatment

services, all people entering substance abuse treatment receive an HIV risk assessment, access to counseling and testing referrals, and receive ongoing risk reduction education. The NH Bureau of Drug and Alcohol Services reported \$9.5 million was available in NH for substance abuse services in FY09.²⁰

Housing Opportunities for People With AIDS (HOPWA)

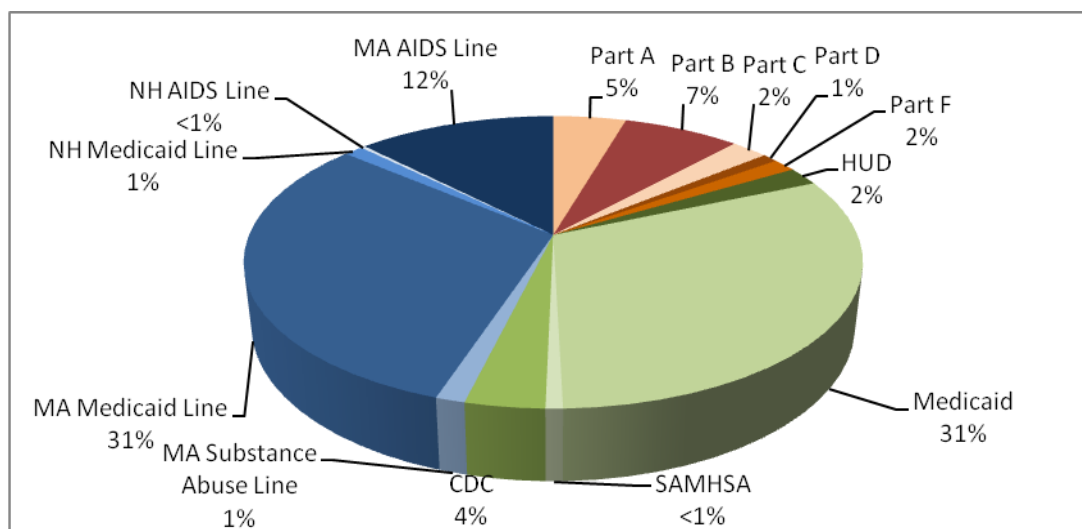
Ninety-percent of HOPWA funds are distributed to eligible metropolitan service areas through the formula award; 10% of HOPWA funds are awarded through competition for SPNS. In FY09, HOPWA was awarded \$315 million.²¹ In MA, formula awards are allocated to Boston, Lynn, Lowell, Springfield, Worcester and MDPH. Housing Opportunities for People with AIDS formula awards to Rhode Island include funding for Bristol County, MA. The Boston EMA contains twelve HOPWA grantees. In MA, HOPWA is used for emergency assistance, long-term rental assistance & services connected to housing.

Conclusion

As diverse as the array of services provided is the variety of funding sources. Within the Boston EMA, there are over 10 payers, with Medicaid contributing the most dollars (62% of funding). Massachusetts State funds is the second biggest payer of HIV/AIDS services. Housing Opportunities for People with AIDS, BSAS, NH Bureau of Alcohol, Tobacco and Other Drugs, Private Insurance, Medicaid, Commonwealth Care/Choice, NH state funds, and Ryan White dollars all also contribute to the general funds for HIV/AIDS services.

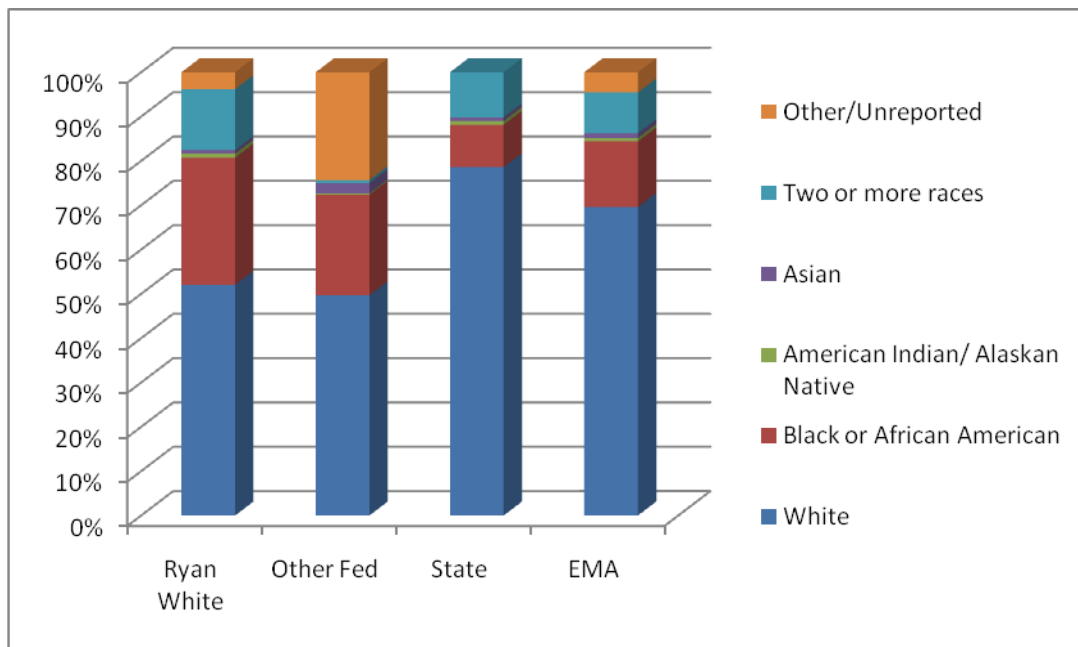
To summarize, Figure 9 illustrates the contribution of each of the aforementioned payers to the HIV/AIDS continuum of care in the Boston EMA.¹²

Figure 10: Funding Streams Breakdown in the Boston EMA



Comparing the demographics of the consumers using services in the Boston EMA across multiple funding streams helps assure there is proportional population-specific service delivery and outreach to all the impacted populations. Figure 10 illustrates the proportional representation of racial populations within multiple funding streams for FY08.

Figure 11: Boston EMA Utilization by Race for Each Funding Stream



Section VI: Implications and Conclusions

This section discusses how barriers to care and instances of unmet need create unique challenges to delivering health-related services in the Boston EMA.

Advances in treatment and services that enable PLWH to live longer, coupled with newly diagnosed infections, have led to an increase in the number of PLWH, while the cost of services and medications is rising. Identifying PLWH who know their HIV status but are not in care, and serving those with unmet need continues to present a challenge and additional cost to the service system. Further challenges include disparities in risk, infection rates, mortality, poverty, health insurance status, access to care among special populations and complex interactions among co-morbidities that affect the cost and complexity of care for PLWH. The rising costs of services; in particular ADAP, and the decreasing funding for supportive services (local factors such as a severe affordable housing crisis, as well as, federal factors such as revisions of the Ryan White legislation) create service delivery challenges.

Improvements in the medical care of HIV infection and the availability of a continuum of care, including early intervention services for PLWH, have resulted in a more than 60% decline in AIDS deaths since 1996.^{2,3} AIDS deaths, however, continue to be substantially higher for Blacks and Hispanics than for Whites.^{2,3} The number of new AIDS cases has also continued to decline in the Boston EMA, but there have been significant increases in the number and proportion of women, and people of color who make up the total number of AIDS cases as compared to national averages.^{2,3,4} The diversity of the EMA's epidemic increases the severity of need for services among PLWH, and impacts the type and range of services needed to bring people into care and keep them healthy. Regional variations in the demographics of the HIV epidemic in the EMA add additional challenges due to the need for culturally and linguistically appropriate strategies and types of services within each area.

The increase in co-morbidities, homelessness, and poverty affecting PLWH has meant that consumers entering care do so with a more complicated set of interconnected issues than in earlier years of the epidemic, and they have a wide array of service needs. All of these factors combine to present multiple service delivery challenges that require the maintenance of a flexible continuum of care that can meet the varied needs of PLWH.

Since FY01, Massachusetts has implemented significant reductions to state-funded public health programs, including a \$19 million reduction for HIV/AIDS services (a 38% reduction since FY01) and an \$11 million reduction for substance abuse treatment. The FY05 reduction to the EMA's Part A award (\$1.2 million reduction), and the \$733,000 reduction in the FY09 award has also impacted the continuum of care. While core services for PLWH have been maintained as much as possible, HIV services such as home care, day care, respite care, adoption/foster care, complementary therapies, STD services, positive prevention programs, counseling and testing, integrated HIV/STD/Hepatitis C services, services that link patients to health care and maintain residents in community-based housing, and substance abuse treatment for opiate-dependent PLWH have been reduced or eliminated. State funding for evaluation, technical assistance, and training for HIV/AIDS programs have mostly been eliminated and will impact the quality of services offered by health care and support service providers. With these ongoing reductions to critical health-related support services, maintaining people in medical care will continue to become more challenging.

Reductions in funding have destabilized the comprehensive, high quality continuum of HIV-related services that has been built in the Boston EMA. There is always a need for more money, and core services need additional resources to maintain a growing system. However, the network of supportive services, such as peer support, food services, transportation, and housing support, have played critical roles in helping PLWH gain and maintain their access to medical care. Therefore, the challenge will be in how to balance the need for both types of services. Reduced funding also creates an incentive to develop economies of scale by supporting larger multi-service organizations. The challenge is how to continue to support smaller community-based organizations that are located in communities of color and have the cultural and linguistic capacity to reach those new to care and those who know their HIV status, but are out of care. With more PLWH being identified and brought into care, the capacity of the services system will continue to be strained.

Section VII: Recommendations

The mandate of the Planning Council is to improve the quality of the lives of all people living with HIV/AIDS throughout the Boston EMA by responding to their existing and emerging needs. The recommendations listed below are ways the Council, the Grantee, and the Boston EMA can continue responding to the Council's mission, both directly and indirectly.

Maintain a stable, high quality continuum of core and support services for people living with HIV/AIDS in the Boston EMA.

- Develop methods for bringing into care those who are HIV-positive but not in treatment.
- Maintain a continuum of care that reflects the needs of all people living with HIV/AIDS.
- Continue to review and revise existing standards of care for each service category, as needed and as services come up for bid, to ensure high quality services and develop new standards for new services, as needed.
- Continue to assess the need and appropriately allocate funds for core health services as well as health-related support services that facilitate, enhance, support or sustain the delivery, continuity, or benefits of health services for individuals and families with HIV.

Improve the capacity of programs and agencies in the Boston EMA to meet the needs of their clients and to deliver high quality services.

- Ensure that local programs have knowledge of and access to recent grants awarded to the region for technical assistance and capacity building programs.

Facilitate collaboration among agencies in the planning and delivery of services to ensure comprehensive care for consumers.

- Guide agencies into closer collaborations through the Request for Proposals (RFP) process in order to maximize efficiency and reduce program duplication.
- Create a central database for information sharing across agencies and funders.

Ensure coordination and collaboration with substance abuse service providers, including the Massachusetts Bureau of Substance Abuse Services (BSAS), the EMA's largest funder of substance abuse services.

- Ensure continued representation from substance abuse service providers on the Planning Council.

- Continue to work with the Bureau of Substance Abuse Services to collect information annually on the range of services provided and clients served, in order to coordinate services, identify gaps in the continuum, and ensure that Part A funds are the payer of last resort.

Ensure coordination with the Massachusetts and New Hampshire Medicaid programs, the largest funders of services for people living with HIV in the EMA.

- Ensure representation from Medicaid on the Planning Council.
- Continue to work with the MA Office of Medicaid to collect information annually on the range of services provided, clients served, and eligibility requirements.

Reduce the complexity of the service system and the burdens to providers and consumers.

- Explore establishing centers of excellence in HIV care to provide “one stop shopping” for services by consolidation of services where practical and efficient.
- Explore the feasibility of moving other services into collaborative arrangements.
- Explore the feasibility and impact of different contract cycles or structures (e.g., longer cycles, all services in single RFP, maintain existing structure, etc).

Develop methods for bringing into care those who are HIV-positive but not in treatment, with particular attention to eliminating the disparities in access and services among affected populations and historically underserved communities.

- Use guidance from HRSA and other EMAs to develop and implement strategies for bringing people into care who know their serostatus.
- Use support services contracts and existing bi-annual needs assessment activities to gather data on this population.
- Work collaboratively with the Massachusetts Part B program to gather this information on the needs of people with HIV/AIDS not in care to reduce burden and prevent duplication of effort.
- Maintain and strengthen links between counseling and testing sites and Part A funded programs to ensure a seamless continuum of care and to facilitate points of access to services after a person tests HIV positive.

Monitor and respond to programmatic changes in the Massachusetts Health Reform, National Health Reform, the Medicaid waiver in Massachusetts and in expanding Medicaid eligibility to those who are HIV-positive.

- Monitor annual expenditure data from Medicaid, and utilization data from Part A and Part B/state programs to detect potential impacts of the expanded coverage.
- Adjust funding allocations appropriately to respond to the increased availability of some services to a greater proportion of people living with HIV/AIDS in the Boston EMA, and to the increased need for services not covered by Medicaid.

Develop greater collaboration with HIV prevention programs within the EMA.

- Ensure representation from the Massachusetts HIV/AIDS Bureau's Prevention Programs and the New Hampshire Department of Health and Human Services Prevention Programs on the Council.
- Begin to collect funding and service program data on prevention programs in the EMA to be incorporated during the annual planning and resource allocation processes.

Ensure that the administrative mechanism is efficient, open, and rapidly allocates funds to the areas of greatest need.

- Continue providing a forum at Council meetings for the Grantee to report on its progress in allocating Part A funds.
- Certify annually, by vote of the Council, that the Grantee has rapidly allocated funds in accordance with the Council priorities.
- Continue providing regular presentations by the Grantee on the agency monitoring process.

Develop skills among people living with HIV to assume leadership roles on the Council and in the community.

- Continue to develop and refine the Council orientation process to ensure that Council members get adequate information about the Council's work and about working with community members on the Council.
- Continue offering the Laptop Program for consumers and provide further training to empower their participation on the Council.
- Ensure that Council members are receiving training and technical assistance.
- Encourage participation in the Consumer Committee, especially new Council members.

Ensure that the Council continues to be reflective of the epidemic in the EMA.

- Monitor HIV and AIDS surveillance data for emerging trends in the epidemic.
- Continue to develop and implement strategies annually for recruiting potential Council members from all affected populations throughout the EMA.
- Ensure that recruitment of applicants and final appointments meet membership requirements.
- Sponsor annual presentations throughout the EMA to provide information about the Council and its work and to solicit interest and potential applicants.

Ensure that the Consumer membership of the Council continues to exceed the minimum requirements.

- Continue to develop and implement strategies annually for recruiting potential consumer members of the Council from all affected populations throughout the EMA.
- Sponsor annual presentations throughout the EMA to provide information about the Council and its work and to solicit interest and potential applicants, with particular focus on Consumer Advisory Boards and other consumer focused programs and spaces.

Ensure that support services are not only available, but enable access to and maintenance of existing funded support services.

- Continue to apply for a core medical service waiver, to assure that non-core services are funded.

Remain in constant communication with key stakeholders.

- Continue having organization updates from the Grantee, MDPH, and NHDHHS at every Council meeting.

Ensure agencies are following the standards of care.

- The Grantee will continue to conduct site visits and collect quarterly and yearly reports.
- Monitor health and quality of life outcomes of PLWH in the Boston EMA.

Identify the current service needs of PLWH in the Boston EMA through surveys and research studies.

- The Grantee will continue to contract out with evaluation agencies for assessment purposes.
- Evaluate data to identify changes in service patterns.

Appendices

Table 1: AIDS Incidence, AIDS Prevalence and HIV Prevalence by Demographic Group and Exposure Category

	AIDS INCIDENCE 1/1/07 - 12/31/08		AIDS PREVALENCE as of 12/31/08		HIV PREVALENCE as of 12/31/08		HIV/AIDS PREVALENCE as of 12/31/08	
	The number of <u>new</u> AIDS cases as reported to the CDC		The number of people living with AIDS		The number of people living with HIV (non-AIDS)		The number of people living with HIV (non-AIDS) and AIDS	
Race/Ethnicity	#	%	#	%	#	%	#	%
White, not Hispanic	250	40%	3849	46%	3269	49%	7118	48%
Black, not Hispanic	217	35%	2541	31%	1892	28%	4433	30%
Hispanic	138	22%	1774	21%	1323	20%	3097	21%
Asian/Pacific Islander	16	3%	131	2%	100	2%	231	2%
American Indian/Alaska Native	1	<1%	8	<1%	7	<1%	15	<1%
Not Specified ¹	0	0%	13	<1%	56	1%	69	<1%
Total	622	100%	8316	100%	6647	100%	14963	100%
Gender								
Male	414	67%	5951	72%	4662	70%	10613	71%
Female	208	33%	2365	28%	1985	30%	4350	29%
Total	622	100%	8316	100%	6647	100%	14963	100%
Age at Diagnosis (years)²								
<13 years	0	0%	14	<1%	47	1%	61	<1%
13-19 years	12	2%	55	1%	112	2%	167	1%
20-44 years	383	62%	3040	37%	3282	49%	6322	42%
45 + years	227	36%	5207	63%	3206	48%	8413	56%
Total	662	100%	8316	100%	6647	100%	14963	100%
Mode of Exposure								
Men who have sex with men (MSM)	192	31%	2741	33%	2753	41%	5494	37%
Injection drug users (IDU)	96	15%	1987	24%	1114	17%	3101	21%
MSM / IDU	26	4%	284	3%	195	3%	479	3%
Heterosexual Sex ³	221	36%	2564	31%	1880	28%	4444	30%
Perinatal	11	2%	119	1%	170	3%	340	2%
Other ⁴	3	<1%	80	1%	22	<1%	102	1%
Risk not reported/identified	73	12%	541	7%	513	8%	1003	7%
Total	622	100%	8316	100%	6647	100%	14963	100%

¹Race was either not specified or unknown; includes multi-race (NH)

²Prevalent cases in the New Hampshire counties of the EMA are reported by age at diagnosis

³Includes presumed heterosexual, unknown risk of partner and primary risk categories have been denied

⁴Includes hemophilia and all other cases with identified modes of transmission not listed here

SOURCE: MDPH and NHDHHS

Table 2: Issues Affecting Access to Care for PLWH

ESTIMATED ANNUAL HIV CARE COSTS		
For PLWH without advanced disease	For PLWH with advanced disease	Data Source
<ul style="list-style-type: none"> • \$25,200 for PLWH initiating ART with CD4 cell count <200/microliter 	<ul style="list-style-type: none"> • \$25,574 for PLWH initiating ART with CD4 cell count <350/microliter 	Schackman BR, et al. The Lifetime Cost of Current Human Immunodeficiency Virus Care in the United States. <i>Medical Care</i> . 44.11(2006)
POVERTY STATUS		
Estimated percentage of people in EMA below 100% of FPL	Estimated percentage of PLWH in EMA below 100% of FPL	Data Source
<ul style="list-style-type: none"> • 9% of EMA population; 549,401 people below 100% FPL • 21% of EMA population; 1,255,947 people below 200% FPL • 33% of EMA population; 2,028,615 people below 300% FPL 	<ul style="list-style-type: none"> • 79% of Part A clients below 100% FPL • 90% of Part A clients below 200% FPL • 93% of Part A clients below 300% FPL 	<ul style="list-style-type: none"> • United States Census Bureau, American Community Survey 2008 • BPHC, Part A utilization data FY08.
INSURANCE STATUS		
Estimated percentage and number of people in EMA without insurance coverage, including without Medicaid, 2007-2008	Estimated percentage of PLWH in the EMA without insurance coverage, including without Medicaid	Data Source
<ul style="list-style-type: none"> • 7.3% of non-elderly MA adults; 14% of non-elderly NH adults; 400,620 non-elderly adults • 5.4% of MA population; 10.4% of NH population; 481,300 people 	<ul style="list-style-type: none"> • 6% of Part A clients 	<ul style="list-style-type: none"> • Kaiser Family Foundation State Health Facts Online, 2007-2008. • BPHC, Part A client utilization data FY08.
UNEMPLOYMENT RATES		
Estimated percentage of people in EMA who were unemployed in July 2009	ESTIMATED PERCENTAGE OF PLWH IN EMA WHO WERE UNEMPLOYED IN DECEMBER 2008	DATA SOURCE
<ul style="list-style-type: none"> • 8.8% in MA • 6.9% in NH 	<ul style="list-style-type: none"> • Not available. 	<ul style="list-style-type: none"> • United States Department of Labor, Bureau of Labor Statistics.
MEDICAID COVERAGE		
Estimated percentage and number of people in EMA enrolled in Medicaid, 2007-2008	Estimated percentage and number of PLWH in EMA with Medicaid coverage	Data Source
<ul style="list-style-type: none"> • 17.4% in MA • 6.9% in NH • 1,197,600 people 	<ul style="list-style-type: none"> • 13,141 PLWH enrolled in EMA counties of MA • 65% of PLWH in the 	<ul style="list-style-type: none"> • Kaiser Family Foundation State Health Facts Online, 2007-2008. • JSI Preliminary data, 2009

	<p>EMA</p> <ul style="list-style-type: none"> • 44% Caucasian • 20% Black • 10% Hispanic 	<ul style="list-style-type: none"> • MA Office of Medicaid, 11/13/08
	<p>Estimated percentage of total funds for care for PLWH in the EMA from Medicaid</p>	<p>Data Source</p>
	<ul style="list-style-type: none"> • 94% of Primary Care Funds • 76% of Medication Funds • 63% of Mental Health Funds • 13% of Substance Abuse Funds 	<ul style="list-style-type: none"> • Kirchgasser, Alison. "MassHealth and People with HIV/AIDS." EMA Planning Council Meeting. Boston, MA. 13 Nov. 2008. Address.
HOUSING AND HOMELESSNESS		
<p>Homelessness among all people in the EMA</p>	<p>Homelessness among PLWH in the EMA</p>	<p>DATA SOURCE</p>
<ul style="list-style-type: none"> • 13,700 individuals in EMA in January 2007 • 7,681 individuals on the streets and in shelters in Boston, MA in December 2008 • 5,029 people received emergency or transitional housing in NH during FY08 • 19,000-29,000 at some point each year in MA 	<ul style="list-style-type: none"> • Among Part A clients: 12% homeless or living in uninhabitable shelters • 12% facing eviction or in need of housing placement • 40-60% PLWH experience homelessness in lifetime 	<ul style="list-style-type: none"> • HUD: <i>The Third Annual Homeless Assessment Report to Congress</i>. 2008 • City of Boston. <i>Homelessness in the City of Boston: Annual Census Report 2008</i> • NHDHHS. <i>Emergency Shelter and Homeless Coordination Commission Annual Report, 2008</i> • UMASS Boston. <i>Hard Numbers, Hard Times: 1999-2003</i> • Suffolk University. <i>Annual Outcomes Report FY07</i> • AIDS Housing Corporation 2/14/08.
SUBSTANCE ABUSE		
<p>Prevalence within the general population of the EMA</p>	<p>Prevalence among PLWH in the EMA</p>	<p>Data Source</p>
<ul style="list-style-type: none"> • 11% of MA population (534,000 people) and 10% of NH population (101,000 people) had alcohol or illicit drug dependence or abuse in 2006-2007 • 121,076 substance abuse admissions to treatment programs in MA in 2008 • 6,523 substance abuse admissions to treatment programs in NH in 2008 	<ul style="list-style-type: none"> • 28% of PLWH in MA received substance abuse treatment between 2001-2006 • 29% of PLWH surveyed in <i>VOE</i> reported current substance abuse problems • 24% of PLWH in the EMA with exposure to HIV through IDU 	<ul style="list-style-type: none"> • SAMHSA's Office of Applied Statistics, 2007 • MDPH, Bureau of Substance Abuse, 10/8/09. • NH DHHS, Bureau of Drug and Alcohol Services, 1/10/08. • Suffolk University, 2003 (<i>VOE</i>). • MDPH Surveillance Program, data as of July 2009. • NHDHHS, Bureau of Communicable Disease Surveillance, July 2009.

MENTAL ILLNESS		
Prevalence within the general population of the EMA	Prevalence among PLWH in the EMA	Data Source
<ul style="list-style-type: none"> • Estimated percentage and number of adults with serious psychological distress (mental illness) in 2006-2007: • 513,000 or 10% of adult population in MA • 112,000 or 11% of adult population in NH 	<ul style="list-style-type: none"> • Percent of HIV-infected clients with active psychiatric diagnosis: 49% 	<ul style="list-style-type: none"> • SAMHSA's Office of Applied Statistics, 2007. • John Snow Institute, Title I Clinical CQI Chart Review, 2006.
SEXUALLY TRANSMITTED DISEASES		
Prevalence within the general population of the EMA	Prevalence among PLWH in the EMA	Data Source
<ul style="list-style-type: none"> • Increase in Primary and Secondary Syphilis: 28% over 2007, with 209 cases in 2008 (3 per 100,000 residents) • Increase in Chlamydia: 6% over 2007, with 13,240 cases in 2008 (255 cases per 100,000 residents) • Decrease in Gonorrhea: 25% from 2007, with 2,094 cases in 2008 (28 per 100,000) 	<ul style="list-style-type: none"> • 34% of early syphilis cases in the EMA reported among PLWH 	<ul style="list-style-type: none"> • NH DHHS, Bureau of Communicable Disease Surveillance, July 2009. • MDPH, Surveillance Program, data as of July 2009.
HEPATITIS B		
Prevalence within the general population of the EMA	Prevalence among PLWH in the EMA	Data Source
<ul style="list-style-type: none"> • MA EMA counties: 19 acute and 188 chronic confirmed cases reported in 2009 • NH EMA counties: 6 acute cases reported in 2009 (chronic case counts not available) 	<ul style="list-style-type: none"> • 18% of PLWH surveyed 	<ul style="list-style-type: none"> • MDPH, Surveillance Program, data as of July 2009. • NHDHHS Bureau of Communicable Disease Surveillance, July 2009 • Suffolk University, 2003
HEPATITIS C		
Prevalence within the general population of the EMA	Prevalence among PLWH in the EMA	Data Source
<ul style="list-style-type: none"> • MA EMA counties: 2,895 chronic HCV confirmed cases reported in 2008, in increase of 27% over 2007 	<ul style="list-style-type: none"> • 3,303 HIV/HCV co-infected in MA (2007) • 46% of PLWH surveyed for <i>VOE</i> 	<ul style="list-style-type: none"> • MDPH Surveillance Program, July 2009 • MDPH Communicable Disease Update, Summer 2007 • Suffolk University, 2003

FORMERLY INCARCERATED POPULATIONS

Impact on service delivery by former prisoners who were released in the preceding 3 years and had HIV/AIDS diagnosis on the date of their release	Data Source
<ul style="list-style-type: none"> • The HIV prevalence among MA inmates is 2.5%; among NH inmates it is .6%; in Suffolk County House of Corrections it is 3% • MA has the highest percentage (1.3%) of confirmed AIDS cases among prisoners, nationwide (tied with NY) • 932 PLWH in MA counties of EMA and 92 in NH were diagnosed while incarcerated • Among MA prisoners released between 1999 and 2004, more than 22% had no health insurance of any kind at the time of their release; 19% had no available housing options; 48% had a history of mental illness and 96% had a history of substance abuse 	<ul style="list-style-type: none"> • HIV in Prisons, 2006 (US Department of Justice)- revised 4/22/2008 • MDPH HIV/AIDS Summary Report, 6/2008 • NHDHHS, Bureau of Communicable Disease Surveillance, September 2008 • HRSA-CDC Corrections Demonstration Project for People Living with HIV/AIDS, 2007.

Table 3: Unmet Need Estimate

Population		Value		Data Source(s)
A.	Number of persons living with AIDS (PLWA), as of 12/31/08	8,316		Living AIDS cases reported in the Boston EMA, from the Massachusetts Department of Public Health and the New Hampshire Department of Health and Human Services
B.	Number of persons living with HIV (PLWH)/non-AIDS/aware, as of 12/31/08	6,647		Living HIV (non-AIDS) cases reported in the Boston EMA, from the Massachusetts Department of Public Health and the New Hampshire Department of Health and Human Services
C.	TOTAL number of HIV+/aware as of 12/31/08	14,963		
Care Patterns		Value		Data Source(s)
D.	Number of PLWA who received the specified HIV primary medical care during the 12-month period [1/1/08 – 12/31/08]	7,359		For NH region of EMA: proportion of cases with met need generated by the New Hampshire Department of Health and Human Services (HARS; NH CARE Program) For MA region of EMA: Suffolk University study
E.	Number of PLWH/non-AIDS/aware who received the specified HIV primary medical care during the 12-month period [1/1/08 – 12/31/08]	5,868		For NH region of EMA: proportion of cases with met need generated by the New Hampshire Department of Health and Human Services (HARS; NH CARE Program) For MA region of EMA: Suffolk University study
F.	TOTAL number of HIV+/aware who received the specified HIV primary medical care during the 12-month period [1/1/08 – 12/31/08]	13,227		
Calculated Results		Value	Percent	Calculation
G.	Number of PLWA who did not receive the specified HIV primary medical care	957	11.5%	Value: Value A – Value D. Percent: Value G / Value A
H.	Number of PLWH/non-AIDS/aware who did not receive the specified HIV primary medical care	779	11.7%	Value: Value B – Value E. Percent: Value H / Value B
I.	Total HIV+/aware not receiving the specified HIV primary medical care (quantified estimate of unmet need)	1,736	11.6%	Value: Value G + Value H. Percent: Value I / Value C

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