

ISSUE BRIEF

The Massachusetts Health Policy Forum

HIV/AIDS in the Commonwealth of Massachusetts: Historical Trends and Policies for the Future

Wednesday, December 1, 2004

8:30 to 9:00 - Breakfast

9:00 to 9:30 - Presentation of Policy Brief

9:30 to 10:00 - Respondents

10:00 to 11:00 - Discussion

Omni Parker House Hotel
School and Tremont Streets
Boston

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HIV/AIDS in Massachusetts: A Decade of Change and Challenge

John Orwat, AM, LICSW

Executive Summary

The character of HIV/AIDS in Massachusetts has changed over the past decade, including who is at risk and staggering improvements in scientifically based prevention and treatment which has dramatically reduced death from HIV/AIDS and improved the health and quality of life of people living with this disease. At the same time, access to these prevention and health care systems has not been distributed equitably. Public and private financial investment and effective policies in the prevention and treatment of HIV/AIDS in the first part of the past decade led to a host of innovative programs. However, inadequate funding over the past few years has reduced services and jeopardized the Commonwealth's leadership role in the prevention of and care for people living with, HIV/AIDS.

Epidemiology. As of October 2004, an estimated 22,000- 24,000 people were infected with HIV in the Commonwealth of Massachusetts. The prevalence of those infected with HIV/AIDS has increased 20% in the years 1999 to 2003. Racial and ethnic minorities, women, particularly women of color, immigrants, youth aged 13 to 24, and men who have sex with men are at particular risk. Mother to child transmission of the virus, however, is down substantially. The number of people with HIV/AIDS and exposure mode vary based on region of the state. Biological, social and economic factors contribute to the greater risk HIV infection, including gender inequality, racism, homophobia, poverty, socialization patterns, inadequate health care, and stigma. Cutting edge educational efforts that deliver accurate, culturally appropriate, and timely risk and test site information, stress the importance of testing and encourage testing necessary to reduce the spread of the epidemic. Finally, as people live longer with HIV/AIDS, the number of people over 40 years old who are HIV infected has increased, providing new treatment challenges, such as toxicity of medications after longer-term use and the need for psychosocial support.

Funding in Massachusetts. Federal, state, and private sources that fund the range of HIV/AIDS services gradually increased over the first few years of the last decade then declined substantially. Flat federal funding and declining state funding since December 2001, has resulted in substantial reductions in medical and non-medical services. Although some state funding has been restored for fiscal year 2005, the gap between current and needed funding has widened for prevention, testing, and treatment. The gap grows even wider when the losses in infrastructure and lost opportunities to build infrastructure for prevention and treatment is considered. Trends in private, institutional philanthropy are somewhat unclear, but it appears funding is declining from private US-based institutional philanthropy.

Cutbacks in funding have reduced prevention and testing efforts which, in addition to a stiff human toll, will be more costly to private and public payers of health care in the future. Reduced funding for health education as well as other demands on resources has challenged the ability of local school districts to offer comprehensive health education that includes AIDS education and

condom use instruction in middle and high schools, despite its proven effectiveness. Several challenges continue to exist with the implementation of needle exchange programs, a scientifically proven strategy to reduce HIV infection. Massachusetts is one of just three states where it remains illegal to possess a hypodermic needle without a prescription.

Massachusetts remains a leader in the effort to provide care to reduce further disability by providing care early in the illness of people living with HIV, extending MassHealth beyond federal requirements to include those who may not be able to afford early treatment but are not yet disabled, thus slowing disease progression. The HIV Drug Assistance Program (HDAP) provides financial assistance for HIV and AIDS medications, including assistance with co-payments for those with insurance and coverage for those who are under- or un-insured. Finally, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990, is a key source of federal funding for community based care and treatment.

Policy Implications and Recommendations. Legislators, policy makers, and advocates need to stay engaged with policy efforts, especially with regards to funding for prevention and the care of people living with HIV/AIDS. Despite major improvements in scientifically based prevention and treatment, funding has not kept up with need. The Commonwealth is expecting another budget gap of more than \$900 million in FY06, rising overall costs, and the risk of losing \$600 million in federal Medicaid waiver funds. Further, the Ryan White CARE Act is up for reauthorization in the fall of 2005.

The state needs to bolster and target prevention efforts that deliver clear and culturally appropriate information about how the disease is spread and can be avoided. Prevention efforts need to be funded and expanded, do a better job at reaching high risk populations, and be based on the latest public health research. Success will require the participation of high risk communities in the development and construction of new prevention approaches, and state and federal funding is critical to this effort. Prevention efforts must also focus on the wide range of social factors that influence health and the prevalence of HIV/AIDS. Social policies need to address complex social issues that transcend the life course and address the economic, social, and cultural determinants in which this epidemic is embedded.

Despite staggering advancements in the treatment of HIV, it is important to fund programs that ensure equitable access and adherence to medications, including substance abuse treatment, housing, and HDAP. This is cost-effective and critical to slow the progression of this epidemic.

Finally, although a substantial number of Americans believe AIDS is a pressing issue and requires more public investment, this report clearly demonstrates that funding is not keeping up with prevention and treatment needs.⁴⁴ The lack of adequate funding will lead to increased transmission, entail greater human costs, and increase downstream economic costs. Both public and private financial investment and effective policies in the prevention and treatment of HIV/AIDS in the first part of the past decade led to innovative and substantial programming efforts that got us to where we are today. As the nature of the illness has changed public policy and private efforts need to modify existing programs and strategies, creatively target new innovation, and renew and enhance financial commitments. This is the only way we can reverse current trends and control this epidemic.

HIV/AIDS in Massachusetts: A Decade of Change and Challenge

John Orwat, AM, LICSW

The past decade has seen advances in the prevention and treatment of HIV and AIDS, including major developments in scientifically based prevention, medical treatment, and medications. Public and private financial investment and effective policies in the prevention and treatment of HIV/AIDS in the first part of the past decade led to innovative and substantial programs in the Commonwealth. The result has been a dramatic reduction in the number of deaths from HIV/AIDS and greatly improved health and quality of life of people living with this disease. However, both public and private financing have not kept pace with the rising cost of prevention and treatment leading to major reductions in these efforts or threaten their very existence. The consequences of shortfalls in funding will, in the long term, take a human and financial toll.

Despite medical advancements that have dramatically reduced death from AIDS, treatment for HIV/AIDS has become more complex and expensive: resistance to HIV medications may occur if not taken properly, and co-occurring conditions, such as hepatitis C and substance abuse, make the management of the illness difficult. The character of the epidemic is also different than in years past as HIV disease disproportionately strikes people in poverty, racial and ethnic minorities, and others underserved by healthcare and prevention systems. These groups include a disproportionate number of blacks, particularly black women, youth, an overall aging of those living with HIV/AIDS and a resurgence of men who have sex with men. Further, the number who contract the disease through heterosexual sex is on the rise. This paper examines the changes and

challenges of HIV/AIDS over the past decade in Massachusetts. Changes in epidemiology, public and private funding, and trends in prevention will be reviewed. The paper will conclude with policy recommendations.

Epidemiology

Over the past decade, the distribution of HIV and AIDS in the population of the Commonwealth has changed as reflected in:

- A disproportionate number of women of color affected,
- The proportion of new diagnoses growing among youth 13-24,
- An overall aging population with HIV/AIDS,
- A resurgence among men who are having sex with men, and
- Regional variation in who contracts the disease and how.

As the population of those at risk for and infected with HIV becomes increasingly diverse, the challenges of prevention and treatment become more complex. Understanding changes in epidemiology is key to the development of prevention and treatment policy and programs. It is just as critical to understand the social determinants that increase one's risk of contracting the disease. A social determinants framework is useful when considering policy alternatives for an infectious disease like HIV/AIDS. This perspective focuses on the interaction of culture, economic and environmental factors in which the disease is embedded, thus permitting a closer examination of the social factors that influence health and

disease prevalence.^{1,2} This makes it possible to target prevention and treatment policies, to reduce health inequalities, and more effectively address this disease.²

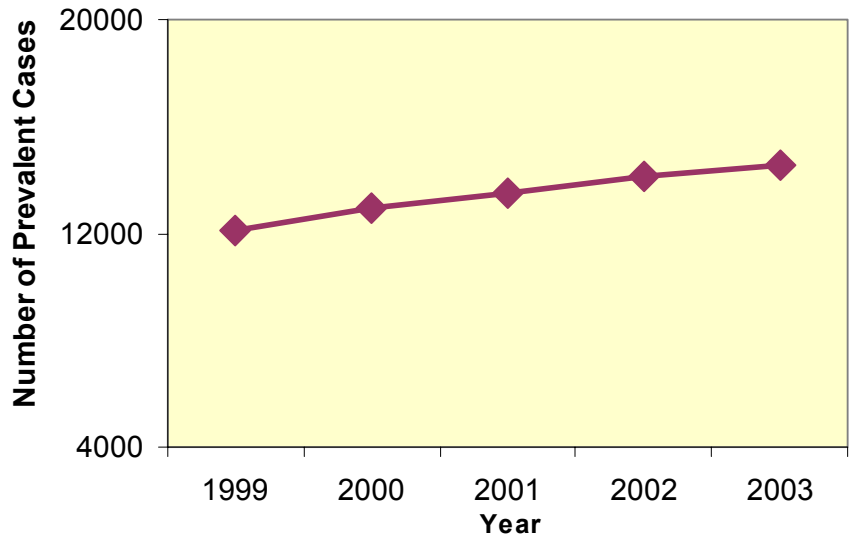
An estimated 22,000- 24,000 people are infected with HIV in the Commonwealth of Massachusetts as of October 2004, but many do not know their status.³ About two thirds (14,727) are known to be infected with HIV and have been reported to the HIV/AIDS Surveillance Program while an additional 2,500 know their status but have not yet been reported.³ Those who know their status and have been reported are more likely to have received at least one clinical care visit.

It is estimated that about 25% of those infected with HIV do not yet know their status, amounting to 5,500 people.^{4,5} As a result, this group is not receiving medical treatment for HIV and may not adopted safer sex behaviors which may lead to unknowingly spreading the virus. These people do not receive HIV medications that would reduce viral load and likely decrease the risk of transmission.⁵⁻⁸ Further, delayed diagnosis and treatment may have adverse

* The Massachusetts Surveillance System collects HIV and AIDS case information, including diagnosis year, demographics, and risk information from health care providers using a non-name system, identifying those who tested HIV-positive and/or entered medical care. The surveillance system does not identify when infection occurred or when an individual first tested positive. AIDS case information has been collected since 1981; HIV reporting was required in January 1, 1999 with all previous cases of HIV infection known to that provider reported by the end of that year.

⁵ This number is estimated based on the Centers for Disease Control and Prevention (CDC) techniques for estimating HIV prevalence (CDC, 2003).

Figure 1 Trends in HIV/AIDS Prevalence by Year: MA, 1999-2003



Source: MDPH HIV/AIDS Surveillance Program; Data as of 7/1/04

health consequences that makes treatment of the disease far more expensive.^{9,10} There are several reasons people do not get tested, such as a belief they are not at high risk for contracting HIV, a lack of knowledge about testing options, concerns about confidentiality, fear of deportation by immigrants, denial, and stigma.^{11,12} Cutting edge educational efforts that deliver accurate and timely risk and test site information to diverse groups of people is critical to reduce the spread of this epidemic.

Trends in HIV/AIDS Prevalence⁹

The number of people in the Commonwealth living with HIV/AIDS has increased over

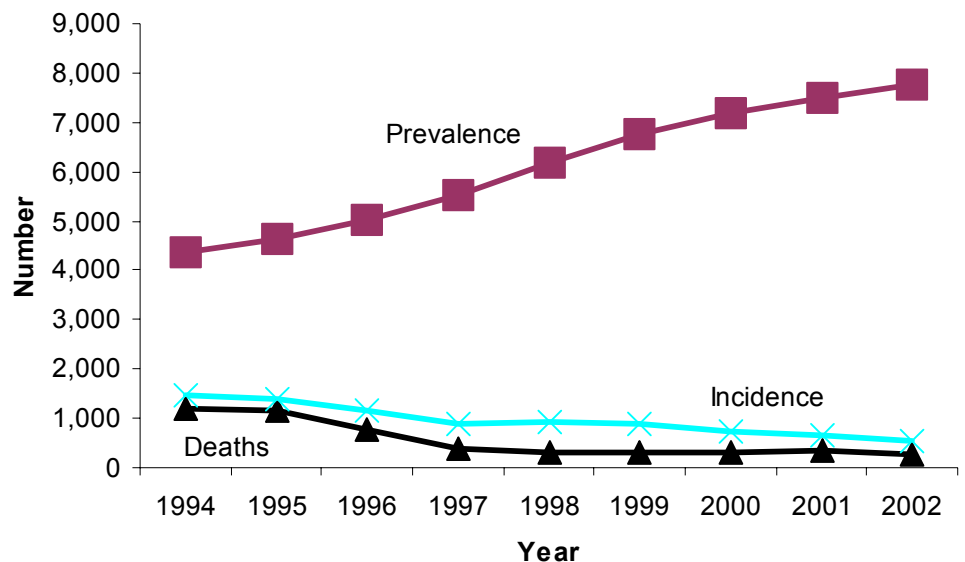
⁹ HIV (Human Immunodeficiency Virus) is the virus that causes AIDS (Acquired Immune Deficiency Syndrome), which might develop as a result of HIV infection. HIV is transmitted through the exchange of bodily fluids such as blood, semen, vaginal secretions, and breast milk during sexual contact, needle sharing, childbirth, and breast feeding.

the past decade while the number of new cases of AIDS and AIDS deaths have decreased. Prevalence, a function of new HIV/AIDS cases and survival among those living with HIV/AIDS, increased 20% in the years 1999 to 2003 (Figure 1).³ As of July 2004, a cumulative total of 25,442 people have been reported to have HIV and/or AIDS since reporting was first implemented in 1985. Of those, 42% (10,715) have died, 26% (6,615) are reported to be living with HIV diagnosis, but have not been diagnosed with AIDS, and 32% (8,141) are currently living with an AIDS diagnosis.³ Injection drug use and male-to-male sex are the leading reported risks for HIV infection, accounting for 33% and 30% of all exposures, respectively.³ The number of people living with AIDS has increased steadily since the start of data collection in 1985 (Figure 2).³ Incidence, or the number of newly reported cases of AIDS, declined at the start of the decade, but has remained steady at around 900 cases per year.³ Annual AIDS deaths peaked at 1,206 in 1994, followed by a decline to 316 deaths per year in 1998, and remained fairly constant since.⁴ Mortality has increased for females, blacks and Hispanics, and among injection drug users.⁴ The reduction in AIDS prevalence and AIDS deaths is due to the successful introduction of highly active anti-retroviral therapies (HAART) in the mid 1990s. However, incidence, prevalence, and death rates vary dramatically within the population of the Commonwealth.

Women and HIV/AIDS

Although men still account for the majority of people living with HIV/AIDS in the Commonwealth, the impact on women, particularly women of color, has grown over the past decade and those numbers are projected to increase, as they have worldwide. From 2000 to 2004, there was a 23% increase in the number of women living with HIV/AIDS.⁴ As of July 2003, women accounted for 32% of all people diagnosed with HIV/AIDS in the Commonwealth. Women of color are particularly at risk and are disproportionately affected. Black females represent 51% of all new cases of HIV among females in 2003, up from 40% in 1999 while the proportion of white women decreased from 31% to 18%.³ Black women living with HIV represent 38% of all females living with HIV/AIDS as of 2003.⁴ The proportion of AIDS related female deaths are up from 16% in 1999 to 30% in 2003.³ For women, exposure mode varies by

Figure 2 AIDS Prevalence, Deaths, and Incidence by Year: MA, 1994-2003



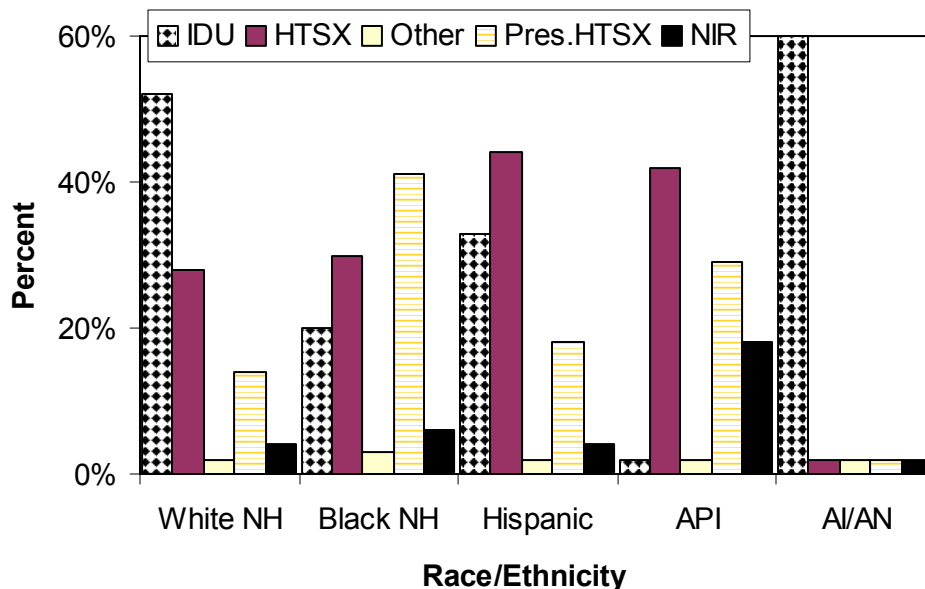
Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/2003

race/ethnicity (Figure 3). The dominant mode of exposure among white females is injection drug use (IDU) (53%), among black females is presumed heterosexual sex (39%) and among Hispanic females is heterosexual sex (45%).^{†,4} This is much different for men. Male-to-male sex is the primary risk for white males (65%), IDU the primary risk for Hispanic males (53%), and for black males there is a mix of pathways: IDU (32%), male-to-male sex (23%), and presumed heterosexual sex (21%).⁴

Women are at risk for contracting HIV due to many biological, social and economic factors. In the US, most women acquire

HIV from a monogamous heterosexual partner who is not known to be at risk for HIV.^{13,14} In Massachusetts, heterosexual sex or presumed heterosexual sex is the primary exposure mode for women overall, accounting for just under 70% of new diagnoses of HIV in 2002, up from 55% in 1999.⁴ Black women are particularly at high risk for HIV infection as a result of having sex with men, although this varies with country of birth with US born women more likely to acquire the virus through IDU than non-US born women.¹⁵ A significant number of women are infected through heterosexual sex with a partner who acquired the virus through intravenous

Figure 3 Women Living with HIV/AIDS by Exposure Mode and Race/Ethnicity: MA



IDU=Injection Drug Use, HTSX=Heterosexual Sex, Pres.HTSX=Presumed Heterosexual Sex, NIR=No Identified Risk, NH=Non-Hispanic. Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/1/04

[†] “Presumed heterosexual” refers to those individuals who reported no other risk except heterosexual sex with a partner of unknown HIV status or risk. This category is unique to Massachusetts; the Centers for

Disease Control and Prevention (CDC) categorizes these cases as “no identified risk.”

drug use, and thus attribute their infection to the IDU epidemic. Biologically, women are at a greater risk of infection during unprotected penile-vaginal intercourse with an HIV-infected partner than men, due to high mucosal exposure and high concentrations of HIV in their partner's seminal fluids.¹⁶ Untreated sexually transmitted diseases that lead to ulcerations of the vagina also increase the risk of infection.^{17,18}

Gender inequality increases women's risk for HIV.^{13,19} Women are expected by society to remain monogamous while their male partner may be engaging in high risk behaviors, such as unprotected sex with men, multiple partners or injection drug use.^{13,20} The negotiation of condom use is critical, however women have been found to be reluctant to insist when faced with undue pressure or threats of physical violence, abandonment, and/or the loss of economic support.^{13,19,21,22} Women in violent, intimate relationships with men are at particularly high risk for HIV as their male partners are more likely to engage in high-risk behaviors outside of the relationship.²¹ Other factors associated with increased risk of heterosexual transmission include alcohol use, history of sexual abuse, and use of crack or cocaine.^{13,14,23}

Although women suffer from the same complications of HIV/AIDS as men, they also experience gender-specific manifestations.¹³ Gynecological conditions, such as vaginal yeast infections and pelvic inflammatory disease, are often more recurrent, persistent, and difficult to treat compared to uninfected women. These gender specific manifestations increase the risk for other illnesses, such as cervical cancer, and become more severe as the immune system weakens.¹⁶

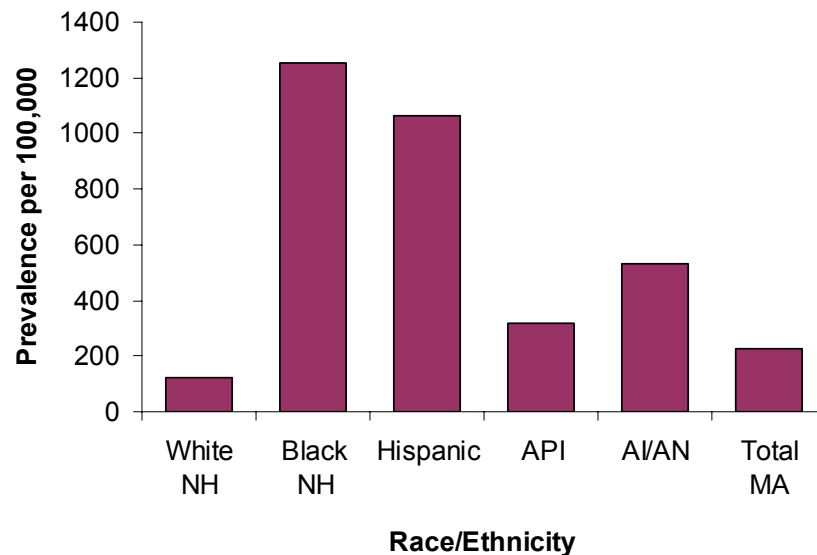
Women are more likely to neglect their own health care because they are more likely to be caring for other family members, particularly children, in addition to work responsibilities.^{13,24} Further, obtaining proper care becomes more complicated if others in the household also have HIV. Adherence to treatment regimen is made difficult with these responsibilities, particularly if there is a lack of social support. When women are diagnosed with HIV/AIDS, they face greater discrimination and rejection than their male counterparts, predominately due to differentials in power.^{13,14,24}

Men Who Have Sex With Men

Massachusetts has seen a resurgence of HIV infection among men who have sex with men (MSM) and there are indicators that this trend will continue.²⁵ Men who have sex with men represented 35% of HIV diagnoses in 2003, up from 28% in 1999.⁴ The increase in syphilis infection among men who have sex with men has increased concern about potential increases in HIV transmission since syphilis infection which facilitates the acquisition and transmission of HIV and in some settings has been a precursor to an increase in the number of new HIV infections.²⁶ The proportion of syphilis infections among MSM in Massachusetts has increased substantially from 24% in 2000 to 56% in 2002 and the number of cases has tripled from 34 to 113.⁴ Younger MSM are more likely to engage in risky sexual practices.²⁷

Trends indicate increased sexual risk behavior are related to various psychosocial and situational factors, particularly beliefs about HIV transmission risk and substance abuse.^{25,28} Studies demonstrate that an increasing number of MSM may not think they are at risk as they do not identify

**Figure 4 Age-Adjusted HIV/AIDS
Prevalence Rate per 100,000 Population
by Race/Ethnicity: MA**



NH=Non-Hispanic, API=Asian/Pacific Islander, AI/AN=American Indian/Alaska Native

Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/01/04

themselves with being gay or have internalized societal homophobic messages. Further, beliefs about HIV transmission have been shown to be related to sexual risk taking, including a belief that medications eliminated the risk of HIV transmission and/or that genetic factors or a healthy immune system result in virus resistance.²⁹⁻³¹ The perception that advances in medical treatment has greatly reduced the seriousness of HIV/AIDS may lead to more sexual risk taking among HIV-negative MSM.^{25,30} The use of recreational drugs dramatically increases the risk of unprotected sexual behavior.³² Reducing HIV transmission in this population requires constantly reinvigorated prevention efforts that address recreation drug use, homophobia, and the limits of HIV treatment, and target black and Latino women and men, HIV positive men, and young MSM.²⁵

Race and Ethnicity

The impact and incidence of HIV/AIDS varies significantly by race and ethnicity, with blacks overwhelmingly represented among those living with the disease. Although blacks represent only 5% of the Commonwealth's population, they represent 34% of new HIV infections and 27% of those living with HIV/AIDS.⁴ Age-adjusted HIV/AIDS prevalence rate per 100,000 by race demonstrates that blacks are diagnosed with HIV/AIDS in Massachusetts at 11 times and Hispanics at 9 times the level of whites (Figure 4).³ Black and Hispanic women are impacted at levels 20 and 13 times that of white women, respectively.³ Black and Hispanic men are impacted at levels 8 times that of white men.³ Hispanics represent 24.5% of people living with HIV/AIDS, but represent just 7% of the

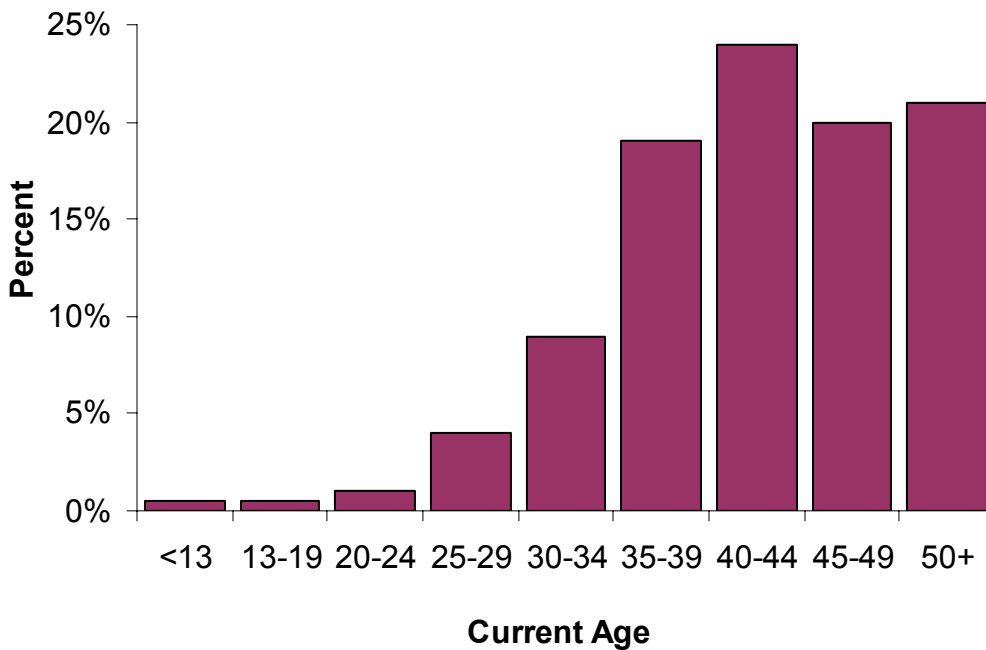
population of the Commonwealth. Finally, members of communities of color living with HIV/AIDS are increasingly more likely to die from the illness. The proportion of overall deaths related to HIV/AIDS from 1993 to 2003 declined from 60% to 51% for whites, but increased among blacks from 21% to 24% and Hispanics from 19% to 24%.³

Research shows an inverse relationship between the incidence of HIV/AIDS, and income as well as several problems related to poverty, such as less access to HIV prevention information and lower quality health care.³³ Race and ethnicity are not in and of themselves risk factors for HIV/AIDS and the differential HIV/AIDS incidence, prevalence, and mortality among blacks has not been adequately explained by individual behaviors. However structural and

contextual factors play a substantial role, including poverty, socialization patterns, and inadequate health care.^{2,13} According to the 2000 Census, 21% of black residents of the Commonwealth live below the poverty level and 30% of Hispanics as compared to 6% of white residents.³

Although denial of homosexuality and drug abuse are pervasive in society, taboos in the black community related to these routes of HIV transmission, are particularly strong and demonstrate the need for culturally targeted messages that address these behaviors. For example, many black men who have sex with men identify themselves as heterosexual or may not identify with a predominately white gay community.^{34,35} Prevention messages designed for openly gay white men will not reach this group because they do not identify with being a

Figure 5 People Living with HIV/AIDS by Current Age: MA



Data on pediatric HIV not included.

Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/01/04

member of this risk group.¹³ Beyond injection drug use risk, substance abuse increases the possibility of high risk behaviors, such as unprotected sex.^{36,37} For the same reasons as HIV transmission, blacks in the US have the highest rate of sexually transmitted diseases. When compared to whites, US blacks are 24 times more likely to have gonorrhea and 8 times more likely to have syphilis.³⁸ Some STDs increase the chance of contracting HIV three to five fold and increase the likelihood of spreading it to others.³⁹

Residential segregation by race/ethnicity and tight social networks increases the likelihood of engaging in sexual relations with an HIV infected partner. Black males are also disproportionately incarcerated, which destabilizes social networks and monogamous relationships, increasing the likelihood of multiple same sex partners, thus heightening the risk of transmission.¹³

Finally, mistrust and/or distrust of the system, due to historical racism, impact the decision of blacks to test for HIV and seek treatment. For example, one study showed that nearly half of Blacks believe that HIV/AIDS is a government conspiracy against them.⁴⁰

Blacks are also far more likely to be diagnosed concurrently with HIV and AIDS. This means they have been infected with HIV for a very long time, but were not tested until HIV progressed to AIDS.[‡] For blacks, 35% were diagnosed concurrently with HIV and AIDS, compared to 29% of white males and 30% of Hispanic males, a symptom of racial and ethnic disparity.³ Those diagnosed concurrently are often

[‡] “concurrent diagnosis” refers to people who are diagnosed with HIV and AIDS at the same time, or if they received both an HIV and AIDS diagnoses within a two month period.

sicker as they have not benefited from cost-saving and life enhancing treatments.

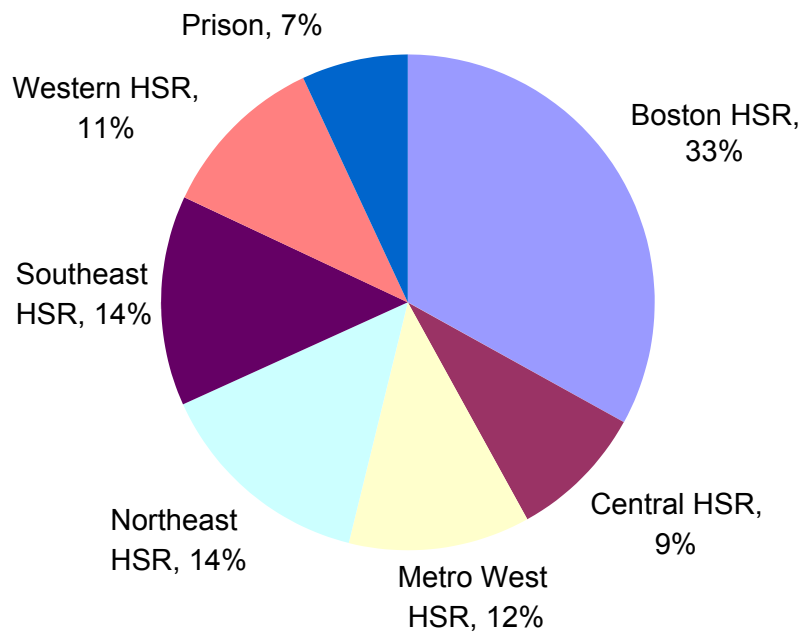
Immigrants and Refugees

A significant and growing number of HIV infected people born outside of the US (including Puerto Rico and other US dependencies) are living in the Commonwealth, which presents new challenges to prevention and treatment and adds a new complexity to racial and ethnic differences. As of July 2003, 29% of people infected with HIV were born outside the US, up from 18% in 1999, while the proportion of US born individuals decreased.³ Among Blacks, 53% were born outside the US compared to 27% of Hispanics and 7% of whites over 2000- 2003 period. Non-US born residents are more likely to be diagnosed and enter care later in the course of the disease, evidenced by 38% of non-US born individuals diagnosed concurrently with HIV and AIDS compared to 27% of those born in the US, Puerto Rico, and other US Dependencies.³ Prevention messages and health care is challenging for this population as there are few organizations that serve these communities, many fear deportation if diagnosed HIV positive, and recent changes limit access to publicly funded health care. To work with these groups requires an understanding of different cultures and languages, which is difficult for a system rooted in a white Western model of care.

Youth

There is an increasing number of new infections among youth. Although the majority of people living with HIV/AIDS are 35 years and older (83%), the proportion of new HIV infection occurring among youths aged 13 to 24 has increased from 6.1% of new diagnoses in 1999 to 8.7% in

Figure 6 People Living with HIV/AIDS in Massachusetts by Health Services Region



Prisons include persons who were diagnosed with HIV/AIDS while in correctional facility;

Source: MDPH HIV/AIDS Surveillance Program, Data as of 7/01/04

2002.⁴ Unlike those over 25, the majority of whom are male, the proportion of each gender is fairly equal, although young men are more likely to contract HIV through same-sex contact whereas young women are more likely to contract it through heterosexual contact.⁴¹ Since there are few safe socializing venues for young men who have sex with men, young men are more likely to socialize in adult settings, such as bars or cruising areas, making them more at risk as they are interacting with an older population with a higher prevalence of HIV.⁴² For young women, it appears that they, too, are becoming infected by partners from older age groups, since their heterosexual male peers have low rates of HIV.⁴³ Higher rates of other sexually transmitted diseases among young men and

women indicate there is an overall increase in unprotected sex in this age group.⁴¹⁻⁴⁴

An Aging Population

Since people live longer with HIV/AIDS, the number of people over 40 years old who are living with the disease has increased. As of July 2004, 65% of those living with HIV/AIDS are 40 years of age or older, and 21% are 50 and older, up from 9% in 1999.³ The average age of those living with HIV/AIDS is expected to rise, primarily due to medical advances (e.g., HAART) which have significantly extended life and late diagnoses of others who were not thought to be at risk. Challenges in the treatment for the older population include response and safety of antiretroviral therapies, toxicity

related to longer term use of medications, interactions with other drugs that may treat other conditions common in aging, and psychosocial support.⁴⁵

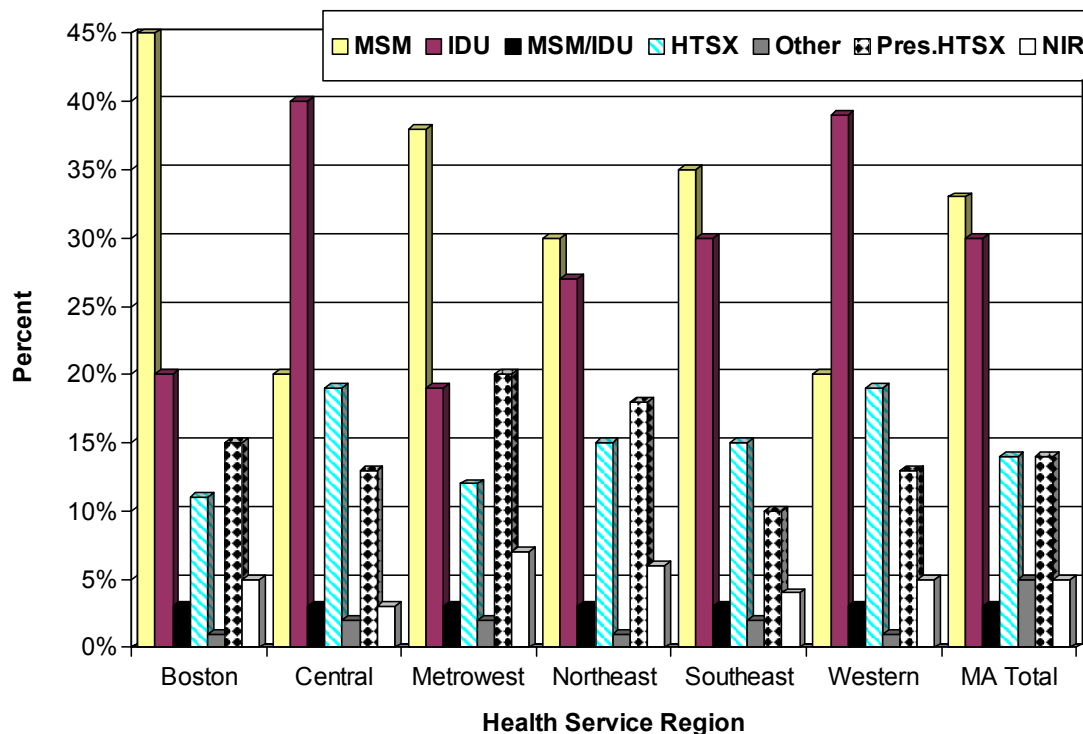
Health Services Regions

The number of people with HIV/AIDS and mode of exposure vary based on region of the state. These variations have been persistent over the past decade and this suggests that more targeted prevention strategies are needed. The average annual rate of HIV infection diagnoses per 100,000 over the three-year period 2000-2002 was highest in Provincetown, followed by Holyoke, Boston, and Springfield. These same cities top the list for rate of HIV/AIDS per 100,000 living in Massachusetts, with Provincetown again leading the state.⁴

Although men who have sex with men account for the highest number of cases in the Commonwealth, the mode of HIV exposure varies depending on the Health Service Region (HSR) (Figure 7).

Men who have sex with men represent the predominant mode of exposure in Boston HSR, Metrowest HSR, and Southeast HSR while injection drug use (IDU) is the dominant mode of exposure in the Central HSR and Western HSR.³ Over the past decade, this trend has persisted. Gender and racial distribution of HIV infection also varies by HSR. Within the 2001- 2003 year period, the Boston HSR was predominately male (74%) while other HSRs were fairly consistent with females ranging from 31 to 39% and the proportion of males 61 to 69%.³ White individuals make up the largest proportion of those infected with

Figure 7 People Living with HIV/AIDS by Health Service Region and Mode of Exposure: MA



HIV across all HSRs, with the exception of the Western HSR, which is predominately Hispanic (49%).⁴ Regional variation underscores the importance of funding flexible prevention, testing, and counseling programs so that communities that were traditionally not thought of as being at risk are educated and people are properly referred for testing and treatment.

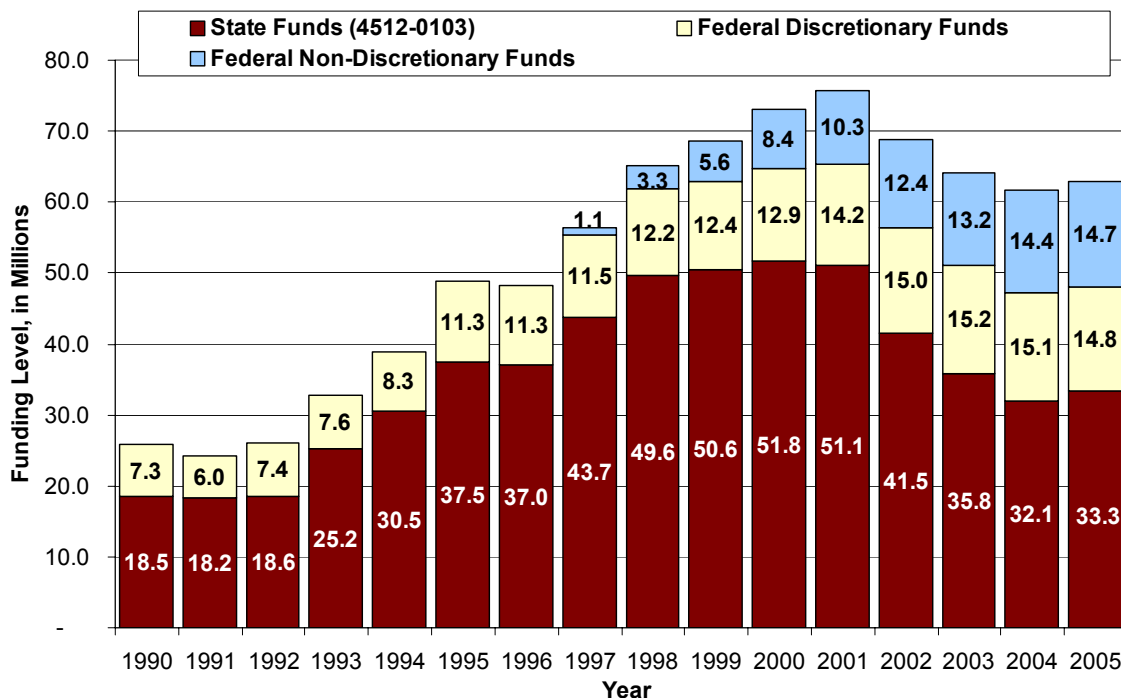
Funding in Massachusetts

The myriad of federal, state, and private sources funding the range of HIV/AIDS services gradually increased over the first few years of the last decade then declined substantially since 2001. Flat federal funding and declining state funding since December 2001, and has resulted in substantial reductions in medical and non-medical services. Although some of the funding was restored for fiscal year 2005, the loss of prevention and treatment infrastructure as well as lost opportunities to

build infrastructure has had a dramatic effect on the gap between current funding and resources needed for prevention education, testing, and treatment.

The decline in the Commonwealth's budget for HIV/AIDS has led to the reduction of important prevention, testing, and support services. The Massachusetts Department of Public Health HIV/AIDS Bureau purchases services from community based organizations, who implement several support services, including HIV counseling and testing, HIV prevention and education, and core access/support services for people with HIV/AIDS such as primary and specialty care (ACT Now Centers).⁴⁶ These funds were cut \$19M between FY01 and FY04, a 38% reduction.⁴⁴ Some funding has been restored in FY05 for an annual appropriation of \$33.3M, but this is down from \$51.1M in 2001. The decline in funding is also far greater than the numbers imply since these are not adjusted for inflation, greater need

Figure 8 Historical AIDS Bureau Funding
Includes State Account, HRSA and CDC 1990-2005



for prevention and care, and rising medical costs.

Direct non-medical services for people living with HIV/AIDS have been reduced to maximize the provision of life sustaining and saving interventions. These provide not only life and cost saving treatment, but also yield a public health benefit by reducing viral load in those currently infected, potentially reducing the likelihood of transmission to others. However, many of these services support medication adherence, particularly important since appropriate medication use is critical to effectiveness and to avoid drug resistance. Service reductions include: HIV specialty care, such as home care, mental health services and jail-based programs; support services for those living with HIV/AIDS, such as case management, housing support, and food vouchers; and complementary therapies. Reductions in substance abuse treatment funding has decreased the availability of heroin treatment and detoxification. Finally, reductions in the budget have reduced staff capacity, and the ability to develop and implement the new programs and strategies necessary to keep pace with the changing dynamics of the epidemic.⁴⁴

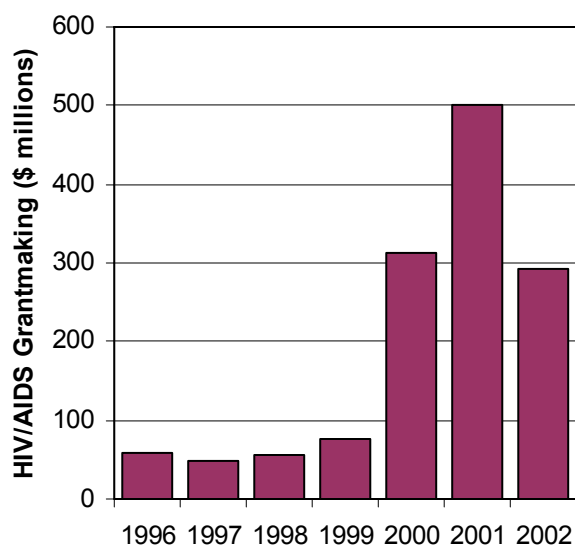
Ryan White CARE Act Funding

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 is a key source of federal funding for state-wide care and support services. The goal of the Act is to assure equitable access to state-of-the-art care and treatment and eliminate barriers to that care. Services include the Minority AIDS initiative; formula grants to fund medical care and support services such as medications for those who cannot afford them through the AIDS Drug Assistance Program (ADAP), called the HIV Drug

Assistance Program (HDAP) in Massachusetts; community health providers and care for the under and uninsured; support for community based organizations to provide care for women, children, and adolescents affected by HIV/AIDS; funding for dental programs; and additional funds to areas hardest hit by HIV/AIDS such as the Boston Eligible Metropolitan Area (EMA), which stretches west to Worcester and north into New Hampshire, and Springfield, an emerging community.

Ryan White funding has increased over the past ten years, although the past two years have been fairly flat. Ryan White provided \$48M to Massachusetts last fiscal year (FY04) and 10,500 consumers were served with these funds.⁴ Increases in funding have been primarily driven by the ADAP portion of the grant since medications continue to become more important and more expensive. In fact, the past two years have seen the base allocation decrease while the ADAP component has increased minimally. The allocation for FY05 increased only

Figure 9 Total HIV/AIDS Grantmaking 1996-2002: US



Source: Funders Concerned About AIDS (2003)

\$25,000, and the Title I allocation (for the Boston EMA) was cut \$.5M. The state is not expecting significant increases in the coming year.⁴⁷

Congress will take up re-authorization of the Ryan White CARE Act in January of 2005, which may change the structure of the allocation formula. The goal of reauthorization is to evaluate the progress of the act in meeting its goals and objectives. Although medical services and equitable access are expected to be prioritized, reauthorization is contentious and debate will surround structure and funding levels. It will be important for advocates to be engaged in the debate and to educate legislators about the nature of the epidemic and the importance of equitable access to care and treatment for all persons with HIV/AIDS.

Private, Institutional Philanthropy

Hundreds of private institutional philanthropic organizations, including private, family and community foundations, public charities, and corporate programs, grant funds to a variety of programs in various geographic regions. Trends in funding are somewhat unclear, but it appears funding is declining from private US based institutional philanthropy and grantmaking is supporting more international efforts to combat HIV/AIDS.⁴⁸ This to some extent mirrors public funding which has been flat for domestic efforts at the same time the government has increased international funding.⁴⁸ Although private, institutional grantmaking commitments were up 60% from 2000 to 2001, they dropped 42% from 2001 to 2002.⁴⁸ US-based grantmakers committed an unduplicated total of over \$500 million in 2001 in 3,755 HIV/AIDS-related grants, but in 2002 committed \$291 million in 3,652 grants.⁴⁸ It remains unclear

if this decline represents an overall downward trend since funding paid out in 2002 from multiyear grants exceeded that of previous years. Reductions in funding were primarily concentrated among four major grantmakers, and preliminary data from 2003 indicate this decline may not be a trend. Further, the decline may be the result of the recent economic downturn. Corporations have made a significant contribution to HIV/AIDS in their grantmaking, but also with various in-kind donations of necessary resources and workplace programming that include non-discrimination policies, prevention activities, and access to care. There is a great deal of capacity to increase funding to HIV/AIDS as one quarter of grantmakers committed 10% or more of their grant dollars to HIV/AIDS in 2001.⁴⁸ As grantmakers see the connection between HIV/AIDS and traditional areas of funding, they are making funding for HIV/AIDS an important part of their portfolios.

Prevention Education, Counseling and Testing

Since there is no cure for HIV, prevention is the only way to slow the epidemic, specifically through multi-level interventions on the individual, group, and community level. However, the past few years have seen funding reductions for prevention efforts and challenges based on ideology rather than scientific studies that demonstrate effectiveness. The impact of budget cuts have reduced prevention and testing efforts, which will, in the long run, be more costly to private and public payers of health care. Budget cuts have reduced the number of HIV tests performed by 16,000 over 2001-2003.⁴⁴ The need for testing and counseling is significant, as demonstrated by the increase in the estimated number of HIV positive people

who are currently unaware of their status and the medical and public health benefits to early detection.⁴⁴ This section of the paper will focus on two important prevention efforts: comprehensive health education for adolescents and needle exchange.

Comprehensive health education that includes AIDS education and condom use instruction in middle and high schools has been shown to delay sexual activity and reduce the likelihood of engagement in other AIDS risk behaviors, such as injection drug use and unprotected sex and multiple sexual partners, if sexually active.⁴⁹ However, school districts are finding it hard to deliver such programs due to substantial reductions in funding for health education and more demands on their resources, such as preparation for the Massachusetts Comprehensive Assessment System (MCAS) exam. The Health Protection Fund awarded \$21- \$28M to school districts to support health education. However, this money has been taken back into general revenues due to fiscal shortfalls since 2001, leaving local districts to cut or fund these health education efforts themselves.⁴³

The decision to provide health education and the contents of that education is a local decision. The Massachusetts Department of Education (DOE) supports local efforts in an advisory capacity. Support is funded by the CDC through a Cooperative Agreement with the Commonwealth of MA. Per requirement of the Cooperative Agreement, the Youth AIDS Advisory Panel and AIDS Advisory Panel, comprised of key stakeholders from parent groups, community based organizations, academia, philanthropy, and public health, reviews scientifically sound outreach and educational strategies and materials for use in schools across Massachusetts. DOE surveys indicate that schools initially dealt with the cuts by

decreasing health specialists and coordinators without decreasing health education classes. However between 2002 and 2004, the numbers of required health classes offered dropped 8% from 94% to 86%.⁵⁰ There was no change in content between the two years: if the district was teaching health, they were teaching the same things and 95-99% said they were including HIV/STDs/ sexuality in their health classes.⁵⁰

Needle exchange. Injection drug use (IDU) accounts for 40% of people living with HIV/AIDS in the Commonwealth today: 34% of HIV infections were acquired directly through IDU and an additional 6% of infections acquired through heterosexual contact with an injection drug user.³ As a result of using “dirty needles,” injection drug users are at increased risk for HIV, as well as several other health problems such as Hepatitis C. Availability of syringes through various outlets, such as needle exchange programs and pharmacies, are a proven strategy to reduce infection rates. Scientific studies continue to demonstrate that syringe availability does not increase drug use, decreases needle sticks to law enforcement, bridges injection drug users to treatment, reduce the spread of HIV, and provides access to an otherwise hidden population.^{51,52} However, programs that make sterile syringes available remain controversial.⁵¹ For example, a ban on using federal funds for needle exchange programs persists and it is illegal to possess a hypodermic needle in Massachusetts without a prescription. These systemic barriers reduce the likelihood of obtaining clean needles.

Massachusetts is one of three states where it remains illegal to possess a hypodermic needle without a prescription.⁵³ However, local communities may implement needle

exchange, leaving the decision for this charged issue in the hands of local leaders who often have less public health information and knowledge. Four cities have enacted needle exchange programs: Northampton, Cambridge, Provincetown, and Boston. Communities that voted not to have needle exchange and have the highest rates of HIV infection through IDU include New Bedford (54%), Fall River (46%), Lawrence (36%), Lowell (39%), Worcester (45%), and Springfield (43%).³

Communities with needle exchange have some of the lowest rates of infection through IDU, including Provincetown (2%), Boston (21%), and Cambridge (18%).³ In some communities without needle exchange, programs have been developed by affected communities.

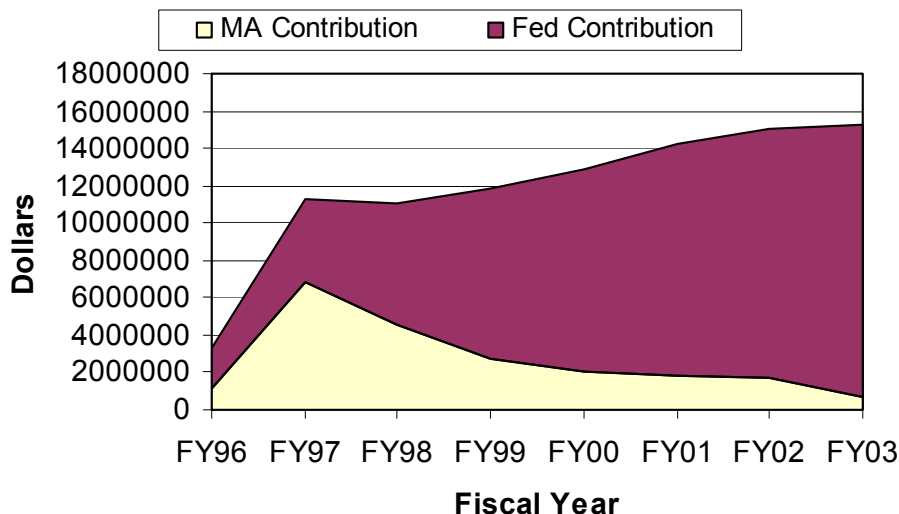
More education of the public about needle exchange is recommended. Most do not know it is illegal, and 60% of Massachusetts adults between 18 and 64 support needle exchange.^{54,55} The enforcement of laws preventing needle exchange should be viewed by law enforcement officials, police and district attorneys, as a low priority. Such enforcement does not advance the public health.

Massachusetts house bill 4578 seeks to allow the sale of syringes without a prescription by pharmacists, much like other medical equipment, however it is unlikely to pass legislative session. Sale of needles by pharmacists without a prescription would allow access to clean needles without cost to the state and would reduce new infections of both HIV and hepatitis C.⁵¹ Needle exchange is clearly effective: Connecticut saw a 40% drop in needle sharing among IDU since legalizing pharmacy sales of syringes in 1992.^{52,56,57}

Treatment Financing

MassHealth (Medicaid) continues to be the largest payer of HIV/AIDS treatment in the Commonwealth contributing in excess of \$100M per year in both state payments and federal matches. In addition to providing care for those meeting income requirements and disability requirements for traditional MassHealth, the Commonwealth's Medicaid Waiver (1115) extends coverage to those living with HIV and who are low income, living at or below 200% of federal poverty level. This gives access to those who may not be able to afford early treatment, thus slowing disease progression and disability. Massachusetts is a leader in the effort to

Figure 10 Federal and State Contribution to HDAP: Massachusetts



provide care to reduce further disability by providing care early in the illness of people living with HIV.

The recent budget crisis has led to reductions in MassHealth programs. The income limit for the MassHealth HIV waiver was dropped to 133% of the federal poverty level (FPL), or an income of \$11,943 per year. This had the effect of disenrolling hundreds of members, many of whom had no access to regular care. Although the 200% FPL standard was reinstated in July of 2004, new premium charges were exacted for approximately 17,000 lower income households, including those living with HIV, making it difficult for people to obtain costly medical care. MassHealth coverage was also eliminated for adult legal immigrants living with HIV/AIDS in the Commonwealth as of August of 2003. These immigrants are not eligible for MassHealth under federal guidelines due to their immigration status. MassHealth Essential restored coverage for 36,000 long-term unemployed adults effective October 2003.

Medication Support

The HIV Drug Assistance Program (HDAP) is a “payer of last resort” for HIV/AIDS medications, providing financial assistance for medications, including assistance with co-payments for those with insurance and coverage for those who are under- or uninsured. The program also fills the gap for those waiting for public insurance programs, such as acceptance to or meeting spend-down requirements for MassHealth. The program served 2,267 people in the Commonwealth and filled 10,106 prescriptions in July of 2004.⁵⁸

HDAP is funded primarily through Title II of the Ryan White CARE Act and with state

funds. HDAP is not an entitlement program, but funded through annual federal and state appropriations. Massachusetts administers the HDAP program by determining such program elements as eligibility criteria and drug formularies. Compared to other states, Massachusetts has been a leader in this program by expanding coverage for HIV drugs, thus slowing progression to AIDS. There has never been a waiting list, and the program covers a full range of resistance testing, and recognizes the need for higher financial eligibility limits to ensure access to medications.

For both public health and treatment reasons, medications and medication adherence programs are critical to fund. People who cannot afford these expensive medications are less likely to take their medications or follow a medication regimen. Although the person may not initially get sick, improper medication use increases circulating viral load and mutation into drug resistant strains. Individuals living with HIV will incur higher medical care costs. Higher circulating viral load leads to higher transmission rates of a drug resistant virus so that even “treatment naïve” patients will experience drug resistance.

While the HDAP is likely to be adequately funded in FY05, increasing numbers of clients and rising costs of drugs are likely to result in shortfalls in FY06 and future years. However, shortfalls were projected in FY04, the result of cuts in Medicaid, the rising per person costs of medications, increasing numbers of people living with HIV/AIDS, and level federal funding over the past several years relative to the costs and number of persons requiring medications. In other states, this has led to rationing of treatment and waiting lists. In some states, deaths have been attributed to waitlists and denied access to drugs.

Substance Abuse Treatment

Substance abuse treatment is a critical service for both prevention and treatment efforts, but has also sustained major cuts, some of which were restored for FY05. Just over 40% of those living with HIV were exposed to HIV infection through injection drug use or the injection drug use of their partner.³ Massachusetts has the highest heroin rate in the US, with over half of all admissions to drug treatment programs for heroin addiction (48,946), and exceeding admissions for any other drug, including alcohol. Heroin related admissions increased 25% in the years 2000 to 2001.⁵⁹ In addition to IDU as a mode of exposure, substance use such as alcohol increases the likelihood of HIV risk behaviors, such as high risk sexual behaviors.⁶⁰ Finally, substance abuse also complicates treatment for HIV/AIDS. Substance abuse treatment services are a necessary component of both prevention and treatment.

The budget for the Massachusetts Bureau of Substance Abuse Services (BSAS) has seen significant reductions. Since FY2001, the substance abuse treatment line item has been reduced by about 25%, over \$11M. The reduction in funding has led to a reduction in capacity and a reduction in drug treatment admissions of 7%, or a drop of 8,643 FY03. An emergency supplemental budget in FY05, however, increased funding primarily because budget cuts over the past few years led to a failure to maintain capacity, threatening \$9.1M in federal matching funds.

Policy Implications and Recommendations

The character of HIV/AIDS has changed over the past decade, including the demographics of who is at risk and staggering improvements in scientifically based prevention and treatment which have dramatically reduced death and improved health and quality of life for people living with HIV/AIDS. At the same time, access to these prevention and health care systems has not been equitably distributed. Further, declines in funding over the past few years have reduced prevention, care, and research efforts. The Commonwealth is facing a budget gap of more than \$900 million in FY06, mandated spending increases in other areas, and is at risk of losing \$600 million in federal Medicaid waiver funds.⁶¹ Failing to fund HIV/AIDS at current levels will result in further reductions in prevention and health care programs. It is important to stay engaged with policy efforts, encouraging innovation and funding for targeted prevention and the care of people living with HIV/AIDS. Nationally, this is particularly important in light of the coming debates for the re-authorization of the Ryan White CARE Act.

Targeted prevention efforts that include resources for testing and counseling as well as for the provision of culturally appropriate information about how the disease is spread and can be avoided are critical to prevent disease transmission. Prevention efforts

need to be funded and expanded in both schools and the community and do a better job at reaching high risk groups such as women, minorities, immigrants, people living in disenfranchised communities, and youth, particularly gay, lesbian and bisexual youth.^{35,41} These efforts must be based on the latest public health research and then tested to see if they result in behavior change. Access must be available to clean needles and prevention messages must be clear and targeted. They should not be based on ideology or dogma. Success will require mobilization of high-risk communities to participate in the development and construction of new public health approaches to prevention, as well as adequate funding from state and federal agencies.

To slow the spread of the disease, efforts must focus on the social determinants of HIV transmission by addressing complex structural issues, including poverty, taboos toward sexuality and drug abuse, and inequities, such as gender inequality and racism. This warrants an expansion of the how policy change in HIV/AIDS is understood by focusing not just on health policy, but social policies that address complex social issues that transcend the life course and address the economic, social, and cultural determinants in which this epidemic is embedded.

Advances in treatment, particularly medications, provide a valuable life saving and cost effective public health and treatment function. However, the effectiveness of treatment depends on adherence to costly and expensive medication regimes. The funding of important public health programs that ensure access and adherence, including substance abuse treatment, housing, and HDAP, are

key to slowing the spread of the epidemic as well as ensuring that treatment is available to even the most vulnerable among the Commonwealth's population. To meet this goal, it is also important to integrate treatment systems. Treatment helps to delay disability among those infected with HIV/AIDS, and allows them to work and contribute to the future prosperity of the Commonwealth. It is important to continue to fund treatment and research, as well as non-medical support services.

Engaging the business sector and private philanthropy is critical. The business sector provides crucial public health effort in the prevention and treatment of HIV/AIDS including the purchase of health care for employees that cover HIV/AIDS treatments and provide valuable prevention information to their employees. It is important that we continue to engage this sector as corporate citizens. It is also important to engage private philanthropy in the discussion of how HIV/AIDS funding is related to their foundational goals.

Finally, although a substantial number of Americans believe AIDS is a pressing issue and requires more public investment, this report clearly demonstrates that funding is not keeping up with prevention and treatment needs.⁴⁴ Both public and private financial investment and effective policies in the prevention and treatment of HIV/AIDS in the first part of the past decade led to innovative and substantial programming efforts that got us to where we are today. As the nature of the illness has changed public policy and private efforts need to modify existing programs and strategies, creatively target new innovation, and renew and enhance financial commitments. This is the only way we can reverse current trends and control this epidemic.

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