

# HIV/AIDS in Cambridge: The Changing Face of an Epidemic

## Overview

In 1981, an article in *Morbidity and Mortality Weekly* reported that a rare form of pneumonia, which had previously affected only people with severely challenged immune systems, had struck a group of apparently healthy gay men in Los Angeles. This story did not begin to forecast the global epidemic we now know as HIV/AIDS.<sup>1</sup>

In little more than two decades, HIV/AIDS has killed 20 million people worldwide, and is the sixth leading cause of death on the planet.<sup>2,3</sup> Today, 38 million people are living with HIV or AIDS.<sup>2</sup> Transmission through heterosexual sex accounts for more than 70% of global infections, and women represent nearly 50% of all people living with HIV.<sup>2</sup>

In developed countries, treatment options have reduced new AIDS cases and deaths by as much as 70% during the past ten years.<sup>4</sup> Meanwhile, behavioral scientists continue to discover new ways to motivate people to adopt behaviors that will reduce their risk of acquiring HIV.<sup>5</sup>

Despite these breakthroughs, the HIV/AIDS epidemic is being propelled by entrenched social ills, such as poverty, gender discrimination, racism, homophobia, substance abuse, violence, social dislocation, and lack of access to critical health services. AIDS-related stigma<sup>6</sup> endures as a threat to both meaningful prevention and care.<sup>7,8,9</sup> Global inequities mean that more than three-quarters of individuals infected with HIV lack access to life-saving medications.<sup>10</sup>

### **What is AIDS?**

AIDS is the most serious form of an illness caused by the Human Immunodeficiency Virus (HIV). The virus attacks or disables the body's immune system. Over time, if the immune system becomes seriously damaged, the body loses the ability to combat a variety of illnesses, called opportunistic infections. Each new infection further wears down the body's defenses. These infections and cancers, such as pneumocystis pneumonia and Kaposi's sarcoma, are the real killers of people with HIV.

*Text excerpted from  
Project Inform @ [www.projinf.org](http://www.projinf.org)*

The current status of HIV/AIDS in the United States reflects significant accomplishments and ongoing challenges. The early years of the epidemic were marked by a rapid rise in infections and increasing mortality. However, the number of AIDS-related deaths in the U.S. began to decline in the mid-1990s when the multi-drug "cocktail," otherwise known as highly active antiretroviral therapy (HAART), was introduced.<sup>11</sup> Then, between 1996 and 1997, the number of AIDS-related deaths fell by a promising 42%.<sup>12</sup> Since 1999, the number of AIDS-related deaths in the U.S. has remained fairly constant at about 18,000 a year.<sup>13</sup>

Today, an estimated 850,000 to 950,000 people in the U.S. are living with HIV/AIDS<sup>14</sup> and another 40,000 people become newly infected every year.<sup>15</sup> Black and Latino individuals account for a disproportionate share of new HIV/AIDS cases in the United States.

## Trends and Data

### Massachusetts

More than 25,000 people in Massachusetts have been diagnosed with HIV or AIDS since 1981; 42% of these individuals are no longer alive.<sup>16</sup> As of July 1, 2004, the Massachusetts Department of Public Health reported 14,727 Massachusetts residents were living with HIV/AIDS.<sup>16</sup> The department estimates that another 8,300 residents are infected with HIV and have either not been diagnosed or reported to the state.<sup>16</sup>

The rate of new HIV infections and the rate of people dying from HIV/AIDS in Massachusetts have both been declining since 2000.<sup>17</sup> At the same time, disparities among HIV-infected people from different racial and ethnic groups are increasing. In 2003, the age-adjusted prevalence rate of HIV/AIDS among black residents in the Commonwealth was 10 times greater than for white residents. Among Latinos, the age-adjusted prevalence rate was nine times greater than for white residents.<sup>18</sup>

According to the Massachusetts HIV/AIDS Bureau, the distribution of men and women diagnosed with HIV remained stable between 1999 and 2003, with men accounting for 68% to 71% of new infections and women accounting for 29% to 32% of new cases.<sup>19</sup> What did change, however, was the racial composition of Massachusetts women diagnosed with HIV during this time. The proportion of black women diagnosed with HIV increased from 40% to 51% between 1999 and 2003, while the proportion of white women diagnosed with HIV decreased from 31% to 18%.<sup>19</sup>

Reflecting the global nature of the epidemic, immigrants and refugees comprise an increasing proportion of people living with HIV/AIDS in Massachusetts. Between 1999 and 2003, the proportion of foreign-born people diagnosed with HIV infection increased from 18% to 29%.<sup>19</sup> These individuals represent 110 countries, and are predominantly people of color.<sup>17</sup>

Approximately 40% of women and 24% of men diagnosed with HIV infection in Massachusetts between 2001 and 2003 were foreign-born.<sup>19</sup> Among black women diagnosed with HIV infection between 2001 and 2003, 61% were born outside the U.S., compared to 7% of white women and 21% of Latina women.<sup>19</sup> Among black men, 45% were born outside the U.S., compared to 7% of white men and 29% of Latino men.<sup>20</sup>

A troubling issue in Massachusetts is the number of people who do not learn about their HIV status until they are already quite sick and within two months of being diagnosed with AIDS. A late diagnosis reduces opportunities for effective treatment and increases the likelihood that an individual may unknowingly transmit the virus. Late diagnoses (also known as “concurrent diagnoses”) comprise about 30% of recent HIV diagnoses in Massachusetts. Statewide, 61% of black individuals concurrently diagnosed with HIV infection and AIDS from 2001 to 2003 were foreign born, compared to 34% of Latinos and 9% of white individuals.<sup>20</sup>

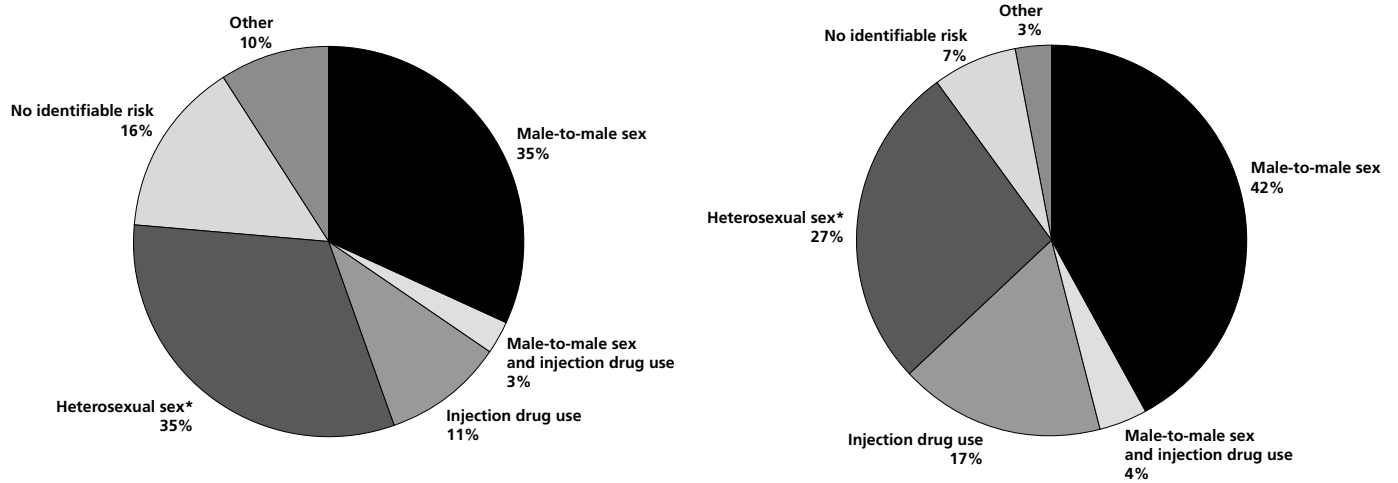
### Cambridge

Approximately 600 people in Cambridge have been diagnosed with HIV or AIDS since the beginning of the epidemic.<sup>17</sup> As of October 1, 2004, the Massachusetts Department of Public Health reported 328 Cambridge residents living with HIV/AIDS.<sup>17</sup> This figure underrepresents the actual number of infected people due to undiagnosed infections, lags in reporting, and limitations in data collection.

The advent of improved therapies has substantially decreased HIV/AIDS mortality in Cambridge. Since the epidemic began, 240 Cambridge men and 43 Cambridge women have died from HIV or AIDS.

\* The Cambridge Public Health Department is aware that there are at least 400 Cambridge residents living with HIV/AIDS, based on 2004 data from the federal Ryan White CARE Act program.

**Figure 1:  
HIV/AIDS by Mode of Transmission, Cambridge**



*All Residents Diagnosed with HIV/AIDS Between 1999-2003*  
 NOTE: \*This category includes "presumed heterosexual sex."  
 SOURCE: Massachusetts Department of Public Health Surveillance Program. Data as of 9/1/04.

*All Residents Living with HIV/AIDS*  
 NOTE: \*This category includes "presumed heterosexual sex."  
 SOURCE: Massachusetts Department of Public Health. HIV/AIDS Surveillance Program. Data as of 7/1/04.

The vast majority of these deaths occurred prior to 1999. Since 2000, only six Cambridge residents have died from HIV/AIDS-related causes.<sup>17</sup> The number of new HIV cases diagnosed annually in Cambridge remained stable between 2001 and 2003, with an average of 18 new HIV infections reported each year.<sup>21</sup>

During the early 1980s, women comprised less than 10% of all AIDS cases diagnosed among Cambridge residents.<sup>22</sup> Today, women account for approximately 25% of all Cambridge residents living with HIV/AIDS.<sup>21</sup>

Compared to the overall population of Cambridge residents who are HIV-positive, people who were diagnosed more recently (1999 through 2003) are more likely to have been infected through heterosexual sex and less likely to have been infected through injection drug use (see figure 1).

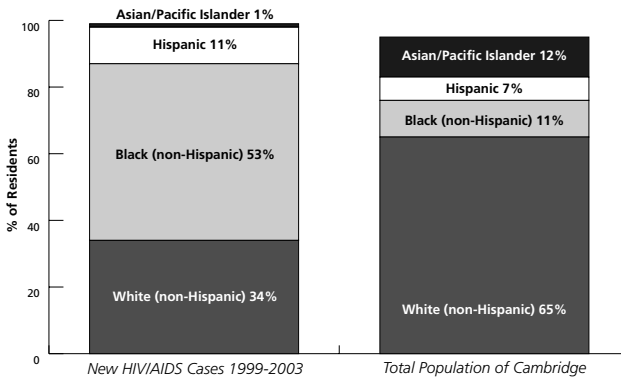
Among Cambridge men, male-to-male sex accounted for 47% of new HIV infections diagnosed between

1999 and 2003, heterosexual sex<sup>\*\*</sup> accounted for 22%, and injection drug use accounted for only 9%.<sup>21</sup> The majority of Cambridge women diagnosed between 1999 and 2003 were infected through heterosexual sex<sup>\*\*</sup> (72%), followed by injection drug use (14%).<sup>21</sup>

Like elsewhere in Massachusetts, people of color in Cambridge are disproportionately affected by HIV/AIDS (see figure 2). While black residents comprise only 11% of the city's population, they made up 53% of new HIV diagnoses between 1999 and 2003. Latino residents, who comprise 7% of the city's population, accounted for 11% of new diagnoses during the same period.<sup>21, 23</sup>

\*\* In this report, *heterosexual sex* combines two Massachusetts Department of Public Health exposure categories: heterosexual sex and presumed heterosexual sex. The latter category is used in Massachusetts to reassign people who are reported with no identified risk but who are known not to have reported any other risks except heterosexual sex with a partner of unknown HIV status or risk.

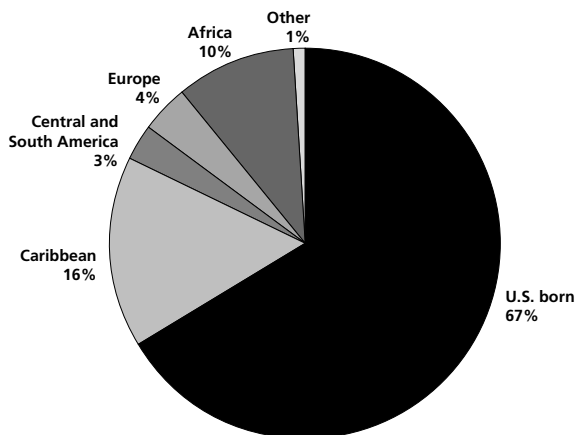
**Figure 2: Cambridge Residents Diagnosed with HIV/AIDS from 1999-2003 by Race**



SOURCE: 2000 U.S. Census data from MassCHIP v3.0 r310.0. Massachusetts Department of Public Health, HIV/AIDS Surveillance Program. Data as of 9/1/04.

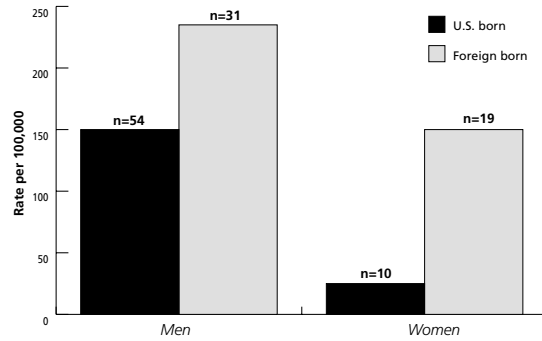
The state reported 85 new HIV infections among Cambridge men between 1999 and 2003. Of these cases, 45% were among black men, 39% were among white men, and 14% were among Latino men. During the same period, the state reported 29 new infections among Cambridge women. Of these cases, 76% were among black women, 21% were among white women, and 3% were among Latina women.<sup>21</sup>

**Figure 3: Foreign-Born Residents with HIV/AIDS by Region of Birth, Cambridge**



NOTE: Numbers may not add up to 100 due to rounding.  
 SOURCE: Massachusetts Department of Public Health, HIV/AIDS Surveillance Program. Data as of 10/1/04.

**Figure 4: Cambridge Residents Diagnosed with HIV/AIDS from 1999-2003 by Gender and Country of Origin**



NOTE: U.S.-born category includes U.S. dependencies (e.g., Puerto Rico)  
 n=The number of people diagnosed with HIV/AIDS.  
 SOURCE: Massachusetts Department of Public Health, HIV/AIDS Surveillance Program. Data as of 9/1/04.

Within the city's communities of color, first-generation immigrants from the Caribbean, Latin America, and Africa have been deeply affected by HIV/AIDS (see figure 3). Although residents from the Caribbean, Central and South America, and Africa comprise only 9% of the city's population, they account for 28% of total HIV/AIDS cases in Cambridge.<sup>17, 24</sup>

This trend has become more pronounced in recent years. Foreign-born people living in Cambridge accounted for 44% of new HIV/AIDS infections in Cambridge between 1999 and 2003. Of the 29 Cambridge women diagnosed with HIV during this period, 19 were foreign-born. Of the 85 Cambridge men diagnosed during this period, 31 were foreign-born (see figure 4).<sup>17</sup>

In addition, 50% of late diagnoses since 1999 have occurred among foreign-born individuals, nearly 40% of whom are women.<sup>17</sup> The Cambridge Public Health Department does not have data on the ethnic or racial backgrounds of these individuals.

For more data on HIV/AIDS in Cambridge see table 1.

**Table 1: HIV/AIDS in Cambridge Data as of September 1, 2004**

	HIV Diagnoses in Cambridge 2001–2003 <sup>1</sup>		All People Living With HIV/AIDS in Cambridge <sup>1,2</sup>		Cambridge Demographics <sup>3</sup>	
	N	%	N	%	N	%
<b>Gender:</b>						
Male	38	72%	245	75%	49,674	49%
Female	15	28%	82	25%	51,681	51%
<b>Place of Birth:</b> <sup>4</sup>	N	%	N	%	N	%
US and Territories	27	51%	222	68%	75,137	74%
Non-US	26	49%	106	32%	26,218	26%
<b>Race/Ethnicity:</b>	N	%	N	%	N	%
White (non-Hispanic)	16	30%	153	47%	65,425	65%
Black (non-Hispanic)	27	51%	136	42%	11,627	11%
Hispanic	8	15%	32	10%	7,455	7%
Asian/Pacific Islander	1	2%	3	1%	12,055	12% <sup>5</sup>
Other/Unknown	1	2%	3	1%	4,793	5%
<b>Exposure Mode:</b>	N	%	N	%	N	%
Male-to-male sex (MSM)	16	30%	137	42%	NA	NA
Injection Drug Use (IDU)	5	9%	54	17%	NA	NA
MSM/IDU	0	0%	13	4%	NA	NA
Heterosexual Sex	8	15%	34	10%	NA	NA
Other	1	2%	11	3%	NA	NA
Total Undetermined	23	43%	78	24%	NA	NA
Presumed Heterosexual Sex <sup>6</sup>	12	23%	54	17%	NA	NA
Undetermined <sup>7</sup>	11	19%	22	7%	NA	NA
<b>Age at Diagnosis</b>	N	%	N	%	N	%
Under 13 <sup>8</sup>	1	2%	3	1%	9,977	10%
13 to 19	0	0%	8	2%	8,852	9%
20 to 24	3	6%	20	6%	16,090	16%
25 to 29	10	19%	49	15%	14,721	15%
30 to 34	11	21%	78	24%	10,481	10%
35 to 39	7	13%	66	20%	7,486	7%
40 to 44	10	19%	56	17%	6,456	6%
45 to 49	7	13%	27	8%	5,752	6%
50+	4	8%	20	6%	21,540	21%
<b>TOTAL</b>	<b>53</b>	<b>100%</b>	<b>327</b>	<b>100%</b>	<b>101,355</b>	<b>100%</b>

<sup>1</sup> Note: Percentages may not add up to 100% due to rounding.

<sup>2</sup> Massachusetts Department of Public Health, HIV/AIDS Surveillance Program, data as of September 1, 2004.

<sup>3</sup> U.S. Census Bureau, Census 2000, data from MassChip v3.0 r310.0.

<sup>4</sup> Data as of October 1, 2004. Note: Numbers may not be the same for selected categories due to different collection dates of data.

<sup>5</sup> Non-hispanic Asian/Pacific Islander.

<sup>6</sup> "Presumed heterosexual sex" is a category used in Massachusetts to reassign people who are reported with no identified risk but who are known not to have reported any other risks except heterosexual sex with a partner of unknown HIV status or risk.

<sup>7</sup> Includes those still being followed up for risk information and those lost to follow-up.

<sup>8</sup> Data on pediatric cases of HIV infection (non-AIDS) are not indicated here.

## HIV/AIDS Prevention, Treatment, and Support Services

HIV/AIDS remains a devastating infectious disease for which there is no vaccine or cure. While new medicines have prolonged the lives of infected people, they are expensive and can have serious side effects. Moreover, unfavorable attitudes and beliefs about HIV/AIDS, homosexuality, bisexuality, and injection drug use lead some people to deny risk, avoid testing, and delay treatment.<sup>25, 5</sup>

Unlike many other chronic diseases, HIV/AIDS predominantly afflicts people in their mid-20s to mid-40s.<sup>13</sup> Faced with an incurable, life-threatening illness, these people must grapple with fear, pain, and premature death (including leaving behind partners and children). They may also experience discrimination that can lead to job loss, eviction, and isolation from family and community.<sup>25</sup> The majority of people living with HIV/AIDS are poor, and lack access to health and social services. The outward signs of poverty – precarious housing, lack of transportation and child care, poor health, and weak social support networks – pose real barriers to treatment.<sup>26</sup>

In the nation's struggle against HIV/AIDS, public health efforts have focused on preventing new infections, providing medical care, and offering a wide range of support services to people living with the disease.

HIV/AIDS programs receive funding from a variety of sources. At the federal level, the Centers for Disease Control and Prevention (CDC) provides support to state and local prevention programs. The Ryan White CARE Act, administered through the U.S. Department of Health and Human Services, awards more than \$2 billion annually in grants nationwide for HIV primary care, treatment, and essential support services to low-income people.<sup>26</sup> The U.S. Department of Housing and Urban Development provides housing assistance to

low-income individuals living with HIV/AIDS. The Massachusetts Department of Public Health helps administer these federal funds and also provides additional dollars for prevention, treatment, and services. Locally, the City of Cambridge and Cambridge Health Alliance offer financial support to community-based organizations like Cambridge Cares About AIDS.

Since 2000, however, Massachusetts HIV providers and their patients have been confronted with dwindling or stagnant state and federal funding at a time when the number of people living with HIV/AIDS is growing. The state's ongoing fiscal crisis has resulted in deep cuts to HIV/AIDS prevention and support services. Between fiscal years 2001 and 2004, the Massachusetts HIV/AIDS Bureau lost \$19 million in state funding, which had the greatest impact on prevention programs, support services, and substance abuse treatment. State funding for medical treatment of HIV patients has remained stable during the past four years. Since 2002, Congress has not increased funding for most federal HIV/AIDS programs.

By many accounts, Cambridge has been fortunate in terms of the level of care and services it is still able to provide. Community-based organizations in Cambridge receive \$1 million of the state's \$9 million budget for prevention services.

The following sections discuss the range of prevention, treatment, and support services currently available in Cambridge, as well as opportunities for strengthening the city's HIV/AIDS programs.

### HIV Prevention Services

Preventing new infections is the most effective way of controlling the HIV/AIDS epidemic. Over the past 20 years, prevention efforts have helped reduce the number of new HIV cases in the United States from about 150,000 a year during the mid-1980s to about 40,000 a year currently.<sup>5</sup>

Prevention activities have focused on helping people make healthy decisions and sustain protective behaviors. This approach has contributed to fewer infections among some high-risk populations, such as men who have sex with men, injection drug users, and people who are incarcerated. In the United States, voluntary testing of pregnant women and the use of antiretroviral drugs have dramatically reduced the number of babies who are born infected with HIV.<sup>5</sup>

The declining rate of HIV/AIDS deaths among Cambridge residents since the 1990s, as well as the drop in new HIV infections since 2000, can likely be credited to the combined effects of improved treatment and sustained prevention.<sup>27</sup>

Cambridge has embraced progressive, and sometimes controversial, HIV/AIDS prevention initiatives over the past 15 years. Efforts have focused on reducing HIV transmission among gay and bisexual men and injection drug users through comprehensive harm reduction services. Outreach, education, and support services have been established for youth, women, homeless individuals, people of color, and recent immigrants. More recently, programs have begun offering counseling and support services for couples in which only one partner is infected.

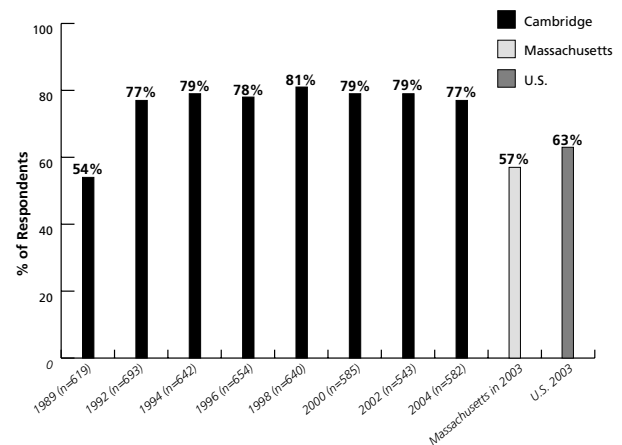
Cambridge supports a broad range of HIV education and risk reduction programs that include:

**Youth education and health services.** Young activists at Cambridge Rindge and Latin School began handing out condoms and AIDS fact sheets to their fellow students in fall 1989. The following spring, the Teen Health Center (based at Cambridge Rindge and Latin School) began dispensing condoms as part of a broader AIDS education and prevention program. By the early 1990s, services at the Teen Health Center included HIV counseling and testing, family planning, and condom availability. The health center also began offering supportive programs for gay, lesbian, bisexual, and transgender youth.

**Successes**

- The number of new HIV infections in Cambridge dropped from 32 cases in 1999 to 19 cases in 2003.<sup>21</sup>
- HIV transmission related to injection drug use accounted for only 17% of the cases of people living with HIV/AIDS in Cambridge in 2003 compared to 31% at the state level. Only 9% of new cases in Cambridge diagnosed between 2001 and 2003 were associated with injection drug use.<sup>21</sup>
- Condom use among sexually active students at Cambridge Rindge and Latin School increased from 54% in 1989 to 77% in 1992. Condom use has remained at this high level for the past 12 years (see figure 5).<sup>29</sup>
- The proportion of Cambridge teens at Cambridge Rindge and Latin School who reported ever having had sexual intercourse decreased from 51% in 1989 to 43% in 2004.<sup>29</sup> The most recent figure is slightly below the national average of 47%.<sup>30</sup>

**Figure 5: Condom use among sexually active teens**



NOTE: Students were asked the question: The last time you had sexual intercourse, did you or your partner use a condom?  
 n=The number of sexually active teens.  
 SOURCE: Cambridge Teen Health Survey, 1989-2004.

**Needle exchange program.** The Cambridge Cares About AIDS needle exchange program is nationally recognized for its comprehensive approach to harm reduction. The program links clients to drug treatment, HIV testing and counseling, treatment of sexually transmitted diseases, and medical and mental health services. Participation has grown steadily. In fiscal year 2004, a total of 203,000 needles were distributed.<sup>28</sup> Established in 1992, the program is one of only four comprehensive needle exchange programs in Massachusetts.

**Counseling and testing.** Cambridge Health Alliance provides counseling and confidential testing for HIV, viral hepatitis, and other sexually transmitted diseases (STDs) at The Cambridge Hospital and community health centers. Additional testing and referrals are offered through the Alliance's prevention programs for Portuguese-speakers and Haitians, as well as through targeted outreach to gay and bisexual men.

Cambridge Cares About AIDS offers anonymous and confidential HIV counseling and testing to gay and bisexual men, injection drug users, and homeless and street youth. Massachusetts Alliance of Portuguese Speakers (MAPS) offers anonymous and confidential HIV counseling and testing to at-risk gay and bisexual men. Concilio Hispano offers HIV and sexually transmitted disease counseling.

**Outreach programs.** Concilio Hispano provides prevention services to Latino injection drug users, as well as Latino teens and women who are considered at high risk for HIV infection. Concilio also offers HIV education at Cambridge Rindge and Latin School and in the community. MAPS offers outreach services to Portuguese-speaking men, women, and teens. Cambridge Cares About AIDS provides street and community outreach to gay and bisexual men, and their partners. The agency also offers risk reduction

counseling to injection drug users, men who have sex with men, and homeless youth and their partners. The Alliance offers HIV prevention, outreach, and education to Haitian and Portuguese-speaking communities in eastern Massachusetts.

### **Challenges**

Reduced funding for prevention services. In fiscal year 2004, Cambridge Health Alliance did not receive any state funding for HIV/AIDS prevention, reducing its ability to provide prevention education to the most vulnerable members of the community. Prior funding cuts resulted in the closure of the Alliance's hepatitis C program and the Latino Safety Net program.<sup>31</sup> However, the state has continued to fund local organizations (Cambridge Cares, MAPS, Concilio Hispano) to provide HIV education and outreach to people at high risk for infection. The Alliance collaborates with these agencies, providing clinical services to people who are identified at risk for HIV infection.

Youth services in Cambridge have also been impacted by state budget cuts. The Teen Health Center no longer offers HIV testing to adolescents due to funding shortfalls.<sup>32</sup> State funding for teen pregnancy prevention programs and sex education classes has also been reduced.<sup>33</sup>

**Sexually transmitted diseases.** Risky behaviors that lead to sexually transmitted infections may increase a person's likelihood of becoming infected with HIV. In addition, certain sexually transmitted diseases can increase susceptibility to HIV transmission. Syphilis, genital herpes (type 2), and other infections that cause genital or rectal ulcers may increase the risk of HIV transmission per sexual exposure 10 to 50 times for male-to-female transmission and 50 to 300 times for female-to-male transmission. Chlamydia and gonorrhea have been shown to increase risk of HIV transmission two to five times.<sup>34</sup>

In Cambridge, the number of reported syphilis cases nearly doubled between 2000 and 2003, from 12 cases to 21 cases. In 2003, the syphilis rates in Cambridge were more than twice that of Massachusetts. Chlamydia and gonorrhea rates in Cambridge were also higher than that of the state. Chlamydia rates in Cambridge have been steadily increasing since 2000.<sup>35</sup> While gonorrhea rates in Cambridge have fluctuated over the past several years, the average annual rate between 2000 and 2003 was nearly two times higher than it was in the mid-1990s.<sup>35, 22</sup>

Some local HIV providers have expressed concern that Cambridge does not have a free walk-in clinic for sexually transmitted disease counseling and testing.

**Outreach to vulnerable populations.** Cambridge HIV providers have identified a greater need for prevention services for specific risk groups, including men who have sex with men but do not identify as gay or bisexual, gay or bisexual men (especially young men of color), and heterosexual men and women (particularly those from immigrant communities). Providers also feel there is a shortage of prevention services for people who do not speak English, and that some neighborhoods, notably Central Square, are not adequately served.

**Barriers to HIV testing.** People at risk for HIV infection may avoid testing for a number of reasons, including limited or inaccurate knowledge about the disease, lack of access to anonymous testing, fear of rejection from their family and community, inability to afford treatment, dislike of counseling, the anxiety of waiting for results, and fear of a positive result.<sup>36, 37</sup> Moreover, foreign-born residents at risk for HIV infection may avoid getting tested because they believe that a positive result could jeopardize their ability to acquire a green card, could restrict their ability to travel outside the U.S., and could lead to deportation.<sup>38</sup>

**Positive prevention.** Historically, HIV prevention efforts have focused on keeping uninfected individuals from getting the disease. Now that people who are HIV-positive are living longer, the Centers for Disease Control and other health agencies have recognized the need for supporting HIV-positive people in protecting their partners from infection.

Local HIV/AIDS providers report varying amounts of success in promoting “positive prevention” among people living with the disease. Cambridge Cares About AIDS has integrated positive prevention messages and information in its intake packages for new clients. Concilio Hispano offers peer-led support groups on positive prevention. In 2004, the Zinberg Clinic at The Cambridge Hospital launched a major quality improvement project to ensure that staff speak to patients at every medical encounter about the risk of transmitting HIV to uninfected partners. At the same time, Cambridge providers worry that the message may not be reaching all HIV-positive individuals, especially those who receive health care in other settings such as emergency rooms and private doctors’ offices.

### **Treatment Services**

Treatment for HIV varies depending on how far the disease has progressed in an individual patient. In the least serious stage of the disease, patients do not have any symptoms of illness and their blood contains low amounts of the virus and high amounts of infection-fighting blood cells. At this juncture, most physicians defer treatment and focus on helping the person maintain good overall health.

As the immune system begins to weaken, however, most people with HIV start taking antiretroviral drugs. People on antiretroviral therapy must strictly follow their treatment plans because drug resistance can occur when doses are skipped.<sup>39</sup> Despite this

risk, people often have trouble sticking to their regimens. Certain antiviral drugs require fasting or other food restrictions. Uncomfortable side effects such as nausea, vomiting, and fatigue can also hinder compliance. In addition, some antiretrovirals can cause serious health problems like muscle and bone injury, liver damage, and redistribution of body fat (which significantly alters a person's appearance). One Cambridge physician likened HIV medicines to "taking chemotherapy at home."

Other issues such as poverty, inadequate housing, lack of continuous and comprehensive health insurance, mental illness, substance abuse, and fear of stigma can also negatively impact treatment outcomes.

The Zinberg Clinic at The Cambridge Hospital is the only dedicated HIV/AIDS treatment center in Cambridge. In 1988, the Zinberg Clinic became one of the first federally funded HIV clinical care demonstration projects.<sup>40</sup> Four years later, the Zinberg Clinic was one of eight regional sites in Massachusetts funded by ACT Now, a state-operated program that provides free and confidential primary care to people who are HIV-positive and uninsured.

A large number of Zinberg patients live in chronic poverty. Some also suffer from mental illness and drug or alcohol addiction. Many are homeless. The majority of patients depend on either Medicaid or "free care" from the state's Uncompensated Care Pool to cover the cost of their doctors' visits and medicine. (Of the approximately 300 people with HIV who regularly receive care at the Zinberg Clinic or Somerville Primary Care, 36% are uninsured and 30% are enrolled in Medicaid.)<sup>41</sup>

To meet some of the unique challenges posed by their patients' circumstances, the Zinberg Clinic has adopted a holistic approach to treatment. Zinberg physicians, nurse practitioners, nutritionists, and social workers work as team to address individual patients' medical and psychosocial needs. The clinic offers HIV/AIDS and

sexually transmitted disease counseling, testing, and treatment; primary care; gynecology; psychiatric care; case management; drug counseling; nutrition services; and acupuncture. The Cambridge Hospital provides additional services for Zinberg patients, including tuberculosis treatment, a methadone clinic, emergency care, and specialty care.

Although Zinberg's multidisciplinary approach is an expensive model of care, staff believe HIV/AIDS patients greatly benefit from having most of their needs met in one location. Zinberg consistently receives excellent outcome scores<sup>\*</sup> for its ability to help patients maintain medical care: the vast majority of patients miss fewer than four medical appointments in a given six-month period.<sup>42</sup> In addition, Zinberg helps patients develop personal strategies for remembering to take their medications.

The best measure of treatment success is improved health outcomes for patients with HIV/AIDS. In simplest terms, a person with a high count of certain infection-fighting white blood cells (known as CD4+ cells) and a low amount of HIV in the bloodstream is less likely to develop AIDS-related complications or to require hospitalization.

Based on 2002 data, health outcomes among Zinberg's continuing patients compared favorably to those of patients receiving care at other ACT Now clinics in Massachusetts. Among the 19 participating clinics, Zinberg had the lowest percentage (10%) of continuing patients who were at risk for opportunistic infections (i.e., CD4+ counts below 200). In addition, 81% of Zinberg continuing patients had low amounts of HIV in

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\* These outcome scores are based on a sample of Zinberg patients who receive Ryan White Title I services through the federal government. During the most recent evaluation period (March 2003-August 2003), a sample of 86 Zinberg patients scored 96 out of a possible 100 for ability to maintain medical care (e.g., missing fewer than four medical appointments during the six-month period).

their blood (i.e., viral loads below 400). People with very low or undetectable viral loads have a reduced risk of disease progression. Finally, Zinberg had the lowest percentage of hospitalizations among continuing patients compared to the other clinics.<sup>43</sup>

These findings are especially impressive because Zinberg patients in 2002 were more likely to have AIDS (60% of patients), more likely to be foreign born (41%) and somewhat more likely to report active mental illness (52%) than patients receiving care at other ACT Now sites.

Regarding preventive care at Zinberg, the 2002 ACT Now data indicated that a high percentage of patients were screened for hepatitis B (96%) and hepatitis C (93%). Areas for improvement, at the time, included improving vaccination rates for hepatitis B and pneumococcal pneumonia, and discussing risk reduction with patients.

Since receiving the ACT Now data in 2004, the Zinberg Clinic has launched a major quality improvement project to ensure that staff speak to patients at every medical encounter about how to reduce the risk of transmitting HIV to uninfected partners. Zinberg staff also identified patients who had not been immunized against hepatitis or pneumonia, and offered them vaccinations. In the near future, the clinic hopes to develop a customized electronic medical record for HIV patients that would prompt providers about vaccinations and other routine HIV-specific health care needs. This system would also make it easier to gather the type of data required by outside funders.

### Challenges

**Late diagnoses & missed opportunities.** Undiagnosed infections may be propelling the HIV epidemic in Massachusetts. According to state estimates, about one quarter of people who are infected with HIV in Massachusetts are not aware of their status. Many of these people do not seek medical care until they are severely ill. In Cambridge, for instance, about 30% of

residents who were diagnosed with HIV between 1999 and 2003 learned about their HIV status within weeks of developing AIDS.<sup>17</sup> These individuals lost the opportunity for early care and treatment that could have eased their suffering and prolonged their lives. In addition, they could have unknowingly infected other people.

Local providers interviewed for this report stated that missed opportunities for early diagnosis and prevention occur in many settings, including private doctors' offices, university health services, and hospitals. Complicating efforts to improve HIV screening may be resistance on the part of immigrants to having their status documented for fear of deportation or stigmatization within their communities.

**Funding concerns.** Both HIV providers and their patients are concerned about the changing financial situation within the health care arena, particularly as it relates to Medicare and Medicaid benefits. They cited changing reimbursement mechanisms and ongoing financial uncertainty about the HIV Drug Assistance Program, which helps low-income people gain access to medications.

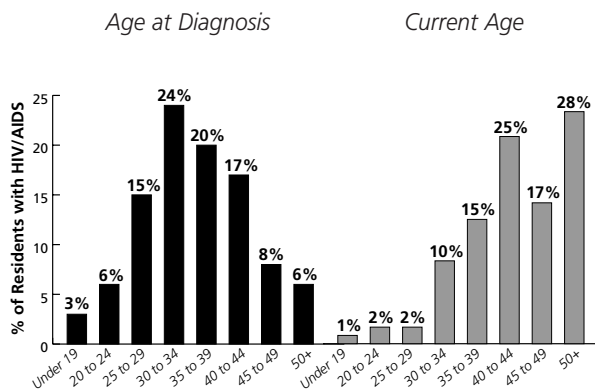
In June 2004, advocacy efforts led to the temporary restoration of MassHealth coverage to HIV-positive individuals whose incomes fell between 133% and 200% of the federal poverty line.<sup>44</sup> Advocacy efforts also led the state legislature to allocate an additional \$2.4 million for the HIV Drug Assistance Program, which should ensure that no one who is eligible will be denied medication in fiscal year 2005.<sup>45</sup>

### Support Services

The lack of effective medical treatment in the early years of the AIDS epidemic spurred the development of community support services in Cambridge to help ease the suffering of those dying of AIDS. During the past decade, however, programs have had to reorient themselves to support clients living with HIV/AIDS.

The majority of Cambridge residents living with HIV/AIDS are over 40 years old (*see figure 6*). As infected individuals lead longer, more productive lives, they face practical life challenges that require job skills training, assistance finding employment and permanent housing, and social and emotional support. In addition, many people with HIV/AIDS are also affected by mental illness, substance abuse problems, poverty, and homelessness. These issues require ongoing and comprehensive support services.

**Figure 6:**  
**Cambridge Residents Living with HIV/AIDS by Age at Diagnosis and Current Age**



NOTES: The age at diagnosis category includes 327 people, based on data as of 9/1/04. The current age category includes 324 people, based on data as of 7/1/04. Percentages may not add up to 100 due to rounding.  
SOURCE: Massachusetts Department of Public Health, HIV/AIDS Surveillance Program. Data as of 7/1/04 and 9/1/04.

Among the 344 Cambridge residents with HIV/AIDS who receive medical and essential social services through the Ryan White CARE Act, 50% reported incomes at or below the federal poverty line.<sup>46</sup> The official federal poverty line for a family of four in 2004 was \$18,850 a year.<sup>47</sup> More than 100 individuals reported that they did not have permanent housing. Furthermore, 54% reported they were covered by public health insurance, and 9% were uninsured.<sup>46</sup>

Cambridge offers an array of support services including case management, legal aid, peer

support, transportation, nutrition services (e.g., food pantries, food vouchers, nutritional supplements), substance abuse programs, mental health services, and acupuncture.

Cambridge Health Alliance and community-based organizations have diversified in many ways to address the complex extended lives of clients. Concilio Hispano has integrated trauma and sexual abuse recovery into its HIV services. Cambridge Cares offers counseling to partners of infected individuals. All programs integrate life skills and life planning into case management and peer support services.

In recent years, Cambridge programs have increased their multilingual staff and interpreter capabilities. The Zinberg Clinic has multilingual staff and access to Alliance interpreters who collectively speak several dozen languages. The three community-based agencies have staff who are fluent in the dominant foreign languages spoken in Cambridge: Spanish, Portuguese, and Haitian Creole. Cambridge Cares About AIDS also has staff who speak an assortment of sub-Saharan languages.

### Challenges

**Funding for support services.** State funding cuts have adversely impacted the ability of local agencies to provide comprehensive services to their clientele. Since fiscal year 2001, the Massachusetts Department of Public Health has lost \$2 million in state funding for HIV support services, which has led to cuts to case management services, nutrition services, mental health care, volunteer support, and transportation.<sup>48</sup>

Funding shortfalls experienced by health and social services programs indirectly related to HIV/AIDS care—mental health, substance abuse treatment, Medicaid coverage for dental services, job training, and public assistance—have further exacerbated the burden on HIV service agencies and their clients.

**Housing.** Cambridge has traditionally been successful at securing transitional and permanent housing options for people living with HIV/AIDS. In 2003, however, the federal government sharply reduced funding for its Section 8 housing voucher program, which serves low-income households, seniors, and people with disabilities. The loss of these subsidies has made it increasingly difficult to find homes for precariously housed or homeless people with HIV/AIDS. Until recently, Cambridge Cares About AIDS was able to find housing for everyone on its waiting list within a year. Today the agency is offering “no guarantees” that will be able to place the 70 people currently on its waiting list.<sup>49</sup>

**Linguistically and culturally appropriate services.** While Cambridge programs have made tremendous strides in reaching out and supporting people from diverse backgrounds, these agencies have been challenged by newly arrived immigrants from Africa and other countries for whom there are few linguistically and culturally appropriate services. New immigrants with HIV/AIDS are a particularly vulnerable group. Some do not speak or comprehend English very well, and many hold cultural beliefs about disease and medicine that may be unfamiliar to American-born health care providers. Poor access to health care, risk to immigration status, and fear of stigma also impedes some foreign-born people from receiving care once they have been diagnosed.<sup>38</sup>

**Continuity of Care.** For HIV-positive people, the prospect of living longer also means there is a good chance they will lose trusted service providers during the course of their care. At a focus group meeting with people living with HIV/AIDS, participants spoke about the loss of therapists, doctors, and case managers. One woman stated: *My case manager knew my whole story and she left. They gave me a new case manager – do I want to go through all that again? Telling her everything again?* Participants spoke of the need to

improve coordination of care and suggested that experienced “consumers” participate in educating new case managers, some of whom have limited experience with the intersecting service systems.

**Peer Support.** The participants also spoke about the need for more social support groups that would help them face challenges like medication adherence and practical life planning, as well as establishing meaningful social, emotional, and sexual relationships. Both providers and clients struggle with how to create effective peer support. With so many subgroups (with different sexual, substance abuse, and mental health histories) it can be difficult to craft support programs that work equally well for everyone. Additionally, racial, ethnic, linguistic, and cultural differences demand sensitivity and thoughtfulness that is challenging in a time of fewer resources.

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## Preliminary Recommendations

It is hoped these preliminary recommendations for HIV prevention and care improvements in Cambridge will provide a framework for future collaborative planning, and policy, program, and service development within both the public and private sectors.

### 1. HIV prevention services are not sufficiently available for all at-risk populations in the city.

- a. Cambridge Health Alliance and community-based agencies should coordinate HIV and sexually transmitted disease prevention efforts to ensure adequate distribution of services to at-risk populations and critical geographic areas.
- b. Prevention planning must involve agencies beyond those specifically funded for HIV work, including agencies that address homelessness, substance abuse, youth development, recreation, and health promotion and disease prevention.

### 2. HIV infections diagnosed more recently (2000-2003) among Cambridge residents are particularly concentrated among black men and women (including new immigrants from the Caribbean and Africa), as well as men who have sex with men.

- a. Prevention strategies tailored to these specific groups should be developed with input from providers and individuals at risk for HIV infection. These strategies should address the diverse socioeconomic, cultural, and ethnic backgrounds of at-risk individuals in Cambridge.
- b. Targeted outreach, case identification, and support efforts ought to be developed and should be integrated with existing programs that successfully reach these populations.
- c. HIV providers from different organizations in Cambridge should share "best practices" for establishing linguistically and culturally competent services that meet the needs of diverse clientele.

### 3. About 30% of Cambridge residents who were diagnosed with HIV between 1999 and 2003 learned about their HIV status within two months of developing AIDS. These individuals lost the opportunity for early care and treatment that could have eased their suffering and prolonged their lives. In addition, they could have unknowingly transmitted the virus to others.

- a. Anti-stigma and public awareness campaigns should promote messages that effectively address false beliefs and social attitudes about HIV/AIDS, as well as other barriers that lead people to delay testing and seeking care.

- b. Routine HIV testing opportunities at Alliance sites and other venues in Cambridge should be actively supported and implemented in partnership with local community-based agencies involved in HIV/AIDS prevention, education, and case management.
- c. People who are diagnosed late in their illness, or delay seeking treatment, should be approached for assistance in determining how to reduce barriers to testing and treatment.
- d. Special attention should be given to developing and expanding culturally appropriate prevention services for non-English-speaking people who are at high risk for HIV infection.

### 4. Stigma and discrimination are ongoing challenges for people with HIV/AIDS and those at risk for infection. Unfavorable attitudes and beliefs about HIV/AIDS, homosexuality, bisexuality, and injection drug use lead some people to deny risk, avoid testing, and delay treatment.

- a. Cambridge should address HIV-related stigma and discrimination through citywide social marketing campaigns, civic dialogue, school curricula, and increased visibility of people with HIV/AIDS. Venues include schools, community centers, and the local media.
- b. Opportunities for social connection and interaction, such as peer support groups, should be increased.
- c. Hospitals, clinics, and agencies that provide HIV-related services should encourage people living with HIV/AIDS to participate in their own health care planning and should seek client feedback on services.
- d. Religious institutions should be more engaged in HIV-related awareness and support.
- e. The diversity of people at risk for HIV or already infected (e.g., gay and bisexual men, heterosexual men and women, intravenous drug users, immigrants) needs to be reflected in public awareness campaigns, service planning and delivery, and peer support efforts.

### 5. In a time of limited resources, it is crucial that HIV providers from different organizations in Cambridge work together to streamline access to prevention, treatment, and support services.

- a. The city should facilitate an HIV prevention and care advisory group of people living with HIV/AIDS and their providers to ensure improved program development, coordination, and problem solving.
- b. Integrated care should be supported wherever possible.
- c. Comprehensive HIV care and referral information should be readily available to Cambridge residents living with HIV/AIDS and their providers.

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