Chapter 1 Community Planning in San Francisco: The History and the Future


NATHANIEL KAHN'S
"MY ARCHITECT"
ENDS THURSDAY

SECTION I

San Francisco's Leadership Role in HIV Prevention

The History

San Francisco was one of the first and hardest hit epicenters of the AIDS epidemic. Sadly, as we enter 2004, San Francisco continues to experience one of the most devastating epidemics in the country. Thousands of people – men, women, transgendered persons, youth, and even some infants – have become infected with HIV, many of those have advanced to a diagnosis of AIDS, and far too many have died. This plan is dedicated to all of them. The members of the HIV Prevention Planning Council (HPPC), who developed this 2004 San Francisco HIV Prevention Plan, take very seriously their responsibility to remember the devastation, to build effective and successful strategies to eliminate new HIV infections, and to improve the quality of life for those living with HIV and AIDS.

For more than 10 years, San Francisco has played a leadership role in redefining the way in which public health and the medical community respond to this disease. Community planning is a concept that came of age here in San Francisco during the early years of the epidemic. It is a process that was developed to reflect the belief that determining how best to respond to local HIV prevention priorities and needs is best carried out through local decision-making.

San Franciscans made sure that community planning was included in federal legislation and administrative guidance. The result was the issuance of the Centers for Disease Control and Prevention's (CDC's) guidance on community planning, which requires health departments to work in collaboration with community planning groups (CPGs) to design local prevention plans that best represent the needs of the various communities at risk for, or infected with, HIV. In this spirit, the San Francisco HPPC was formed in 1994. The HPPC has been a consistent, clear voice of the people of San Francisco. In 2003, the national Society for Public Health Education (SOPHE) awarded the HPPC its distinguished Program Excellence Award in recognition of the group's effectiveness in ensuring that affected communities are involved in setting priorities. It was the first time this award was given to a community planning body.

The role of community planning was clear in the early days of this epidemic. Community planning helped identify who was at risk for HIV infection. It acted as a bridge, by helping many populations (including gay men, injection drug users, youth, the incarcerated, and immigrants) who had not had access to safe and appropriate health care communicate with those responsible for the design and delivery of care and prevention services. It was never acceptable to have disparities in health care, and in the era of HIV and AIDS it became a crisis. Community planning made sure that all of these voices were heard.

The elimination of racial and economic disparities in the delivery of health care is at the top of all reasonable health organizations' agendas. In fact, the federal government (e.g., Healthy People 2000 and Healthy People 2010), the American Public Health Association, and others have taken great strides in identifying and strategically attacking those disparities. It is through community planning that these disparities have the best chance to be identified and eradicated. The principles of parity, inclusion, and representation that guide community planning ensure that all affected communities, including people of different racial/ethnic backgrounds, genders, and life experiences, have a place at the table. This place is assured during the setting of the agenda, not in the middle of a process designed by others (as had too often been the historical case).

2004 and Beyond

COMMUNITY PLANNING AND HIV PREVENTION

As we enter 2004, the ten-year anniversary of community planning, there are a number of realities that face those at risk for HIV. First, there is the impact of difficult economic times. There is less money to spend for government-sponsored health and human service programs. Those in power at the federal and state levels face a tremendous challenge in balancing their budgets and making dollars available for all the service that government is counted on to provide. In addition, national security and Department of Defense priorities further restrict the funds that are available for health care and health promotion.

What is the role of community planning in these times? It has never been more important. Those who have been elected to lead us (and the administrators they hire) must be clearly and articulately reminded that real Americans, in real families and real communities, continue to become infected with HIV and to get sick and to die. The epidemic is not over, and we must maintain a strong national commitment. It is the everyday Americans in this city and in other cities and towns who need to raise their voices. In San Francisco, the HPPC is a key tool in identifying those voices, providing training and support in the articulation of needs, and marshalling the resources necessary to respond to those needs with appropriate, effective, and cost-efficient care and services.

This HIV Prevention Plan that you are reading is the result of the work of community planning in San Francisco, of the HPPC and its committees in 2003. A broad spectrum of San Francisco community members have debated the principles contained in this plan. Together we developed priorities for HIV prevention services, and together we recommended strategies and interventions to meet the needs of San Francisco's people.

We believe that state and federal governments work hard to meet the needs of the people. The HPPC understands and enthusiastically accepts its role as a partner in the design, delivery, and evaluation of HIV prevention and health promotion activities. We further believe that the government and the medical and the health care communities will be as successful as we (the HPPC) are in mobilizing the people in all of our communities and neighborhoods, in articulating a shared vision, and in recommending services that originate with those at risk for or living with HIV and their families, partners, and friends.

We take our responsibility very seriously. We take our duty to identify new leaders and develop leadership for the future very seriously. We are committed to the end of this epidemic, the elimination of health care disparities, and the promotion of the health of all San Franciscans, Americans, and people worldwide who can benefit from our experience and successes. As part of this responsibility, we are launching the San Francisco Leadership Initiative.

THE SAN FRANCISCO LEADERSHIP INITIATIVE

In an ideal world, HIV prevention and health promotion activities would be based on sound scientific evidence, the lived experience of the community, and the professional expertise of caring providers. In reality, a critical factor in the design, funding, and delivery of services is politics. At the federal, state, and city levels, political concerns often compete with research, evaluation findings, and community input. The result is that despite the best efforts to conduct effective community planning, community voices get lost in the final implementation process.

The San Francisco Leadership Initiative is our proactive plan for promoting the most efficient, effective use of resources to ensure that HIV prevention in San Francisco will always remain a community-driven, community-based response to the local epidemic. To launch the Initiative, the HPPC, in collaboration with the San Francisco Department of Public Health (SFDPH), is beginning a campaign to educate communities and providers about a shift in CDC policy, which will affect how HIV prevention resources are directed in the years to come.

The CDC published a new initiative known as "Advancing HIV Prevention" (AHP), in the April 18, 2003 edition of Morbidity and Mortality Weekly Report (MMWR 2003a), which can be found at *http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5215a1.htm*.

The principles outlined in AHP are likely to guide the national HIV prevention strategy for the foreseeable future. We believe that AHP will be an important part of a broader local strategy that is effective and appropriate for San Francisco. AHP promotes a medical model for HIV prevention, focused on finding HIV-positive people and linking them to care services, and de-emphasizes community-based health promotion and prevention. In San Francisco, we share the commitment to helping people learn their HIV status in a manner appropriate for our community, which goes beyond the medical model. For example, under AHP, providing counseling when giving an HIV test would no longer be required in certain circumstances. However, San Francisco believes counseling should always be available and offered with testing, because research shows that: (1) providing counseling during HIV testing is an effective method for linking both HIV-negative and HIV-positive people to health and social services (Eichler et al 2002, Heumann et al 2001), and (2) behavior change counseling given during the HIV testing process can reduce the high-risk behaviors that lead to HIV transmission (Dilley et al 2002).

With the release of AHP, the CDC has shifted its thinking about the basic tenets of HIV prevention. The CDC offers a set of ABC's that focus on Abstinence, Being faithful, and Condom use. We do not necessarily disagree with those principles, but they are not reflective of the entire range of individuals and communities at risk for HIV infection in San Francisco. Here in San Francisco we have adopted an additional set of ABC's to reflect our local reality and to promote our local vision of health and wellness for communities. Our ABC's focus on:

- **A**dults and youth who are sexually active
- **B**ehavioral interventions based on evaluation of sound programs
- **C**ofactors that affect HIV risk (e.g., substance use, mental health, homelessness, and many others)

These ABC's are reflected throughout this Plan, and particularly in the Community Assessment chapter, which highlights both the behaviors and cofactors that put adults and youth at risk for HIV. With these ABC's in mind, we have begun to think about our local efforts for the years to come. The first step in the San Francisco Leadership Initiative is to plan strategically for the use of resources beginning in 2004. The two main goals are: (1) to maximize the use of CDC funds (both Cooperative Agreement and direct funding[1]) for programs and interventions that are most in line with AHP, and to use other funding sources for programs and interventions that we know to be effective and relevant for San Francisco, and (2) to support and coordinate the application for CDC direct funding for community-based organizations to ensure that the city's overall needs are met. As part of this Initiative, the SFDPH and the HPPC will continue to educate the community about AHP, to help HIV prevention providers in San Francisco as well as other parts of the country understand how AHP will impact them and the people they serve, and how we at the local level can fully implement AHP and enhance those efforts with local activities designed, delivered, and supported within the community. This is an ideal partnership between the federal government and local HIV prevention providers.

The San Francisco Leadership Initiative is one more critical component of a movement to end HIV and AIDS in the San Francisco community. We invite all those who have been infected and affected by HIV and AIDS in this city to join us in our efforts to make sure that our HIV prevention approach remains effective and cutting edge, even when the political climate is unsupportive.

1. Cooperative Agreement funding is the funding that CDC gives to state and local health departments to use for HIV prevention in their jurisdiction. This is the money that is distributed to community-based organizations (CBOs) in San Francisco every few years via a request for proposals (RFP) process. Direct funding is the funding that CDC gives directly to CBOs through a federal RFP process; it is not distributed to CBOs via the health department.

SECTION II

The Local Epidemic and the Local Response

San Francisco's HIV Epidemic

Since the epidemic began in the early 1980s, over 28,624 people have been diagnosed with AIDS in San Francisco, the third largest number after New York City and Los Angeles. Today, approximately 18,000 to 19,000 people are living with HIV or AIDS in this city. New HIV infections peaked around 1982, followed by a period of rapid decline that lasted until about 1994, when the rate of new infections stabilized at approximately 500 per year. In 2000, the infection rates began to rise again (Exhibit 1). Most of this increase is due to new infections among gay men and other men who have sex with men (MSM). As of 2003, it is estimated that there are approximately 1,082 new infections in San Francisco per year.

Throughout the course of San Francisco's epidemic, HIV and AIDS have affected predominantly gay men, as well as other MSM (which is different from the national profile). Eighty-nine percent of people diagnosed with AIDS over the last 20 years have been MSM (including MSM who inject drugs). Currently, 72% of MSM living with AIDS (including injection drug users) are White, 13% are Latino, 10% are African American, 4% are Asian/Pacific Islander, and less than 1% are Native American (AIDS Surveillance Quarterly Report, September 2003). These trends demand an HIV prevention approach that broadly addresses gay men's health issues and takes their life contexts into account.

Gay men are not the only population affected by HIV in San Francisco. A groundbreaking study conducted in 1997 found high prevalence and incidence among male-to-female (MTF) transgendered persons (Clements-Nolle et al 2001). This population has since become a priority for HIV prevention efforts. Infection rates among injection drug users have remained moderately low and stable over the course of the epidemic, largely due to the availability of needle exchange. The exception among injection drug users is MSM who inject drugs. Their infection rates more closely follow the pattern of MSM as opposed to other injection drug using populations. Finally, (1) women of all sexual orientations, and (2) heterosexual men who do not inject drugs have not been substantially impacted by the epidemic, and new infections among these groups remain very low. These trends in HIV infections must be taken into account during service design and delivery, and the HPPC provides guidance for this in two of the chapters in this plan (Chapter 3: Community Assessment and Chapter 4: Priority-Setting).

In addition to these overall trends, it is critical to acknowledge and deal with the racial/ethnic disparities in HIV and AIDS. In San Francisco, the most dramatic disparity is evident in the disproportionate impact among African Americans, including men, women and male-to-female transgendered persons. Fifteen percent of people living with AIDS are African American, even though African Americans represent less than 8% of San Francisco's population. African American men are particularly affected – 77% of African Americans living with AIDS are men, and most of these men (70%) are gay men and other MSM (AIDS Surveillance Quarterly Report, September 2003). This data is critically important, as it demands specific culturally competent and appropriate responses in service design and delivery. The HPPC has addressed this by making African Americans a high-priority population for HIV prevention as outlined in Chapter 3: Community Assessment and Chapter 4: Priority-Setting.

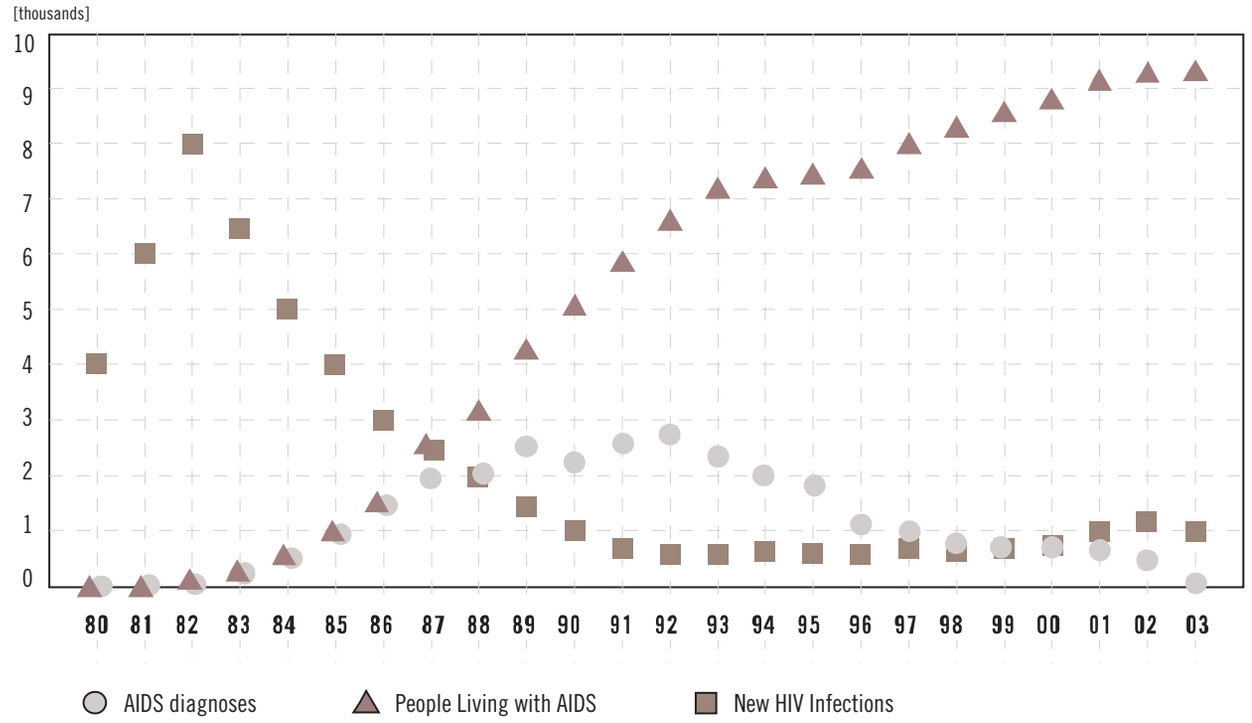
In summary, the state of the epidemic in 2004 can be characterized in the following manner:

- Epidemic levels of HIV among gay men and other MSM and male-to-female transgendered persons (both those who inject drugs and those who do not). (The term *epidemic* means the spread of disease is increasing.) On the eve of the publication of this Plan, there is some new evidence to suggest that high-risk behaviors among gay men may be decreasing and new HIV infections may have reached a plateau. More data is needed, as are continued HIV prevention efforts.
- Endemic levels of infection among heterosexual males who inject drugs and females who inject drugs. (The term *endemic* means a disease persists in a community, without substantially increasing or decreasing over time.)
- No epidemic among non-IDU heterosexuals.
- Racial/ethnic disparities in HIV and AIDS that have resulted in disproportionate effects in the African American community.

The reasons why San Francisco's epidemic is the way it is are complex and multifold. Many milestones have occurred over the last 20 years that help explain the course the epidemic has taken (Exhibit 1). Perhaps the two most significant changes in recent years that have set the stage for the current trends in HIV are: (1) the advent of highly active antiretroviral therapy (HAART) in 1996, and (2) increases in high-risk sexual behaviors among gay men and other MSM, which were first documented around 1998.

EXHIBIT 1

Trends in HIV and AIDS, San Francisco, 1980 – 2003



Source: Adapted from McFarland 2003

HIV Prevention Milestones in San Francisco

1980

First AIDS case diagnosed in San Francisco

1984

HIV identified as the cause of AIDS

1984

Community-based efforts were launched to prevent the spread of HIV among gay men

1985

HIV test becomes available

1987

AZT (the first AIDS treatment) becomes available

1988

Needle exchange becomes available in San Francisco

1994

San Francisco's HIV Prevention Planning Council is formed

1995

Protease inhibitors become available

1996

Highly active antiretroviral therapy (HAART) becomes available

1997

Male-to-female transgendered persons identified as a high-risk population

1998

Increases in high-risk behavior among MSM in San Francisco first documented

2000

Increases in new HIV infections among MSM seen

The availability of HAART has allowed many people with HIV to live longer, healthier lives, and as a result they are able to be more sexually active. The fact that more people are living with HIV now than ever before, due to treatment advances, means that the pool of infection is larger, which may in part explain the increases in new infections. In addition, this new medical advance contributed to a perception, particularly in the gay community, that HIV is a manageable illness as opposed to a fatal disease. This perception may be linked to decreases in condom use.

Not everyone has experienced the same benefits from HAART, however, which partly explains local racial/ethnic disparities in HIV and AIDS. The life expectancy for people living with AIDS is directly impacted by their access to and compliance with HAART. Recent data shows that African Americans living with AIDS have a significantly higher death rate compared with white people living with AIDS. This statistic is directly tied to lower HAART usage among African Americans, which is related to the bigger issue of poorer access to high-quality health care and health promotion services. The importance of HAART is clear, and increasing access to primary medical care, HAART, and related HIV prevention services for HIV-positive people is critical.

The advent of the HAART era is only one of many influences on the sexual behaviors of gay men and other MSM. Drug use (non-injection), mental health issues, a perception that the acceptability of unsafe sex is growing, and the easy access to sexual partners via the Internet are some of the recent trends that may be contributing to increases in high-risk behaviors and the resulting rise in HIV infection rates. In addition, social issues such as racism, discrimination, homophobia, homelessness, and poverty persist, all of which affect how people make decisions about safer sex.

San Francisco's Approach to HIV Prevention

This rapidly changing epidemic calls for a renewed commitment to HIV prevention and a shift in focus. San Francisco has shown extraordinary leadership over the last 20 years. We have created a cutting edge, creative, community-based model for HIV prevention that has been replicated all over the world. We have consistently supported needle exchange, both philosophically and with dollars, because it is an effective prevention strategy. We have prevented the spread of the epidemic among heterosexual men, women, and newborns. And we have a new strategy to confront the challenges we face today.

To fulfill our vision of creating healthier communities, our approach for 2004 and beyond is based on the following principles:

- **Health and wellness.** Health is about what is going on in people's lives and how it affects them. The term health includes mental, emotional, and spiritual health as well as physical health. Individual health is influenced by an infinite number of factors – psychological, social, structural, and political. HIV prevention needs to become part of this larger health and wellness movement in order to have any lasting effect on individuals and communities.

- **Linkages and coordination.** Health and wellness is the goal; linkages are the building blocks to reach the goal. HIV does not exist in a vacuum. People affected by HIV need to be supported in getting the services they need to help them stay healthy. This means that HIV prevention programs need close linkages with other services, including services for people living with HIV, primary care, sexually transmitted disease detection and treatment, mental health services, substance use prevention and treatment, housing, financial assistance, social support services, and many others. Handing out a card with another agency's phone number is not enough. Linkages within and between agencies need to be coordinated, and referrals need to be followed up.
- **Prevention with positives and negatives.** HIV prevention should reach all those affected by HIV – people at risk for HIV, as well as people who are already living with HIV. We need messages for HIV-positive people. We need messages for high-risk HIV-negative people. And we need messages that speak to both, because all affected individuals exist together as part of a larger community.
- **One step ahead.** HIV prevention efforts should focus not only on people who we know to be at high risk today, but should also identify and reach those who might be at high risk tomorrow. This means we are committed to a strong focus on research and evaluation, which help us understand where the epidemic is and where it is going. This also means that this research does not exist in an ivory tower; it is done with the community, findings are given back to the community, and action is taken based on the results of the research.
- **Science + community values = success.** The best HIV prevention happens when scientific research and community values come together to create a picture of what is going on and what needs to be done. The community planning process is one place where this happens. The HPPC, the local community planning group, is committed to providing leadership to make sure that San Francisco always takes both science and community values into account.

With this approach, San Francisco aims to reduce the number of new HIV infections. We have set the following specific objectives for ourselves:

- **Objective 1:** Reduce new HIV infections among gay men and other MSM and male-to-female transgendered persons by 50% by 2008.
- **Objective 2:** Reduce new HIV infections among injection drug users by 50% by 2008.
- **Objective 3:** Eliminate new infections among (1) women, and (2) men who have sex exclusively with women by 2008.
- **Objective 4:** Eliminate perinatal infections by 2008.

This HIV Prevention Plan presents the information needed to implement this approach. It represents the work of the 2003 HPPC, who approved the Plan in the final three months of 2003.

The Epidemiologic Profile tells the detailed story of where the local epidemic is and where it is headed using HIV, AIDS, and other data. The Community Assessment and Priority-Setting chapters follow, and together they lay out the priorities for where and how HIV prevention should be focused. The Strategies and Interventions chapter is the toolbox for designing programs. Finally, the Evaluation chapter provides a roadmap for staying one step ahead of the epidemic.

The HPPC offers this Plan to the larger San Francisco community in the spirit of collaboration. It is our contribution to ending the HIV and AIDS epidemic. Read this 2004 San Francisco HIV Prevention Plan carefully and with a great deal of hope. We believe it contains the tools to stop this epidemic and we want to provide the leadership and effort to make it happen. Please join us.