# *Assessing Washington's HIV/AIDS Policy for the New Millennium*

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Twenty years ago, the first AIDS case was diagnosed in Washington State. At that time, the cause of the disease was unknown, treatment was not available, and death was certain. Much has been learned in the past twenty years, but the challenges associated with HIV/AIDS continue to be great. Today the cause of the disease is known, but a cure still does not exist. Treatments are available, but they are toxic and expensive. Death is delayed, but not prevented. In February 2002, after twenty years of research and prevention work, the 10,000th case of AIDS was diagnosed in Washington. Surveillance data show that more than 7,500 individuals in Washington are living with HIV/AIDS (an underestimate, since one-quarter to one-third of individuals who are HIV-infected do not know their status).

Recently Washington reviewed its approach to describing and meeting the challenges of preventing HIV infection and, in particular, the challenge of addressing the stigma and discrimination associated with HIV and AIDS. Effective policy review can reveal where the policy works as well as where it needs to be updated. Even more importantly, an effective review process can uncover issues that remain untouched by the policies under review.

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## *The policy review process*

The HIV/AIDS review was sparked by Senate Bill 5679, introduced during Washington's 2002 legislative session. This brief, and ultimately unsuccessful, bill required a review of current HIV prevention approaches and the prevention system created by the state's original, comprehensive 1988 AIDS Omnibus Act. When SB 5679 did not make it out of committee, Secretary of Health Mary Selecky took the primary elements of the suggested review and appointed a committee to provide her with an overview of the current HIV prevention system. She charged the committee, composed of 13 members from around the state and chaired by the state Health Officer Dr. Maxine Hayes, to review the goals of prevention strategies under the AIDS Omnibus Act in relation to trends in the current epidemic; to analyze funding streams and levels for the AIDS Omnibus Act and other HIV/AIDS prevention funding; and to review the interaction and coordination of HIV/AIDS prevention programs with care services.

The committee began work in August 2001. It met numerous times and held meetings with each of six regional AIDS networks across the state, hearing input from public health, community organizations, and private individuals in both Eastern and Western Washington. The committee presented its final report (prepared by the UW Health Policy and Analysis Program and available at www.hpap.washington.edu) to the Secretary in March 2002.

The report presented a set of 17 recommendations in five categories: 1. the current structure of the AIDSNets (created by the original Omnibus Act); 2. funding and accountability; 3. education activities; 4. coordination of care, prevention, and other related services; and 5. AIDS Omnibus Act policy support and changes.

## *Stigma remains untouched by policies*

Some of the report's recommendations required only minor changes in the original approach to HIV prevention in Washington, as outlined in the 1988 Omnibus Act. These changes included increasing the collaboration between prevention and care programs and revising the current six regional program boundaries. But some issues cannot be so easily rectified. One of the issues the committee found to be most troubling was the continued stigma associated with HIV, a stigma that impedes successful prevention and treatment of the disease. Despite all of the advances that have been made in understanding HIV and its prevention and treatment, the possibility of discrimination is as real for the 10,000th person diagnosed with AIDS as it was for the first.

The committee is not alone in recognizing that the stigma attached to HIV/AIDS is an ongoing barrier to an effective response to the epidemic. In an article in the March 2002 issue of *American Journal of Public Health* (AJPH) the authors found that although stigma surrounding HIV and AIDS decreased during the 1990s, a significant amount of stigma and discrimination continues to be associated with the disease. The authors concluded that the fears associated with having HIV will affect persons living with HIV and persons at risk for becoming infected, and that these fears will affect the success of programs and policies intended to prevent HIV transmission.

An editorial in the same issue of the AJPH, by Ron Valdiserri, deputy director of the Center for HIV, STD, and TB Prevention for the Centers for Disease Control and Prevention, recognized the many impediments to HIV prevention. He concluded, "As public health practitioners, it is our responsibility to work toward minimizing the negative health consequences of HIV/AIDS stigma."

The topic of discrimination also came up at the International AIDS Conference in July 2002 in Barcelona, Spain. People from countries all over the world recognized that the reduction of stigma, discrimination, and human rights violations plays a crucial role in support of HIV prevention and care programs. The lack of leadership, worldwide, on the issue of stigma, coupled with inadequate protection of the rights of populations most at risk for disease, such as gay men, women, prisoners, and injection drug users, creates an environment that makes those at highest risk even more vulnerable to the disease.

## *Implications for public health*

Despite the fact that the AIDS Omnibus Act contained strong privacy and confidentiality mandates, the review committee heard that the effect of stigma in Washington, as elsewhere, interferes with prevention efforts conducted through the Act directives and funding. Stigma creates barriers to identifying people at risk for HIV and, thus, to providing them prevention information and counseling. It is also a barrier to at-risk people seeking testing. It may be that stigma will remain stubbornly persistent, and perhaps even resistant to policy efforts to overcome it.

Recommendation 14 from the HIV/AIDS review report advised that the Secretary "strongly support the privacy and confidentiality elements of the AIDS Omnibus Act, and should sponsor and support efforts to reduce stigma."

Too often, in the public health arena, opportunities are missed to challenge the misconceptions and biases that arise from misunderstandings about the disease or its mode of transmission. Kates et al. recognize this as a current and future challenge in their article "Critical Policy Challenges in the Third Decade of the HIV/AIDS Epidemic" in which they conclude that although numerous challenges face the control and prevention of HIV, two keys elements will continue to be required: resources and leadership.

Despite the Washington State committee's recommendation, it is clear that the Secretary of Health *alone* cannot address the root causes of the stigma associated with HIV and AIDS. Although the Act reveals foresight in its policies, public health leaders need to recognize the multiple causes of stigma and use their powers to address those causes and champion efforts to address the ongoing problem of stigma and discrimination effectively. These efforts could include diversifying the health care workforce so the care system feels more welcoming to all HIV-infected people; addressing stigma at the community level to make communities aware of their risk for HIV; and working with communities to support HIV-infected persons in practicing behaviors that reduce transmission of disease. Additionally, public health should promote the conditions that lead to healthy relationships and healthy living conditions, such as legally-recognized same sex relationships; work to prevent domestic violence of all types; and show leadership in fighting racial health disparities in HIV.

Twenty years is a long time, and the sense of urgency around HIV/AIDS has faded for many in the general public as well as the public health community and even for some in the communities at risk for HIV infection. Resources, public and private, are dwindling; behavior change is a difficult and ongoing effort; and new threats to the public's health, such as bioterrorism, loom large these days.

Washington State undertook an effective review process to keep its HIV/AIDS prevention efforts responsive to the current epidemic. This process revealed areas where the policies continue to work well and areas they haven't been able to touch. What can public health leaders do to affect such crucial issues as stigma and discrimination? What new role can policy play in addressing entrenched attitudes? How can collaboration between policy makers and affected communities be used effectively? Now that the process of review is over, the time for next steps has come. We must move to action and outcome.

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