

Indian health disservice

By E.J. Levy

IT'S NO SECRET THAT AIDS IS AN UNCOMFORTABLE subject within the Indian Health Service (IHS)—the public health agency responsible for Native American health.

Off the record, sources in and close to the agency confirm that people within the IHS haven't even learned to say the "A-word." Misconceptions that AIDS is "a white man's disease" and that few Indians are gay or intravenous drug users and therefore at risk have compounded people's reticence to confront the issue head-on.

With only 194 AIDS cases among Indians recorded by the Centers for Disease Control (CDC) as of June 1990, many believe AIDS is simply not a problem for Indians. However, with the incidence of sexually-transmitted disease among Indians running two to four times higher than that of the general population, Native Americans are, in fact, at great risk for rapid transmission of HIV and—considering their generally depressed health—potentially for an AIDS epidemic.

"Given the low socio-economic and health status of Native Americans and the high incidence of substance abuse, it's safe to assume that we already have a population with compromised immune systems," says Ron Rowell, executive director of the National Native American AIDS Prevention Center (NNAAPC) in Oakland, Calif.

While documentation of intravenous drug use among Native Americans is scarce, a preliminary study conducted in one rural Indian community found that as much as 14 percent

of the community's 2,500 people were reportedly regular IV users—an "alarmingly" high incidence, concludes the study, which signals the "potential for rapid HIV transmission." A sample survey of Indians in alcohol treatment programs in Seattle taken early last year found 25 percent reported chronic or occasional IV drug use.

Unwritten truths: Similarly, there has been no comprehensive study done of sexual behavior among Indian peoples, although regular lesbian Sun Dances in the Southwest and the "Basket and Bow" gatherings of lesbian and gay Indians in the Midwest during the last several years attest to the existence of a vital Native gay and lesbian community.

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At present, the majority of Native AIDS cases are thought to occur among urban Indians—those who have left their reservations for cities like Los Angeles, San Francisco, Minneapolis, Gallup and Tucson. As a result, health workers contend that AIDS does not pose a threat to Indians living in isolated rural communities like the pueblos of New Mexico.

In fact, there is no way of knowing which Indian communities are most affected by AIDS, since epidemiological reports specify only the state in which each case occurs in order to protect the privacy of Indians who, given the small number of AIDS cases, might otherwise be identified.

Available evidence indicates, however, that rural Indians are not isolated from risk. Sexual interaction is common at the annual Pow Wow and on the rodeo circuits—two cornerstones of Indian social life. In addition, a recent article by Rowell in *Drugs and Society* cites two studies that document a high level of interaction between urban and the so-called "isolated" rural Indians. Conducted in Minnesota and three Northwestern states, the studies reveal that as many as 51 percent of Indians on the reservation have had sexual contact with people off the reservation.

More recently, a 1990 CDC/IHS study of HIV seroprevalence among Alaskan Native and American Indian prenatal patients found .15 percent, or 1.5 in every 1,000 patients in their third trimester, to be HIV positive—a rate similar to that of the overall U.S.

A 1988 CDC study revealed Indians to have rates of HIV infection greater than or equal

to other racial groups in a variety of test settings. Indians had higher rates of infection than either blacks (by 11 percent) or whites (by 43 percent), according to data gathered from California statewide anonymous testing sites. Preliminary data taken from a survey of non-AIDS patients in a portion of the CDC's Sentinel Hospital System indicated that Indians were three times as likely to be HIV seropositive as others.

Erroneous zones: The discrepancy between high levels of HIV infection and low numbers of reported AIDS cases suggests to researchers that the AIDS count among Indians may be erroneous. George Conway, a CDC medical epidemiologist who designed seroprevalence surveys, speculates that the undercount may be partially due to the misregistration of Native Americans as Hispanics by hospital and clinic personnel. In some cases, however, Indians may be reluctant to describe themselves as Native American for fear of being referred back to a reservation for health care.

Whatever the source of the error, it is likely that the actual AIDS count is significantly higher than currently recognized. Many estimate that at least six new cases of AIDS occur among Indians each month—and the NNAAPC's Rowell cites a figure twice that high. "No matter what we do," adds E.Y. Hooper, AIDS coordinator for the IHS, "we know there's a harvest out there that's going to accrue to us. The numbers are only going to increase with time."

Despite the potential for an epidemic, until recently the IHS had neither a policy nor funding for AIDS prevention. While IHS Director Everett Rhoades announced a seven-point AIDS agenda following the 1987 Minority AIDS Conference in Atlanta, the IHS did not require its health facilities to have trained counselors available for HIV testing and counseling until 1988. And it wasn't until fiscal 1989 that the IHS appropriated \$258,000—about 25 cents per person—for AIDS education and prevention.

Hooper contends that limited financial and human resources are responsible for his agency's "belated" response. "There is so much that is affecting the morbidity and mortality of Indians that it's hard to get resources together to combat AIDS," he says. "In certain parts of the country, they don't have the resources to do adequate prenatal care for women or to treat acute types of illnesses. Doctors there are saying, 'We acknowledge the risk of AIDS, but we don't have time to deal with [it].'"

In order to provide funding for AIDS-related programs, the IHS must divert human and financial resources intended for other purposes, adds Hooper. Lacking monies to hire additional full-time employees, developing the programs falls to already overtaxed health providers. Hooper, for example, maintains his position as director of continuing education while acting as AIDS coordinator. When the IHS received a special \$350,000 grant from the CDC to train health workers in HIV testing and counseling in 1988, the agency had to "rob \$3 million to \$4 million from other services" to implement the program, says Hooper.

But limited resources only partially explain the IHS' reluctance to tackle AIDS. Not until fiscal year 1990—three years after Rhoades announced his agenda and nearly a decade into the epidemic—did the agency request AIDS funding, a delay attributed in part to ignorance. Rhoades told a congressional subcommittee in 1988 that until an

effective vaccine or therapy was developed. "throwing money at AIDS ... is not going to do anything about the incidence of AIDS."

"It's not that we're not concerned about prevention," responds Patricia DeAsis, director of communications for the IHS. "But when we start talking about an extremely limited number of people who have AIDS—when people are dying from diseases that are preventable—it doesn't make sense to focus on AIDS." In short, not enough Indians have died yet.

Cool miscalculations: It was this sort of cool miscalculation on the part of the IHS that spurred a group of concerned health workers, including Ron Rowell, to investigate Indian AIDS prevention in 1987. "There was no official response anywhere," says Rowell of that time. "IHS representatives were actually going around the country saying, 'AIDS isn't a problem for Indians.'"

Rowell attributes the lack of IHS response to the current administration's conservative ideology. Pointing out that Rhoades is a Reagan appointee, Rowell asserts that the IHS is staffed largely by "missionaries for whom sex is a very nasty subject. Instead of advocating for Indian health," he adds, "they are fighting this every step of the way."

While the IHS was unable to fund Rowell's proposal for a national Native American AIDS Prevention Center in 1987, the CDC provided monies the following year, enabling NNAAPC to begin distributing information and coordinating AIDS studies among Indians. And in 1989, the center opened a hotline staffed by Native Americans to provide AIDS information, counseling and referrals specific to Indian communities.

Since January 1989, NNAAPC staff members have conducted three-day training sessions that bring together tribal health workers, urban Indian health agency directors, activists and others to learn, network and strategize about ways to prevent the spread of HIV in their communities. The training sessions remind participants that they themselves—not doctors or administrators—are the experts, and, according to Rowell, only this kind of self-determination will improve Indian health care in the long run.

Although critical IHS support in the fight against AIDS is still largely absent, there are signs the agency is coming around. In September, the IHS in Albuquerque conducted a workshop on safe sex practices at the Southwestern Indian Polytechnic Institute, and the Public Health Service has released funding for AIDS education among individual tribes. For the first time, the IHS has appointed an AIDS coordinator with a relevant background.

Most importantly, the IHS, in coordination with the CDC, is continuing to pursue seroprevalence surveys that should in time provide sufficient documentation of HIV infection among Indians to convince the IHS to increase funding. But the studies will take time, and the infection continues to spread.

Even an accurate count of Indian AIDS cases could not gauge the threat the virus poses to these vulnerable communities, a threat best expressed by Terry Tafoya, a therapist originally from Taos Pueblo in New Mexico: "We don't think in terms of five- or 10-year plans," says Tafoya. "We think of the impact to the seventh generation. If we don't get word out to the Native American community about AIDS, there won't be a seventh generation." □

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Squeezing the government for an ounce of prevention

One bit of good news about AIDS: it now costs much less to treat people who have the HIV virus than it does to treat people who have contracted the full-blown disease.

Such early treatment could delay—and maybe even prevent—the onset of AIDS. Once someone develops AIDS, medical treatment climbs to between \$20,000 and \$60,000 a year, depending on the availability of outpatient services. In contrast, pre-AIDS treatment now runs about \$5,500 a year, down from \$9,600 last September.

Not surprisingly, half of the people who need pre-AIDS treatment can't afford it. That means the federal government has a clear economic choice: step in now or risk letting those with the virus contract the disease.

Pre-AIDS treatment consists of counseling, general monitoring and, for people whose CD4 white blood cell count falls below 500 (per cubic millimeter of blood), administering the drug zidovudine, also called AZT.

While AZT drug therapy is the most expensive facet of pre-AIDS care, the recommended dosage has been cut from 1,200 to 500 milligrams a day, and the manufacturer, Burroughs-Wellcome, has dropped the price by 20 percent, largely due to political pressure. An annual dose of the drug now costs about \$2,750.

The price of another important pre-AIDS drug—trimethoprim-sulfamethoxazole—also has decreased. Those with the HIV virus whose CD4 count drops below 200 require medication to prevent *Pneumocystis carinii* pneumonia, the most common and serious opportunistic disease associated with AIDS. Doctors prescribe either a

fancy new drug—aerosolized pentamidine—for \$2,500 a year, or the old-fashioned trimethoprim-sulfamethoxazole (one brand name is Septra) for \$250. Because new evidence has shown that the older drug is more effective, many doctors are switching back to it. Unfortunately, about 20 percent of patients who receive the drug are allergic to it, and so must stick with aerosolized pentamidine, which must be administered via a costly machine called a nebulizer.

While pre-AIDS treatment is now considered standard practice, getting it isn't. Henry Greeley, an associate professor at Stanford Law School, estimates that roughly 50 percent of HIV-infected people have private, employment-related health insurance that should cover 80 percent of their costs. The patients absorb the remaining costs, most of which consist of prescription drug co-payments.

The remaining 250,000 to 550,000 HIV-infected people are left standing in the cold. Medicare, available only to the elderly and the long-term disabled, will not cover them. And Medicaid—available to recipients of Aid to Families with Dependent Children (AFDC), the elderly and the seriously disabled—covers only AIDS patients not on AFDC because they are considered presumptively disabled. In addition, they are eligible for Medicaid only after they "spend down" their resources.

Peter Arno, an economist who studies the impact of AIDS on the health care system at the Montefiore Medical Center in the Bronx, sees a pattern in who receives preventative treatment and who does not.

"It's like the rest of our health care system," says Arno. "There is differential access based on social class: middle-class

gay white men on the coasts are getting care ... poor, black and Hispanic people and intravenous drug users are not getting care."

If federal and state governments don't pay for pre-AIDS treatment now, they will surely pay for it later, when those infected come to public hospitals seeking help for serious opportunistic infections. Treatment costs may fall, but so may the costs of prevention. For example, new prophylactic drugs like dideoxyinosine (ddi) and inosine pranobex may prove safe and effective. And Burroughs-Wellcome may be forced to again lower the cost of zidovudine. The American Civil Liberties Union (ACLU) is considering a lawsuit challenging Wellcome's 17-year use patent, as many believe U.S. government scientists at the National Cancer Institute and Duke University—not Wellcome employees—discovered the compound's HIV-fighting properties.

On September 12, a Senate appropriations subcommittee authorized just \$110 million for HIV-positive health care, gutting the \$875 million authorization bill approved by negotiators from both houses of Congress on August 3. Spread thin over the next two years, the money has yet to be allocated.

Getting preventive care to the 50 percent of HIV-infected people who can't afford it would cost \$500 million a year—well below 1 percent of what the federal government spends on health care annually. AIDS has taught us a cruel lesson: an ounce of prevention is worth 10 pounds of cure. We either spend this money now, or regret it later.

—Rhona Mahoney