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SURVEILLANCE SYSTEMS MONITORING HIV/AIDS AND HIV RISK BEHAVIORS AMONG AMERICAN INDIANS AND ALASKA NATIVES

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Few published reports describe patterns of occurrence of HIV/AIDS among American Indian/Alaska Native (AI/AN) people nationally. Data from national surveillance systems were examined to describe the spread of HIV/AIDS and the prevalence of HIV-related risk behaviors among AI/AN people. These data indicate that HIV/AIDS is a growing problem among AI/AN people and that AI/AN youth and women are particularly vulnerable to the continued spread of HIV infection.

Public health surveillance systems exist to assess public health status, define the need for public health action, evaluate disease control and prevention programs, and stimulate research (Teutsch & Churchill, 1994). For HIV/AIDS, as for other health conditions, public health surveillance provides a foundation for public health action. A variety of surveillance methods are used to characterize the epidemic of HIV infection and AIDS. These include monitoring diagnosed HIV infections, end-stage HIV disease (AIDS), and HIV/AIDS-related deaths, and assessing the prevalence of sexual and drug use behaviors that increase the risk of HIV infection.

The purpose of this article is to describe information from surveillance systems maintained by the Centers for Disease Control and Prevention (CDC), the profile these systems provide about HIV and AIDS among American Indian/Alaska Native (AI/AN) people, and the strengths and limitations of the data.

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DESCRIPTION OF DATA SOURCES AND FINDINGS

THE NATIONAL HIV/AIDS SURVEILLANCE SYSTEM

Data on HIV infections and AIDS among AI/AN people enter the national HIV/AIDS surveillance system from the various health care providers serving AI/AN people. Such providers may include the Indian Health Service (IHS), tribally operated health care facilities, public (state, federal, and local) health care facilities, and private health care providers. These providers, and reference laboratories where diagnostic testing is performed, send reports of cases to the relevant state or local health departments, who in turn send the data, stripped of identifiers, on a monthly basis to the CDC. After it reaches CDC, the data from the states are combined so national trends can be tracked (CDC, 1998c).

AIDS surveillance began in 1981 with the first reports of opportunistic illnesses caused by an unknown agent. Currently all 50 states and the U.S. territories report AIDS cases. The AIDS surveillance system is population based; that is, all AIDS cases are reportable to public health authorities (CDC, 1999; Fleming, Wortley, Karon, DeCock, & Janssen, 2000). Before the widespread use of antiretroviral therapy for HIV infection, AIDS surveillance data reliably reflected changing patterns of HIV infection and related illnesses in specific populations (CDC, 2002a). Because of these attributes, AIDS surveillance data have been used as a basis for allocating federal resources for HIV treatment and care services and as the epidemiological basis for planning state and local HIV prevention services.

In contrast to AIDS surveillance, HIV case surveillance provides data to characterize populations in which HIV infection has been newly diagnosed, including persons recently infected with HIV, such as adolescents and young adults 13-24 years old. As of December 2001, 36 states and four territories conduct confidential name-based HIV case surveillance (CDC, 2002b).[1]

Summary of HIV/AIDS Surveillance Data

Number of Reported HIV/AIDS Cases. According to data from the National HIV/AIDS Surveillance System (CDC, 2002b) through December 2001, a cumulative total of 3,499 HIV/AIDS cases among AI/AN have been reported to the CDC. Of these, 2,537 persons had been diagnosed with AIDS (81% male and 19% female). A total of 962 HIV cases (73% male and 27% female) have been reported among AI/AN from the areas with confidential name-based HIV reporting. Of the cumulative number of AI/AN persons reported with HIV/AIDS, 21% are female compared with 10% among Whites, 29% among Blacks, 20% among Hispanics, and 15% among persons whose race/ethnicity is Asian/Pacific Islander (A/PI). Since 1981, when the syndrome later found to be caused by HIV was first described in the United States, 31 of the 2,357 AI/AN persons reported with AIDS and 13 of the 962 AI/AN persons reported with HIV were children less than 13 years old. Of the cumulative number of AI/AN persons reported with HIV/AIDS, 1.3% are younger than 13 years of age compared with 0.5% of White, 1.9% of Black, 1.7% of Hispanic, and 1.1% of A/PI persons reported with HIV/AIDS.

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1. The following areas have confidential name-based HIV reporting: Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Florida, Idaho, Indiana, Iowa, Kansas, Louisiana, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin, Wyoming, Guam, American Samoa, Northern Mariana Islands, and the U.S. Virgin Islands.

From 1981 through December 2001, 1,286 deaths have been reported among AI/AN persons with AIDS included in the surveillance system. The estimated number of AI/AN persons living with AIDS in 2001 was 1,304 (CDC, 2002b). The number of AI/AN people living with AIDS has been increasing, as it has for all other racial/ethnic groups. The increase in the number of persons living with AIDS is due to a combination of factors. Although drugs that prolong the time from HIV infection to AIDS are available, persons with HIV are still progressing to AIDS. Antiretroviral drugs greatly lengthen the lives of many with AIDS, resulting in increased numbers of persons living with AIDS.

AI/AN people represent a small proportion of the total HIV/AIDS cases reported to the National HIV/AIDS Surveillance System. Through December 2001, AI/AN represented 0.3% of reported AIDS cases and 0.6% of reported HIV cases and, according to the 2000 U.S. Census, make up 0.7% of the U.S. population (or 1.5% when both persons who claim AI/AN race alone and in combination with other races are counted), (CDC, 2002b; U.S. Census Bureau, 2002b) . The cumulative total of 3,455 adult/ adolescent AI/AN persons reported with HIV/AIDS is less than 1% of the total number of adolescents/adults with HIV/AIDS among Whites and Blacks but must be considered in the context of a much smaller AI/AN total population size, and with the understanding that more than 557 ethnically distinct groups make up the AI/AN population, some with a total of less than 1,000 persons (U.S. Bureau of Indian Affairs, 1998).

AIDS Rates. AIDS case rates, unlike the case counts presented above, take relative population size into account. Figure 1 shows estimated AIDS incidence rates from 1995 through 2001 for AI/AN compared with other racial/ethnic groups (CDC, 2002b). Since 1995, the rate of AIDS among AI/AN has been higher than that for Whites. The AIDS rate among AI/AN in 2001 was 11.7 per 100,000 persons, which was lower than the AIDS rate among Blacks, 76.3 per 100,000, and among Hispanics, 28 per 100,000, and higher than the rates among Whites and A/PI, 7.9 and 4.8 per 100,000, respectively.

HIV Diagnosis Rates. Using data from the national HIV reporting system, we calculated rates of HIV diagnosis for the 25 states with confidential name-based HIV reporting since 1994.[2] These data show that the rate of diagnosed HIV infection reported among AI/AN living in these states has averaged 16.4 per 100,000 persons from 1996-2000, more than 1.5 times the average rate for Whites (10.0 per 100,000) and nearly 2.5 times the average rate for A/PI (6.6 per 100,00) for the same 5 years. The rate of diagnosed HIV infection among AI/AN was approximately one fifth the average rate for Blacks (88.3 per 100,000) and less than one half the average rate for Hispanics (39.3 per 100,000) for this period. In 2001, 172 AI/AN persons with HIV were reported from 32 states;[3] 21% of reported HIV cases among AI/AN were female. In comparison, the percentage of females among non-AI/AN persons with HIV reported from these 25 states ranged from17% among Whites to 38% among Blacks, with Hispanics and A/PI having a female percentage similar to AI/AN (21% and 22%, respectively).

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2. Alabama, Arkansas, Arizona, Colorado, Idaho, Indiana, Louisiana, Michigan, Minnesota, Missouri, Mississippi, North Carolina, North Dakota, New Jersey, Nevada, Ohio, Oklahoma, South Carolina, South Dakota, Tennessee, Utah, Virginia, Wisconsin, West Virginia, and Wyoming.

3. The 32 states include the 25 listed above plus Alaska, Nebraska, Florida, New Mexico, Iowa, Texas, and Kansas.

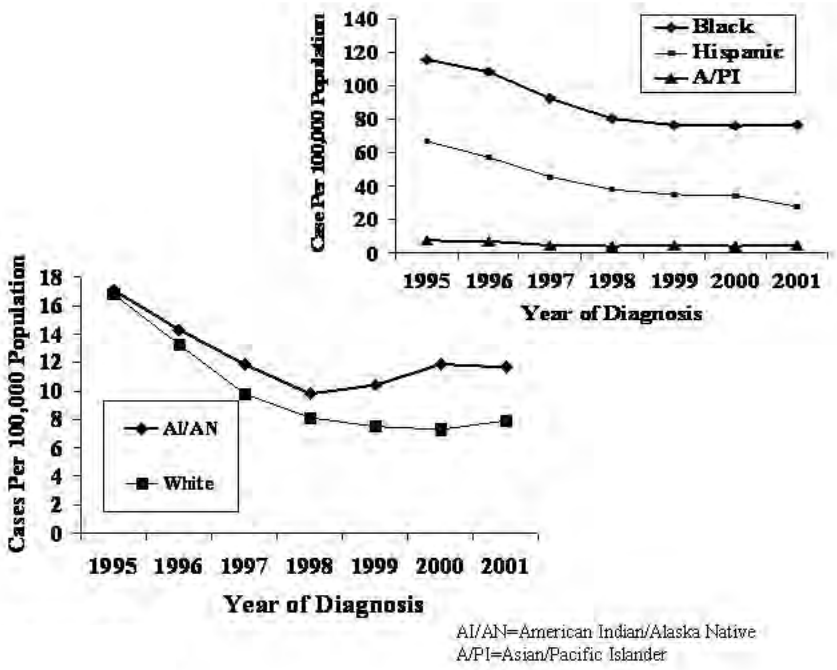

FIGURE 1. Estimated AIDS incidence rates by year of diagnosis and race/ethnicity, 1995-2001 (adjusted for reporting delay).

Late Diagnosis of HIV Infection. The proportion of cases that initially come to the attention of the HIV/AIDS surveillance system because of a diagnosis of AIDS gives an indication of patterns of late HIV testing (percentage of persons not tested/diagnosed with HIV until they seek care for advanced disease). We calculated the proportion of persons with late HIV diagnosis from the 25 states with confidential name-based HIV reporting since 1994. From 1998 to 2000, the percentage of cases that were reported as having an HIV diagnosis in the same month as an AIDS diagnosis was 21% for AI/AN compared with 22% among Blacks, 28% among Whites, 29% among Hispanics, and 33% among A/PI.

Characteristics of AI/AN Persons Reported With AIDS. AI/AN persons with AIDS are likely to be younger than non-AI/AN persons with AIDS; 17% of AI/AN with AIDS reported through December 2001 were between 25 and 29 years of age, compared with 13% of White, 12% of Black, 14% of Hispanic, and 13% of A/PI persons with AIDS (CDC, 2002b). In the absence of antiretroviral therapy, progression from HIV infection to AIDS takes an average of 10 years (Kaplan, Spira, Fishbein, & Lynn, 1992), so many of these young people were likely infected as teenagers. An analysis of cases reported through December 1997 showed that although 68% of AI/AN persons with AIDS lived in metropolitan areas of more than 500,000 population at the time of diagnosis, AI/AN with AIDS were more likely to be residents of rural areas than non-AI/AN persons with AIDS (CDC, 1998a). These data suggest that HIV/AIDS is both an urban and a rural (reservation) problem.

Modes of Exposure to HIV Among AI/AN Persons Reported With AIDS. Figure 2 shows that although male-to-male sexual contact and injection drug use were the most common ways AI/AN persons with AIDS had been exposed to HIV, the percentage of AI/AN persons with AIDS whose mode of exposure was through heterosexual contact has steadily increased from 1998 to 2001 (CDC, 2002b). In 2001 the percentage exposed to HIV through heterosexual contact was equal to the percentage exposed to HIV through injection drug use. The increasing percentage of cases associated with heterosexual contact is in part related to an increasing percentage of AI/AN persons with AIDS who are female (16% in 1995 compared with 22% in 2001), the higher frequency of heterosexual behavior as a reported mode of exposure among females, and the increasing frequency of heterosexual contact as a mode of exposure among AI/AN males with AIDS (1% in 1995 vs. 6% in 2001), (CDC, 2002b).

Male-to-male sexual contact was the mode of exposure for 55% of the cumulative total of male AI/AN with AIDS (72% if those who are exposed through a combination of male-to-male sex and injection drug use are included). For comparison, the percentages of the cumulative totals of non-AI/AN males with AIDS were 55% (for male-to-male sex) and 63% (for male-to-male sex combined with injection drug use). The second most common way male AI/AN AIDS patients were exposed to HIV was through injection drug use (16% of the total number of cases reported, compared with 22% for non-AI/AN). AI/AN males exposed to HIV through heterosexual contact and AI/AN males exposed through receipt of blood products represent 3% and 2%, respectively, of male AI/AN AIDS patients, compared with 5% and 2% of male non-AI/AN AIDS patients, respectively (CDC, 2002b). (Note: Because of implementation of routine screening of blood in the United States, HIV exposure through contaminated blood products has been virtually eliminated.)

In contrast, nearly half (44%) of AI/AN females with AIDS were exposed to HIV through injection drug use, and 37% were exposed through heterosexual contact compared with 39% and 41% of non-AI/AN females with AIDS, respectively. Receipt of HIV-contaminated blood products was the mode of exposure for 3% of AI/AN females with AIDS and 3% of non-AI/AN females with AIDS (CDC, 2002b).

Geographic Distribution of Reported AIDS Cases Among AI/AN Persons. As with the AI/AN population overall, AIDS among AI/AN persons is unevenly distributed geographically. The top five states according to numbers of reported AIDS cases are California, Oklahoma, Arizona, Washington, and Alaska. These five states account for more than half (53%) of AI/AN AIDS cases (McNaghten, Neal, Li, & Fleming, 2001) and correspondingly account for 46% of the AI/AN population (U.S. Census Bureau, 2002a).

Strengths and Limitations of HIV/AIDS Surveillance Data

AIDS case reporting provides the only geographically comprehensive information to monitor any aspect of the HIV epidemic, including the epidemic among AI/AN persons. The major strength of AIDS case reporting, and its major weakness, result from its focus on end-stage HIV disease (Klevens et al., 2001). AIDS patients have serious illness and are likely to come to the attention of health care providers, increasing the likelihood of reporting, particularly for hospitalized patients. But the focus on end-stage HIV disease is also a major limitation because persons progress to AIDS an average of 10 years after HIV infection takes place in the absence of treatment (Kaplan, Spira, Fishbein, & Lynn, 1992), and the time from HIV infection to AIDS diagnosis is even longer among patients treated with antiretroviral medications (Karon,

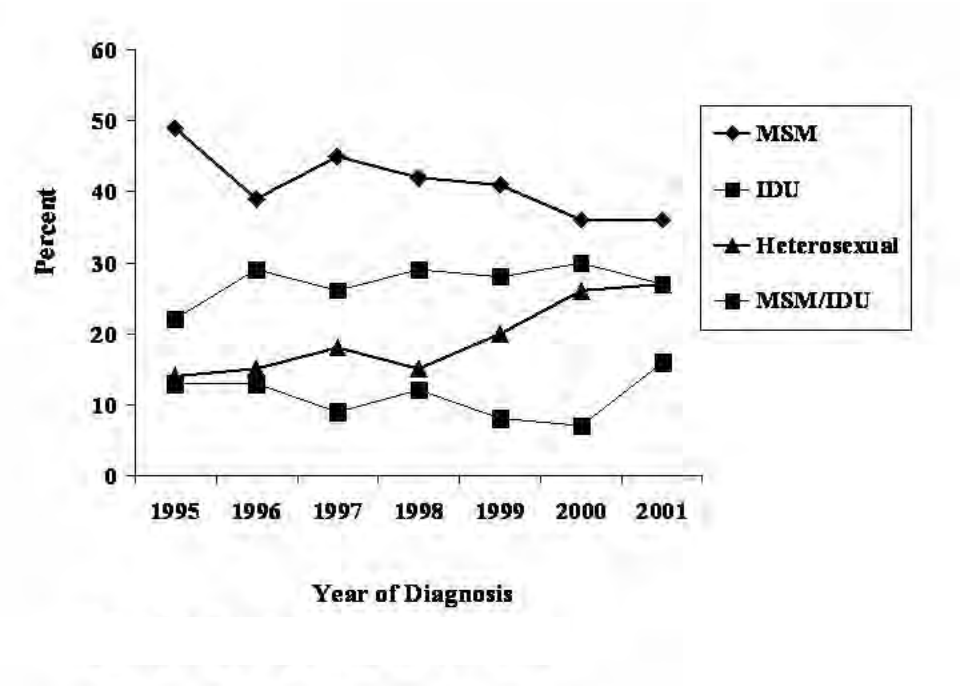

FIGURE 2. Estimated percentage of AIDS cases among American Indians and Alaska Natives, by mode of exposure, 1995-2001 (adjusted for reporting delay and unreported risk).

Fleming, Steketee, & DeCock, 2001). With the advent of more effective therapy that slows the progression of HIV disease, end-stage disease (i.e., AIDS) surveillance data no longer reflect trends in HIV transmission (Klevens et al., 2001).

In contrast, HIV case reporting is designed to provide data to characterize populations in which HIV infection has been newly diagnosed. But HIV reporting also has several important limitations. Unlike AIDS case reporting, HIV case reporting is not currently geographically comprehensive. Name-based HIV reporting is operational in 36 of 50 states, only 25 of which have had it in place long enough to provide reliable monitoring of trends over time (CDC, 2002b). The majority of the HIV/AIDS cases among AI/AN has been reported from western states where the AI/AN population is concentrated (McNaghten, Neal, Li, & Fleming, 2001). But several states with large AI/AN populations have only recently enacted laws requiring HIV case surveillance or have only begun HIV surveillance in the past few years (e.g., New York and Washington). The state with the largest AI/AN population, California, began implementing HIV case reporting by coded identifier in July 2002. That these states with large AI/AN populations are only beginning to report HIV cases is a critical gap that influences the ability to track the spread of HIV among AI/AN.

To be counted by the HIV surveillance system, an HIV-infected person must have had an HIV test. Among those tested for HIV, the surveillance system counts only those tested in settings where identifying information is recorded (confidential test sites). Those who are initially tested anonymously are not counted until they present

for HIV-related care, at which time they are retested confidentially. And the surveillance system can only count cases health care providers have reported, as required by states. For these reasons, HIV surveillance data provide a minimum estimate of the number of infected persons. The data represent the characteristics of persons who recognize their risk and seek confidential testing, who are routinely offered HIV testing (e.g., pregnant women and patients from sexually transmitted disease [STD] clinics), who are tested when they seek HIV-related health care, who are required to be tested (blood donors and military recruits), or who are tested because they present with symptoms of HIV-related illness (CDC, 2002a).

The issue of unidentified cases (because some infected people have not been tested) affects the interpretation of surveillance data for all race/ethnicity groups. The CDC has estimated that one quarter of all HIV-infected people in the United States (180,000-280,000 HIV-infected people) do not know their HIV status (Fleming et al., 2002). Compared with non-AI/AN persons with AIDS, AI/AN persons with AIDS are more likely to reside in a rural area at the time of AIDS diagnosis. AI/AN persons at high risk for HIV infection who live in rural areas may be less likely to be tested for HIV, because of limited access to testing. At-risk AI/AN persons may also be less likely to test because of concerns about confidentiality in close-knit communities where someone who seeks testing is likely to encounter a friend, relative, or acquaintance at their local health care facility (Metler, Conway, & Stehr-Green, 1991; National Commission on AIDS, 1999; National Rural Health Association, 1997). Poor access to health care in general is a problem for the AI/AN population. A study by Korenbrot, Wong, and Crouch (2001) showed that Medicaid-eligible American Indians in California use less health care. The impact of these factors on knowledge of HIV serostatus among AI/AN at risk for HIV infection is not known; testing access and test-seeking behavior among AI/AN persons residing in urban and rural areas is currently being studied.

The HIV/AIDS Surveillance System reflects only cases reported from health facilities and laboratories and is only as complete as reporting is complete. The IHS, which serves 60% of the AI/AN people, is authorized by the Privacy Act (*Code of Federal Regulations*, Title 45, Subtitle A, Part 5b.9) to participate in communicable disease surveillance activities mandated by local or state regulation, including HIV/AIDS reporting. A recent evaluation of AI/AN HIV and AIDS case reporting from IHS to the New Mexico Department of Health HIV/AIDS surveillance system demonstrated that of cases known to IHS facilities in the state, 98% had been reported to the state surveillance system (Leman, Bertolli, & Cheek, 2001). Evaluation of completeness of HIV/AIDS reporting from IHS facilities in other areas is needed. Even less is known about the process and completeness of case reporting from tribally operated health care facilities. Complex jurisdictional and capacity issues are the legacy of historical federal and state Indian policies, leaving gray areas regarding authority and responsibility among tribal, state, and federal public health agencies for surveillance and public health response activities on tribal lands (Kunitz, 1996; Marsden, 1998).

Racial misidentification of AI/AN is another factor that may lead to underestimation of the magnitude of health problems of this group. Studies of state-based disease surveillance systems and registries for multiple health conditions have demonstrated substantial undercounting of AI/AN cases due to racial misidentification (Epstein, Moreno, & Bacchetti, 1997; Partin et al., 1999; Sugarman, Holliday, Ross, Castorina, & Hui, 1996), including studies evaluating misidentification of AI/AN

cases in the AIDS reporting system (Hurlich, Hopkins, Sakuma, & Conway, 1992; Kelly, Chu, Diaz, Leary, & Buehler, 1996; Lieb, Sorvillo, & Nahlen, 1992).

There is a high likelihood that health care personnel involved in reporting cases from IHS or tribal facilities would be aware of the race of an AI/AN person diagnosed there and would correctly designate that person's race in the report sent to the state. But more than half (56%) of the AI/AN population now live in urban areas, and IHS and tribal facilities are predominantly located on or near reservations and are not geographically accessible to AI/AN urban residents (Forquera, 2001). Racial misidentification is more likely to occur among AI/AN persons who obtain health care through non-IHS or nontribal facilities, where health care providers and lab technicians involved in reporting must ask a person's race to record it accurately. For example, findings from a 1995 IHS study of STD reporting in Oklahoma (a state in which large numbers of AI/AN persons receive health care through non-IHS facilities) indicated that chlamydia, gonorrhea, and syphilis rates for AI/AN persons would increase by 32%, 57%, and 27%, respectively, if racial misidentification were corrected (Thoroughman, Frederickson, Cameron, Shelby, & Cheek, 2002).

HIV/AIDS may not be evenly distributed geographically or among distinct AI/AN tribal groupings, but current systems are not able to describe HIV/AIDS rates for individual tribes. In addition, many tribes are so small that there is a problem estimating disease incidence and prevalence precisely. For small population groups, changes in numbers of cases may or may not represent stable estimates. This problem with small numbers affects surveillance for AI/AN populations and creates a paradox for health administrators and tribal leaders, as there is a clear need for data to monitor health status, including HIV/AIDS, at a local community level (Roubideaux & Dixon, 2001).

SUPPLEMENT TO HIV/AIDS SURVEILLANCE PROJECT

The CDC's Supplement to HIV/AIDS Surveillance (SHAS) Project uses the infrastructure of HIV infection and AIDS case reporting to collect additional information on behaviors among HIV-infected persons, who by definition represent those at highest risk. The key features of this project are: (a) it is conducted by local or state health departments; (b) it is linked to HIV and AIDS case reporting; (c) sampling methods are flexible to accommodate local circumstances and data needs; (d) it collects information from interviews of persons diagnosed and newly reported with HIV infection or AIDS; and (e) it includes measures of socioeconomic status, sexual behaviors, drug and alcohol use, and use of health services.

Sites participating in the SHAS project include health departments in Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Los Angeles County, New Jersey, New Mexico, Michigan, South Carolina, and Washington State (Buehler, Diaz, Hersh, & Chu, 1996). Data presented below are from the drug and alcohol use section of the SHAS questionnaire and have not been previously published.

Summary of SHAS Findings

From 1990 to 2000, a total of 265 HIV-infected AI/AN (including persons who listed both AI/AN and Hispanic ancestry) were interviewed through the SHAS project, averaging approximately 30 persons per year during this 10-year period. Of these, 220 (83%) were male and 45 (17%) were female; 48 (18%) had HIV (not AIDS) and 217 (82%) had AIDS; and 81 (31%) had known their HIV-positive status for less than 12 months. Three states, Colorado, Washington, and Arizona, contributed more than half (54%) of the AI/AN persons interviewed. Arizona and Washington each contrib-

uted 17%, and 20% were from Colorado. The AI/AN persons interviewed were comparable to the non-AI/AN respondents on level of educational attainment and income.

Alcohol Use. SHAS data show that the percentage of HIV-infected AI/AN interviewees who met the CAGE criteria (Ewing, 1984) for potential alcohol dependence was nearly twice as high as the percentage of non-AI/AN interviewees who met these criteria (42% compared with 24%).[4] This difference was statistically significant (p = .001). The percentage of AI/AN who met the CAGE criteria was higher than for any other racial/ethnic group: 42% compared with 27% among Blacks, 20% among Whites, 26% among Hispanics, and 9% among A/PI.

Noninjection Drug Use. Likewise, the percentage of HIV-infected AI/AN respondents who had ever used illicit drugs was higher than among HIV-infected non-AI/AN respondents (83% compared with 70%, p = .001) and the percentage who used illicit drugs was higher than among any other racial/ethnic group, 83% compared with 69% among Blacks, 78% among Whites, 58% among Hispanics, and 50% among A/PI. Table 1 shows the primary drugs used by SHAS participants who reported noninjection drug use, by race/ethnicity. The primary noninjection drug used by HIV-infected AI/AN was marijuana (52% of drug users), followed by cocaine (17%). A higher percentage of HIV-infected AI/AN who used noninjection drugs used "speed" (amphetamines) as their primary non-injection drug compared with HIV-infected non-AI/AN (9% vs. 4%). A lower percentage of AI/AN used crack cocaine as their primary non-injection drug compared with non-AI/AN (11% vs. 20%).

Injection Drug Use. Compared with non-AI/AN, a higher percentage of AI/AN respondents who reported illicit drug use had injected drugs with a needle (44% vs. 38%), but this difference was not statistically significant. The percentage of AI/AN who had ever injected drugs was similar to the percentage among Blacks and Hispanics, 42% and 43%, respectively, but higher than for Whites, 34%, and A/PI, 27%. Table 1 shows that AI/AN respondents were more likely to report that the primary drug injected was heroin or "speed" compared with non-AI/AN respondents (heroin, 36% vs. 32%, and "speed," 24% vs. 12%). The AI/AN interviewees who had ever injected drugs began this behavior at younger ages than non-AI/AN interviewees (Table 1(2)): One third of AI/AN injection drug users began injecting drugs before the age of 18 years, compared with one fourth of non-AI/AN injection drug users. Although roughly the same percentage of AI/AN and non-AI/AN respondents began injecting drugs while they were 13-17 years of age (24% vs. 23%), a larger percentage of AI/AN than non-AI/AN (10% vs. 2%) began injecting when they were middle school aged (9-12 years).

Table 2 presents data on needle sharing by race/ethnicity among SHAS participants who injected drugs. More than three fourths (76%) of AI/AN SHAS participants who report injection drug use (and 80% of non-AI/AN respondents) had ever shared needles, indicating the potential for transmission of HIV from these respondents to their needle-sharing partners. Needle sharing among AI/AN more often involved a family member than among non-AI/AN (20% vs. 15%), although roughly the same percentage of AI/AN and Hispanic respondents (19%) reported this behavior. Sharing needles with an HIV-infected person was also more common among AI/AN than among non-AI/AN overall (13% vs. 9% of IDU, respectively), but roughly the same as among A/PI (15%).

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4. CAGE is a mnemonic for cutting down on drinking, being annoyed about criticism about drinking, feeling guilty about drinking, and using alcohol as an eye opener.

TABLE 1. Primary Drug Used Among Persons with HIV/AIDS Who Reported Injection and Noninjection Drug Use, by Race/Ethnicity, SHAS[a]

	Heroin		Cocaine		Heroin+Cocaine		Crack		Marijuana		Speed (Amphetamine)	
Race/Ethnicity	N. inj. No.(%)	Inject No.(%)	N. inj. No.(%)	Inject No.(%)	N. inj. No.(%)	Inject No.(%)	N. inj. No.(%)	Inject No.(%)	N. inj. No.(%)	Inject No.(%)	N. inj. No.(%)	Inject No.(%)
AI/AN N. inj.: *N* = 175 Inject: *N* = 96	10 (6)	35 (37)	30 (17)	28 (29)	—	7 (7)	19 (11)	—	91 (52)	—	15 (9)	23 (24)
Black N. inj.: *N* = 6188 Inject: *N* = 3127	565 (9)	1,166 (37)	1,063 (17)	1,192 (38)	—	673 (22)	2,121 (34)	—	2,348 (38)	—	38 (1)	57 (2)
White N. inj: *N* = 5066 Inject: *N* = 2177	166 (3)	469 (22)	736 (15)	792 (36)	—	186 (9)	268 (5)	—	3213 (63)	—	360 (7)	623 (29)
Hispanic N. inj: *N* = 1966 Inject: *N* = 1091	224 (11)	451 (41)	500 (25)	338 (31)	—	202 (19)	198 (10)	—	900 (46)	—	75 (4)	85 (8)
A/PI N. inj: *N* = 43 Inject: *N* = 16	0 (0)	3 (19)	9 (21)	7 (44)	—	0 (0)	2 (5)	—	22 (51)	—	4 (9)	5 (31)
All Non-AI/AN N. inj: *N* = 13,264 Inject: *N* = 6443	955 (7)	2089 (32)	2308 (17)	2329 (36)	—	1061 (17)	2589 (20)	—	6483 (49)	—	477 (4)	770 (12)

Note. N. inject. = noninjection drug users; inject = injection drug user. [a]SHAS is conducted in Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Los Angeles County, New Jersey, New Mexico, Michigan, South Carolina, and Washington State.

TABLE 2. Injection Drug Use Behavior Among Persons With HIV/AIDS Who Reported Injection Drug Use, By Race/Ethnicity, SHAS[a]

	Age at Initiation of Injection Drug Use														
	9–12 years Old			13–17 years Old			Ever Shared Needles/Works			Ever Shared Needles/Works With Family			Ever Shared Needles/Works With HIV–Infected Person		
Race/Ethnicity	No.	*N*	%	No.	*N*	%	Yes	*N*	%	Yes	*N*	%	Yes	*N*	%
AI/AN	9	92	10	22	92	24	73	96	76	14	70	20	9	71	13
Black	37	3081	1	691	3081	22	2670	3124	85	451	2653	17	195	2652	7
White	43	2137	2	463	2137	22	1588	2189	73	169	1569	11	186	1568	12
Hispanic	32	1070	3	310	1070	29	886	1093	81	164	874	19	84	874	10
A/PI	0	16	0	2	16	13	13	16	81	0	13	0	2	13	15
All Non–AI/AN	112	6304	2	1466	6304	23	5157	6422	80	784	5109	15	467	5107	9

[a]SHAS is conducted in Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Los Angeles County, New Jersey, New Mexico, Michigan, South Carolina, and Washington State.

Drug Treatment. A higher percentage of AI/AN respondents reported that they had been unable to enter drug treatment programs (13% vs. 5% of non-AI/AN). The percentage of AI/AN respondents who were unable to enter drug treatment was higher than for any other racial/ethnic group: 13% compared with 7% for Blacks, 4% for Whites, 5% for Hispanics, and 2% for A/PI. The most common reason for being unable to enter drug treatment was "waiting list," as it was for most other racial/ethnic groups.

HIV Testing. SHAS also provides information on HIV testing. The most common reason AI/AN respondents were tested for HIV was because of illness (34%), as it was for non-AI/AN (41%). The percentage of SHAS participants who were tested for HIV because of illness was 37% among White, 45% among Black, 44% among Hispanic, and 49% among A/PI participants. The most common locations where AI/AN respondents had been diagnosed with HIV infection were "HIV counseling and testing site" (22%), after admission to a hospital (21%), and at an "other clinic" (20%).

Strengths and Limitations of SHAS Data

The SHAS project provides a method for state health departments to collect information about risk behaviors among persons infected with HIV that is useful both locally and nationally for guiding HIV prevention and care programs. The scope of information collected through the SHAS project is modest compared with behavioral research studies that obtain more detailed information on a smaller number of people. Also, at this time, many of the states participating in SHAS only interview patients who have AIDS. However, SHAS provides an important piece of the puzzle, and is a practical approach to behavioral surveillance in the support of HIV prevention. As a source of information about AI/AN people newly diagnosed with HIV/AIDS, it is limited by the small numbers of AI/AN persons available for recruitment at participating study sites. Moreover, because the estimates from SHAS are based on self-reported data, they may be subject to recall and social desirability biases.

ADULT AND ADOLESCENT SPECTRUM OF HIV-RELATED DISEASES STUDY

The Adult and Adolescent Spectrum of HIV-Related Disease (ASD) Study, initiated by the CDC in 1990, is a multicenter study conducted in 11 major metropolitan areas in the United States. HIV-infected persons 13 years of age or older who are receiving health care at participating facilities are eligible for enrollment. Medical records are retrospectively reviewed for the 12-month period prior to enrollment and at 6-month intervals until patient death or loss to follow-up. Data on initial presentation, course of illness, and treatment are abstracted from medical records. These data reflect routine care practices at sites that typically provide primary HIV care (Farizo et al., 1992).

Summary of ASD Data

HIV and STD/TB Co-Infection. Diamond, Davidson, Sorvillo, and Buskin (2001) presented data from three sites participating in the ASD study, Seattle-King County, Denver, and Los Angeles County, which together enrolled 73% of the AI/AN persons included in ASD through June 1998. At these three sites, a total of 11,495 HIV-infected patients: 151 AI/AN; 6,222 White; 2,294 Black; 2,551 Hispanic; 230 A/PI; and 47 of unknown race/ethnicity were enrolled from 1989 to 1998, the period of the analysis. AI/AN HIV patients were more likely to be diagnosed with an acute sexually transmitted disease (such as chlamydia, gonorrhea, trichomonas, or

nongonococcal urethritis) compared with non-AI/AN ($p < .001$). AI/AN with AIDS were three times more likely to have active pulmonary tuberculosis (6% compared with 2% of non-AI/AN).

Antiretroviral Therapy. ASD data have also shown early differences in prescription of antiretroviral medications for treatment of HIV infection. AI/AN persons were less than half as likely to be prescribed highly active antiretroviral therapy than Whites were in 1996, but this disparity was largely eliminated by 1998 to 1999 (McNaghten, Hanson, Dworkin, & the Adult/Adolescent Spectrum of HIV Disease Project Group, 2001).

Strengths and Limitations of ASD Data

Because Seattle and Los Angeles are among the metropolitan areas with the highest percentages of AI/AN with AIDS in the United States (U.S. Census Bureau, 2002a), and because the majority of reported AI/AN AIDS cases are in the western United States, these ASD data are useful in supplementing the data on AI/AN HIV-infected persons usually obtained through case reporting to the HIV/AIDS Surveillance System. However, the study has a number of limitations. Information from ASD, which is based in care facilities, may not represent the population not receiving medical care. The sample size of AI/AN persons is small compared with the large number of non-AI/AN. Furthermore, ASD does not include IHS facilities, and the study sites are located in urban rather than rural areas. Therefore, the data do not represent rural HIV-infected AI/AN persons who live on reservations and who do not travel to urban areas for care, or AI/AN persons who receive all their health care through the IHS (Diamond et al., 2001).

SEROPREVALENCE STUDIES

Upon entrance into active or reserve military service, military service academies, and the Reserve Officer Training Corps, all civilian applicants receive a blood test for HIV antibodies. The HIV seroprevalence data are shared with the CDC on a quarterly basis and provide a way to monitor HIV seroprevalence in a sentinel population that is more representative of the larger U.S. population compared with studies focused on "high risk" groups (U.S. Department of Defense, 2002). HIV testing is also required for entrance into the U.S. Department of Labor National Job Training Program, an occupational training program for economically and educationally disadvantaged youth, 16-21 years old, from rural and urban areas of all 50 states and the U.S. territories. The National Job Training Program recruits high school dropouts or high school graduates in need of additional education or training in order to obtain and hold meaningful jobs. Data sent to the CDC from the National Job Training Program provide a system for monitoring the HIV epidemic in this population, which may be at increased risk for HIV infection (U.S. Department of Defense, 2002).

Summary of Seroprevalence Data

Seroprevalence Among Military Service Applicants. Of 5,727,453 male applicants for military service between October 1985 and December 2001, 4,667 (0.08%) tested positive for HIV antibodies. The seroprevalence among AI/AN males was 0.04% compared with 0.27% among Black, 0.10% among Hispanic, 0.04% among White and 0.02% among A/PI males. Among 1,168,024 female applicants for military service during the same period, 528 (0.05%) tested positive for HIV antibodies. The seroprevalence was 0.02% among AI/AN females compared with 0.12% among Black, 0.03% among Hispanic, 0.01% among White, and 0.02% among A/PI females (U.S. Department of Defense, 2002).

Seroprevalence Among National Job Training Program (Job Corps) Applicants. Of 258,388 male National Job Training Program Program applicants tested from January 1990 through September 1997, 502 (0.19%) were HIV-positive. The seroprevalence among 7,939 AI/AN males tested was 0.06%, compared with 0.31% for Black, 0.14% for Hispanic, 0.07% for White, and 0.02% for A/PI males. Seroprevalence among the 139,902 female applicants tested during this time period was higher than for male applicants (0.29% vs. 0.19%). Of 5,735 AI/AN females, 0.05% were HIV-positive compared with 0.5% of Black, 0.07% of Hispanic, 0.06% of White, and 0.04% of A/PI females (U.S. Department of Labor, 1998).

Strengths and Limitations of Seroprevalence Data

Because they are based on routine HIV testing, seroprevalence data like those for military and National Job Training Program applicants may provide a more complete estimate of the prevalence of HIV in the populations tested than methods that rely on case reporting of infections among persons who have voluntarily presented for HIV testing. These data are representative of persons applying for military service or the National Job Training Program but may not be generalizable to the larger population.

Military applicants are not representative of the general population because of self-exclusion. For example, because applicants who are HIV-positive or who use drugs are not accepted into the military, men who have sex with men, injection drug users, and others who were aware or suspected that they were infected with HIV are likely to be underrepresented in the population of military applicants. In addition, all military applicants must have high school diplomas or the equivalent and, therefore, do not represent those with a lower level of educational attainment (U.S. Department of Defense, 2002). Nonetheless, because of the large number of male and female applicants from all areas of the country, this population provides valuable information about the HIV epidemic, particularly among those who are not recognized as being at high risk of HIV infection.

Likewise, National Job Training Program entrants may not fully represent the larger population of disadvantaged youth. Sexual behavior or history of illicit drug use does not constitute a basis for exclusion from the program. But current illicit drug users, persons with severe medical or behavioral problems, and persons on supervised probation or parole or who are incarcerated are excluded. Because HIV testing is mandatory for National Job Training Program applicants, self-selection for enrollment in the program could either decrease or increase the number of HIV-infected entrants. Although National Job Training Program entrants may not fully represent the larger population of disadvantaged youth in the United States, these surveys nonetheless provide important national information that can be used for planning HIV prevention programs for disadvantaged out-of-school youth (U.S. Department of Defense, 2002).

NATIONAL VITAL EVENTS REPORTING SYSTEM

The National Vital Events Reporting System collects data on births, deaths, marriages, divorces, and fetal deaths. These vital statistics are collected through state-operated registration systems. This system provides data on deaths attributable to HIV infection, which is another way to gauge the impact of the HIV epidemic on population groups, including AI/AN populations.

Standard forms for the collection of the data and model procedures for the uniform registration of events are developed and recommended for state use through cooperative activities of the states and the CDC's National Center for Health Statistics

(NCHS). After a physician completes medical certification and signs the death certificate, the death certificate is returned to a funeral director, who obtains personal facts (including race/ethnicity) about the deceased. Ideally, when the death is certified, the local registrar of vital statistics verifies the completeness and accuracy of the death certificate, and sends the certificates to the local health department or state registrar. The death certificate information may be used by local and state health departments for a variety of public health reasons, such as allocating medical and social services, follow-up of infectious diseases, planning programs, and measuring effectiveness of public health programs. The local health departments also send certificates to the state registrar, who will query incomplete or inconsistent information, compile statistics for the state for use by the health department and interested groups, and send copies of death certificates and summary reports on deaths to the National Office of Vital Statistics, NCHS, which prepares national statistics (CDC, 2003).

Summary of Data from the National Vital Events Reporting System

HIV-Related Deaths. Data from 2000 (Anderson, 2002) show that among AI/AN, the age group including persons 35-44 years old bore the greatest impact from HIV-related deaths. In 2000 the rate of HIV-related death among AI/AN 35-44 years old was 6.6 per 100,000 persons, as compared with 54.0 per 100,000 among Blacks, 7.5 per 100,000 among Whites, 15.4 per 100,000 among Hispanics, and 1.6 per 100,000 among A/PI in the same age group. In the 35-44 year old age group, HIV-related deaths accounted for 2% of all deaths among AI/AN, 15% of total deaths among Blacks, 4% among Whites, 9% among Hispanics and 2% among A/PI.

Strengths and Limitations of the National Vital Events Reporting System

Death statistics are one measure of the impact of HIV on AI/AN, but because of the increasingly long interval from HIV to AIDS and death, they do not provide timely information for directing HIV prevention efforts. In addition, the surveillance value of data on HIV-related deaths is complicated by the fact that they reflect both transmission of HIV and access to health care.

Misidentification of AI/AN race on death certificates has been documented by several studies as a problem leading to undercounting in mortality statistics (Frost, Tollestrup, Ross, Sabotta, & Kimball, 1994; Harwell et al., 2002; Stehr-Green, Bettles, & Robertson, 2002; Sugarman, Hill, Forquera, & Frost, 1992). However, none of these studies has specifically addressed undercounting of HIV-related deaths. The NCHS estimates that the net effect of reporting problems on the overall rate of death among AI/AN is to underestimate it by approximately 21% (Minino, Arias, Kochanek, Murphy, & Smith, 2002).

NATIONAL SEXUALLY TRANSMITTED DISEASE (STD) MORBIDITY SURVEILLANCE SYSTEM

The National STD Morbidity Surveillance System is a population-based case reporting system like the National HIV/AIDS Surveillance System. All cases of nationally notifiable STDs (chlamydia, gonorrhea, syphilis, and chancroid) are reported from health care providers or laboratories to local and state health departments, and from state health departments to the CDC. Case reporting is intended to cover all health care providers and laboratories. All 50 states, the District of Columbia, and U.S. territories are required to report cases of notifiable STDs. At present, STD data are submitted to the CDC on a variety of summary reporting forms (monthly, quarterly, and annually) or electronically, either in summary or individual case-listed for-

mat, via the National Electronic Telecommunications System for Surveillance (CDC, 1997).

Summary of Data from the National STD Morbidity Surveillance System

STD Rates. High chlamydia, gonorrhea, and syphilis rates among AI/AN suggest that the sexual behaviors that facilitate the spread of HIV are relatively common among AI/AN (CDC, 2002c). According to CDC surveillance data, AI/AN have the second highest rate of reported gonorrhea of any racial/ethnic group. In 2001 the rate of gonorrhea among AI/AN was 114 per 100,000 persons compared with 782 per 100,00 among Blacks, 74 per 100,000 among Hispanics, 29 per 100,000 among Whites, and 27 per 100,000 among A/PI. Each year from 1998-2001, the gonorrhea rate among AI/AN was higher than the rates in 1996 and 1997 (CDC, 2002c).

AI/AN also have the second highest rate of reported chlamydia of any racial/ethnic group (CDC, 2002c). In 2001 the rate of chlamydia among AI/AN was 651 per 100,000 persons compared with 1,115 per 100,000 among Blacks, 447 per 100,000 among Hispanics, 150 per 100,000 among A/PI, and 119 per 100,000 among Whites. The same trend is observed as for gonorrhea: an increase in chlamydia rates since 1997 (CDC, 2002c). However, some of this increase reflects greater efforts to test for chlamydia and use of more sensitive diagnostic technology.

AI/AN currently have the second highest rate of primary and secondary syphilis of any racial/ethnic group. In 2001 the rate of primary and secondary syphilis among AI/AN persons was 4 per 100,000 persons compared with 11 per 100,000 among Blacks, 2 per 100,000 among Hispanics, 0.7 per 100,000 among Whites, and 0.5 per 100,000 among A/PI. AI/AN is the only racial/ethnic group in which the syphilis rate did not decline from 1997 to 1999 (CDC, 2002c).

Strengths and Limitations of Data from the National STD Morbidity Surveillance System

High rates of sexually transmitted disease are an indicator of unsafe sexual behavior that may increase the risk of acquiring or transmitting HIV. Epidemiological studies have indicated at least a twofold to fivefold increased risk for HIV infection among persons who have other STDs, including genital ulcer diseases and nonulcerative, inflammatory STDs (CDC, 1998b). Together, the trends in STD infections described above demonstrate that AI/AN people are vulnerable to the spread of HIV.

DISCUSSION

High STD rates indicate that conditions exist for the spread of HIV in AI/AN populations. National surveillance data through December 2001 (CDC, 2002b) show that rates of HIV/AIDS have been consistently lower among AI/AN compared with rates among Blacks and Hispanics but higher compared with rates among A/PI and, since 1995, higher than rates among Whites. Through 2001, 0.3% of reported U.S. AIDS cases and 0.6% of reported HIV cases were among AI/AN persons (CDC, 2002b), figures that are approximately commensurate with the AI/AN percentage of the general U.S. population (0.7%), (U.S. Census Bureau, 2002b). (It is important to keep in mind that the measured rates for AI/AN people as a group may mask higher or lower rates for individual tribes; the problem of measuring rates for small population groups has been discussed above.)

The HIV surveillance data, in general, are likely to underestimate the number of AI/AN cases because, as for other racial/ethnic groups, not all AI/AN persons living with HIV have been tested for the infection. It is not possible to reliably estimate the number of AI/AN persons living with HIV infection who do not know their HIV status. But data on HIV testing can provide some insight into whether receipt of HIV testing varies across population groups. Such data are available from the Behavioral Risk Factor Survey, and provide no evidence that AI/AN who participated in this study were less likely to have received HIV testing than respondents from other racial/ethnic groups (Denny, Holtzman, & Cobb, 2003). However, it is important to note that this study was limited to persons who have a telephone, who may not represent the group of AI/AN people at highest risk of HIV infection.

Analysis of late diagnoses reported in 25 states with confidential name-based HIV reporting since 1994 provides information on timing of receipt of HIV testing among HIV-infected AI/AN persons. These data suggest that getting tested for HIV infection before a diagnosis of AIDS is as common among AI/AN persons as among non-AI/AN. In addition, data from the CDC's SHAS project showed that the percentage of AI/AN respondents who reported that they received HIV testing "because of illness" was lower than for non-AI/AN respondents. However, these two data sources are subject to important limitations and may not be comparable: The HIV reporting system is evolving and thus far excludes data from states with the largest AI/AN populations; the SHAS study is limited by small numbers of AI/AN respondents. Further studies of the AI/AN population's access to HIV testing, as well as reasons for seeking and avoiding HIV testing, are currently under way and will contribute to understanding the effects of HIV testing patterns on the timeliness of surveillance data for this population.

Surveillance systems may also underestimate the number of AI/AN persons with HIV/AIDS because many AI/AN persons with HIV or AIDS are reported to be of another race/ethnicity (Hurlich et al., 1992; Kelly et al., 1996; Lieb et al., 1992). The contribution of midentification of race/ethnicity to underestimation of national HIV/AIDS case counts among AI/AN people is unclear. Whether midentification of race/ethnicity is more common among AI/AN people compared with people of other races/ethnicities is unknown; the degree of racial misidentification of AI/AN persons in the HIV/AIDS surveillance system is also currently being studied.

Underreporting is another factor that may contribute to underestimation of HIV/AIDS rates in the AI/AN population. Completeness of reporting from IHS and tribally operated health facilities is currently being evaluated. That several states with large AI/AN populations are only just beginning to report HIV infections is a critical gap in surveillance of HIV/AIDS among AI/AN people. In addition, the available surveillance data reflect those who recognize their risk and seek confidential testing, are offered a test, are required to be tested, or seek HIV-related health care. Those who receive anonymous tests and do not seek HIV-related care, or who remain untested, are not represented in these data.

Barring significant underestimation of the numbers and rates of HIV/AIDS among AI/AN people, it is possible that lower HIV infection rates among AI/AN are a consequence of later entry of HIV into this population compared with other groups.

In considering the impact of HIV on AI/AN people, it is important to take into account its potential for spread (as evidenced by high STD and drug use rates) and to remember that HIV is added to a number of other health problems (e.g., diabetes) that are common among AI/AN populations (Denny, Holtzman, & Cobb, 2003; Liao,

Tucker, & Giles, 2003) and that AI/AN persons with HIV are more likely to be coinfected with other STDs and TB (Diamond et al., 2001). High STD and drug use rates apparent among AI/AN (Indian Health Service, 2001; Substance Abuse and Mental Health Services Administration, 2001), have been similarly observed preceding the rapid spread of HIV in other groups (CDC, 1998b) and indicate that AI/AN people are vulnerable to the spread of HIV infection.

CONCLUSION

The vulnerability of AI/AN people to the spread of HIV infection emphasizes the importance of accurate and timely surveillance data for this population and of close monitoring of these data from the local to the national level. Available data indicate that there is a window of opportunity to respond with effective public health programs to prevent further HIV transmission in AI/AN populations.

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