

December 2007

# INDIAN HEALTH SERVICE

## HIV/AIDS Prevention and Treatment Services for American Indians and Alaska Natives





Highlights of [GAO-08-90](#), a report to congressional requesters

## Why GAO Did This Study

American Indians and Alaska Natives have the third highest rate of HIV/AIDS diagnosis in the United States. They are also more likely than individuals with HIV/AIDS from other racial and ethnic groups to receive treatment at later stages of the disease and have shorter life spans.

The Indian Health Service (IHS), located within the Department of Health and Human Services (HHS), provides health care services, including HIV/AIDS treatment, to eligible American Indians and Alaska Natives. IHS patients with HIV/AIDS may also receive care through other sources depending on their access to private health insurance or their eligibility for other federal health care programs, such as Medicare and Medicaid.

GAO examined the extent to which IHS provided (1) HIV/AIDS prevention services and (2) HIV/AIDS treatment services. GAO also examined (3) what other HIV/AIDS-related initiatives IHS has undertaken. GAO reviewed documents and interviewed officials from IHS headquarters, area offices, and IHS-funded facilities, as well as advocacy groups. We also conducted site visits in two IHS areas.

To view the full product, including the scope and methodology, click on [GAO-08-90](#). For more information, contact Laurie Ekstrand at (202) 512-7114 or [ekstrandl@gao.gov](mailto:ekstrandl@gao.gov).

## INDIAN HEALTH SERVICE

### HIV/AIDS Prevention and Treatment Services for American Indians and Alaska Natives

## What GAO Found

HIV/AIDS prevention services were generally available from IHS, but these services varied across the 12 IHS areas. HIV/AIDS education was provided in all areas in a variety of settings, such as IHS-funded facilities, schools, and health fairs. In addition to education, IHS offered HIV testing services in all areas; however, the type and extent of services varied. In addition, some IHS officials described other services that were provided as part of their HIV/AIDS prevention activities, such as condom distribution.

According to IHS officials, HIV/AIDS treatment services, while offered at some IHS facilities, were generally received outside of IHS. Five IHS-funded hospitals, such as the Phoenix Indian Medical Center in Arizona, regularly treated patients. Although some other IHS facilities provided limited treatment services, most relied on outside providers. For example, IHS patients with HIV/AIDS might see a specialist outside of IHS every 3 months for their HIV/AIDS treatment services and an IHS provider for other routine care. IHS officials reported that most IHS facilities did not provide treatment services because they had few American Indian or Alaska Native patients known to have HIV/AIDS, had limited resources, focused on other health concerns, or their providers had limited training or experience treating the disease. Additionally, some patients may not access or continue treatment from IHS or outside providers due to concerns about confidentiality and lack of transportation to distant facilities.

IHS has undertaken outreach and planning, capacity building, and surveillance initiatives related to HIV/AIDS. These initiatives are overseen by national and area-level IHS officials. The outreach and planning initiatives include an HIV/AIDS Web site and the development of a national HIV/AIDS administrative work plan. IHS has also undertaken several initiatives aimed at building the capacity of providers to offer HIV/AIDS-related prevention and treatment services, such as training of health care providers and implementation of an HIV/AIDS-related data system that can send providers reminders when patients with HIV/AIDS need care. Finally, IHS has undertaken initiatives related to improving the surveillance of HIV/AIDS in the American Indian and Alaska Native population by developing a prenatal HIV screening measure and an early detection surveillance system.

GAO received written comments from HHS on a draft of this report. HHS substantially agreed with the findings of this report. HHS also offered technical comments to provide additional information or clarify specific findings, which we incorporated as appropriate.

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## Abbreviations

CARE Act	Ryan White Comprehensive AIDS Resources Emergency Act of 1990
CDC	Centers for Disease Control and Prevention
HAART	Highly Active Antiretroviral Therapy
HHS	Department of Health and Human Services
HMS	HIV Management System
HRSA	Health Resources and Services Administration
IHS	Indian Health Service
SAMHSA	Substance Abuse and Mental Health Services Administration
UIHP	Urban Indian Health Program

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United States Government Accountability Office  
Washington, DC 20548

December 14, 2007

The Honorable Byron Dorgan  
Chairman  
Committee on Indian Affairs  
United States Senate

The Honorable John McCain  
United States Senate

The Honorable Jeff Bingaman  
United States Senate

Although they represent less than 1 percent of all HIV/AIDS reported cases, American Indians and Alaska Natives had the third highest rate of HIV/AIDS diagnosis in the United States after blacks and Hispanics in 2005.<sup>1</sup> According to the Centers for Disease Control and Prevention (CDC), an agency within the Department of Health and Human Services (HHS), since the beginning of the epidemic through 2005, a cumulative total of 3,238 American Indians and Alaska Natives have been diagnosed with AIDS.<sup>2</sup> But this estimate may be understated because American Indians and Alaska Natives, particularly those living in rural areas, may be less likely to be tested. They may also be less likely to seek testing because of concerns about confidentiality when living in close-knit communities.<sup>3</sup> Additionally, CDC and others have reported that American Indians and

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<sup>1</sup>In 2005, the rate (per 100,000 persons) of HIV/AIDS diagnosis for American Indians and Alaska Natives was 10.4, compared with 71.3 for blacks, 27.8 for Hispanics, 8.8 for whites, and 7.4 for Asians and Pacific Islanders. See Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS among American Indians and Alaska Natives* (Atlanta, Ga: 2007).

<sup>2</sup>CDC has AIDS surveillance data available for all 50 states. However, CDC's estimates for persons living with HIV/AIDS include only those 33 states and U.S. dependent areas that have had confidential name-based HIV infection reporting since 2001, and not all states with large American Indian and Alaska Native populations have been conducting HIV surveillance. As a result, we cannot provide a more precise estimate of the total number of American Indians and Alaska Natives living with HIV. Therefore, in this report, we use CDC's reported AIDS data only.

<sup>3</sup>In addition, the numbers of HIV and AIDS diagnoses for American Indians and Alaska Natives may be affected by racial misclassification. This occurs when patients either self-identify or are identified by health care providers as being of a racial or ethnic group other than American Indian and Alaska Native.

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Alaska Natives are more likely to receive treatment at later stages of the disease and have shorter life spans compared to most other population groups with HIV/AIDS. Furthermore, American Indians and Alaska Natives experience disproportionately high rates of risk factors for HIV/AIDS, such as sexually transmitted infections, substance abuse, and poor socioeconomic conditions. For example, individuals who are under the influence of alcohol or drugs are more likely to engage in high-risk behavior that can put them at greater risk for contracting or spreading HIV/AIDS.

The Indian Health Service (IHS), part of HHS, provides or arranges health care services, including HIV/AIDS treatment, to eligible American Indians and Alaska Natives.<sup>4</sup> It provided or arranged services for a projected 1.5 million American Indians and Alaska Natives in fiscal year 2007, across 12 federally designated areas that cover all or part of 35 states. Services are provided through IHS-funded facilities, including those operated by IHS, those operated by tribes, and Urban Indian Health Program (UIHP) facilities or through contracts with outside providers.<sup>5</sup> Our prior work found gaps in the health care services IHS provided for American Indians and Alaska Natives that, in some cases, hindered American Indians and Alaska Natives from obtaining needed services.<sup>6</sup> In addition to IHS, American Indians and Alaska Natives with HIV/AIDS may also receive care through other sources depending on their access to private health insurance; their eligibility for other federal health care programs, such as Medicare and Medicaid; or their eligibility for services provided by entities

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<sup>4</sup>American Indians and Alaska Natives eligible for IHS services must generally be members of federally recognized tribes or their descendants. In addition, they must be regarded as American Indians and Alaska Natives by their community, as evidenced by such factors as living on tax-exempt land, owning restricted property, participating actively in tribal affairs, or other relevant factors. Non-American Indians and Alaska Natives may in certain very limited circumstances also be eligible for services.

<sup>5</sup>The UIHP consists of 34 nonprofit organizations nationwide that are funded through grants and contracts from IHS.

<sup>6</sup>GAO, *Indian Health Service: Health Care Services Are Not Always Available to Native Americans*, [GAO-05-789](#) (Washington, D.C.: August 2005).

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funded through Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 grants.<sup>7</sup>

Because access to HIV/AIDS prevention services can affect the number of American Indians and Alaska Natives who have the disease and there may be variation in the availability of treatment services, you asked us to examine IHS's efforts related to HIV/AIDS. Specifically, we examined the extent to which IHS provides (1) HIV/AIDS prevention services and (2) HIV/AIDS treatment services. We also examined (3) what other HIV/AIDS-related initiatives IHS has undertaken.

To examine the extent to which IHS provides HIV/AIDS prevention services, we interviewed the officials identified by IHS as the most knowledgeable about HIV/AIDS services in each of the 12 area offices. The area officials provided varying levels of detail about the IHS-funded HIV/AIDS prevention services provided by the tribes in their area, including those provided at tribally operated facilities. For example, 3 areas included officials from tribal organizations in these interviews, while other area officials said they had limited knowledge of the HIV/AIDS prevention services that were provided at tribally operated facilities. In addition to the interviews, we also reviewed available IHS documentation and interviewed relevant IHS officials about IHS's budget, data systems, and HIV/AIDS prevention services. In addition, we reviewed data from CDC and HHS's Health Resources and Services Administration (HRSA) relevant to American Indians and Alaska Natives with HIV/AIDS. Finally, we interviewed representatives from advocacy organizations, such as the National Alliance of State & Territorial AIDS Directors, the National Council of Urban Indian Health, the National Indian Health Board, and the National Native American AIDS Prevention Center. We also visited 2 IHS areas, Phoenix and Tucson, to interview officials from IHS-funded facilities, tribal health departments, and Ryan White-funded facilities that served American Indians and Alaska Natives. We selected the Phoenix area in order to interview officials at the Phoenix Indian Medical Center, which has the IHS HIV Center of Excellence. In addition, the state of Arizona has the third largest population of American Indians and Alaska

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<sup>7</sup>Medicare is a federal health insurance program for individuals aged 65 and older and for certain disabled adults. Medicaid is a jointly funded federal-state health care program that covers certain low-income individuals and families, including those who are aged or disabled. The Ryan White CARE Act of 1990, referred to in this report as the Ryan White program, makes funds available to states, territories, and metropolitan areas to provide health care and support services to individuals and families affected by HIV/AIDS.

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Natives and the Phoenix area has the second highest number of American Indians and Alaska Natives living with HIV/AIDS. Because of the Tucson area's close proximity to the Phoenix area and the expectation that there would be some variation in the availability of HIV/AIDS services for American Indians and Alaska Natives in the same state, we also visited Tucson.

To examine the extent to which IHS provides HIV/AIDS treatment services, we generally conducted the same activities that we used to examine prevention services. Most of the area officials were able to provide detailed information about the HIV/AIDS services for American Indians and Alaska Natives in their area. We conducted additional interviews with HIV/AIDS service providers both within and outside of IHS in three areas: Albuquerque, in order to gain additional information about the HIV/AIDS services in Colorado; Nashville, because the area provides services in parts of 14 states; and Phoenix, in order to gain additional information about HIV/AIDS services in Nevada. For example, we interviewed IHS physicians with experience treating patients with HIV/AIDS and staff at IHS-funded facilities and Ryan White-funded facilities that treated American Indians and Alaska Natives patients with HIV/AIDS. IHS officials and representatives from the National Native American AIDS Prevention Center helped us to identify these providers. In addition, we used data from HRSA, which administers the Ryan White program, in order to identify Ryan White-funded facilities that provided services to American Indians and Alaska Natives.

To examine what other HIV/AIDS-related initiatives IHS has undertaken, we reviewed relevant IHS documents and data on HIV/AIDS. We also interviewed IHS headquarters officials and those in the area offices knowledgeable about IHS's HIV/AIDS-related initiatives.

The information presented in this report is intended to provide a general description of HIV/AIDS prevention and treatment services available to American Indians and Alaska Natives through IHS. IHS does not routinely collect data or create reports on HIV/AIDS and generally cannot track spending or services provided specifically for HIV/AIDS. Moreover, tribes generally are not required to report detailed information to IHS about the

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health services they provide or facilities they operate using IHS funds.<sup>8</sup> Due to these data limitations, we relied on interviews with the area offices. For each interview, we used a 21-item question set that contained open-ended questions. The area officials we interviewed provided varying levels of detail to answer our questions, with six conducting brief surveys of some of the facilities in their areas to provide information for GAO, while others relied on their general knowledge. Because our questions were open-ended, we cannot be sure that officials provided a complete list of all services or activities they provide. Thus our information from these interviews is illustrative only. We did not independently validate the information provided by the area offices or contained in documents obtained from IHS officials. However, we discussed any questions we had about the information we received with the officials. We conducted our work from September 2006 through November 2007 in accordance with generally accepted government auditing standards.

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## Results in Brief

Although HIV/AIDS prevention services were generally available from IHS, these services varied across the 12 IHS areas. HIV/AIDS education was provided in all areas in a variety of settings, such as IHS-funded facilities, schools, health fairs, and prisons. For example, two tribal health educators said that they play a quiz show about HIV with youth. In addition to education, IHS offered HIV testing services in all areas; however, the type and extent of services varied. IHS officials reported that HIV testing was offered primarily to pregnant women and those at high risk for HIV/AIDS. In addition, some IHS area officials described other services that were provided as part of their HIV/AIDS prevention activities, including partner notification and condom distribution.

While some IHS facilities provided HIV/AIDS treatment services, area officials reported that most American Indians and Alaska Natives with HIV/AIDS received services outside of IHS. Five IHS-funded hospitals regularly treated patients and had staff dedicated to providing HIV/AIDS treatment. For example, the Phoenix Indian Medical Center had staff such

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<sup>8</sup>In general, tribes that receive funds from IHS to operate health facilities are required only to submit to the single-agency audit requirements of 31 U.S.C. §§ 7501-07. *See* 25 U.S.C. § 450c; 25 C.F.R. § 900.3(a)(6); 42 C.F.R. § 137.165. In addition, IHS may negotiate with the tribes to require additional reporting as part of any funding agreement. Finally, certain funding arrangements require tribes to submit an annual report on health status and service delivery; however, these reports are not intended to be a quality assessment or monitoring tool and the contents of the reports are negotiated by IHS and the tribes. *See* 42 C.F.R. §§ 137.200-137.207.

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as a physician experienced in treating HIV/AIDS and an HIV clinical pharmacist providing HIV/AIDS treatment services. Although some other IHS facilities provided limited treatment services, most IHS facilities relied on outside providers to deliver treatment services. For example, IHS patients with HIV/AIDS might see a specialist outside of IHS quarterly for their HIV/AIDS treatment services and an IHS provider for other health care needs. Area officials reported that most IHS facilities did not provide treatment services because they had few American Indian and Alaska Native patients known to have HIV/AIDS, had limited resources, focused on other health concerns, or their providers had limited training or experience treating the disease. Additionally, some patients may not access or continue treatment from IHS or outside providers for reasons such as concerns about others learning of their HIV status or lack of transportation to distant facilities.

IHS has undertaken outreach and planning, capacity building, and surveillance initiatives related to HIV/AIDS, which are overseen by national and area-level officials. IHS's outreach and planning initiatives include an HIV/AIDS program Web site; an HIV listserv, which e-mails information to those working with American Indians and Alaska Natives with HIV/AIDS; and a national HIV/AIDS administrative work plan. IHS also has carried out several initiatives aimed at building the capacity of providers to offer HIV/AIDS-related prevention and treatment services, such as training of health care providers and implementation of an HIV/AIDS-related data system, which can send providers reminders when patients with HIV/AIDS need care. Additionally, IHS has undertaken initiatives related to improving the surveillance of HIV/AIDS in the American Indian and Alaska Native populations by developing a prenatal HIV screening measure and an early detection surveillance system.

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## Background

For fiscal year 2007, IHS projected a user population<sup>9</sup> of about 1.5 million individuals, or about 35 percent of the population who identified themselves as American Indian or Alaska Native in the 2000 U.S. Census.<sup>10</sup>

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<sup>9</sup>IHS defines its user population as the number of American Indians and Alaska Natives, residing within an IHS service delivery area, with at least one visit during the prior 3 fiscal years.

<sup>10</sup>According to the 2000 U.S. Census, American Indians and Alaska Natives represented 1.5 percent of the U.S. population—about 4.1 million individuals. Of the 4.1 million, about 2.5 million self-identified as solely American Indian or Alaska Native and about 1.6 million self-identified as both American Indian or Alaska Native and part of one or more other racial group.

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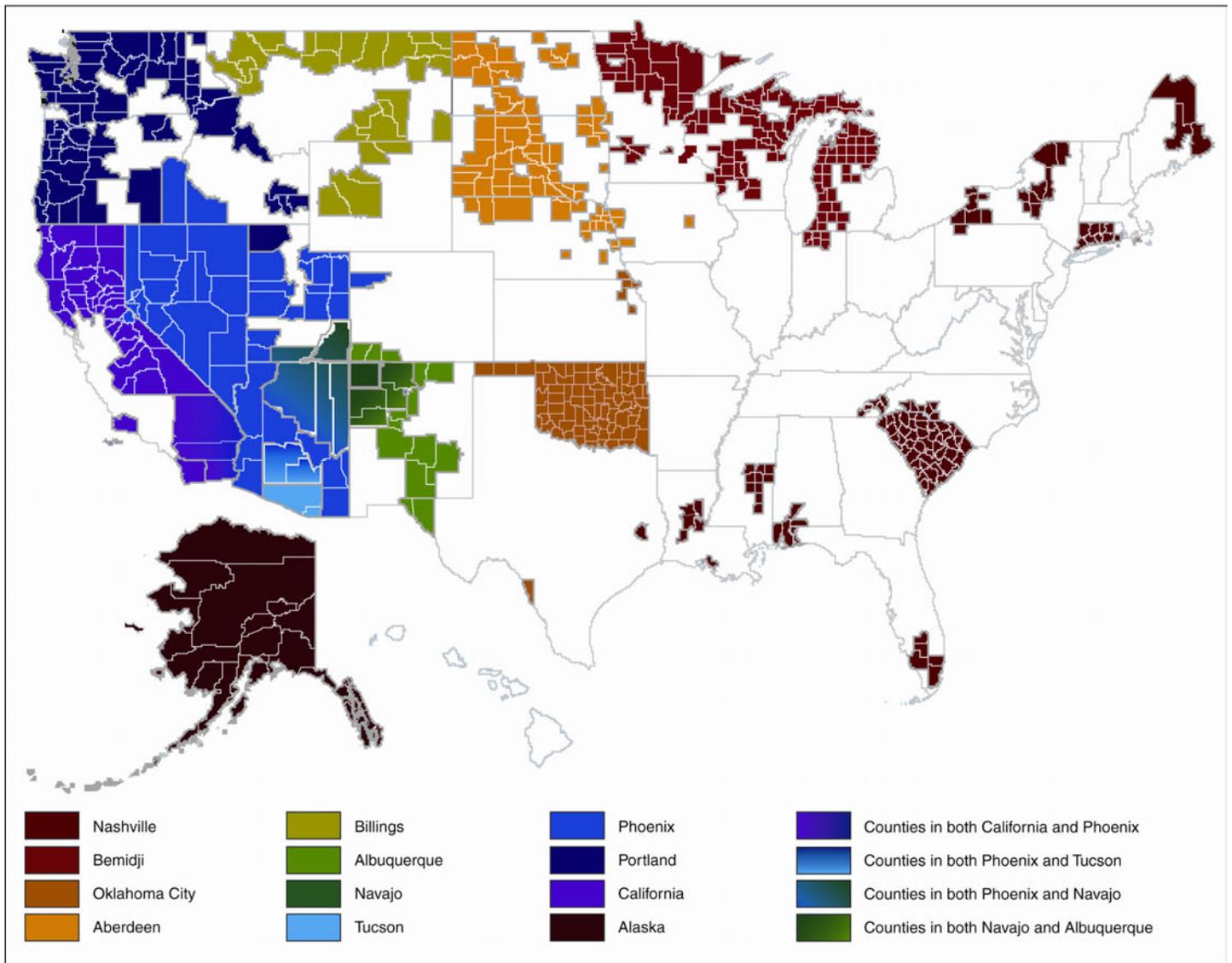
Not all persons self-identifying as American Indians and Alaska Natives in the U.S. Census are members of federally recognized tribes or descendants of such members; therefore they are not all eligible for IHS services. However, more than half of the federally recognized American Indian and Alaska Native population does not permanently reside on a reservation and therefore may have limited or no access to IHS services because of their distance from IHS-funded facilities.

In addition to its headquarters in Rockville, Maryland, IHS consists of a system of IHS-funded facilities organized into 12 geographic areas of various sizes and containing different types of facilities. Each of the 12 areas has an area office, an administrative body that may include an area director, a chief medical officer, and other staff who oversee the area's budget and programs. See figure 1 for a map of the counties included in the 12 IHS areas. These facilities are IHS-operated, tribally operated, or overseen by the UIHP.<sup>11</sup> IHS areas include more than 650 of these IHS-funded health care facilities, including hospitals, health centers, health stations, and UIHP facilities. These facilities mainly offer primary care to small, rural populations, with a limited number of larger health care facilities providing specialty care, such as treatment of HIV/AIDS. The types of facilities in each area vary. For example, the California area has no IHS-funded hospitals, while the Aberdeen area has nine small hospitals. The estimated IHS user population in each of the 12 areas ranges from about 24,000 to about 310,000 (see table 1).

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<sup>11</sup>Under the federal laws governing health services for Indians, tribes have three options for receiving their health care: (1) directly from IHS; (2) through contracting with IHS to have the administrative control, operation, and funding for health programs transferred to American Indian and Alaska Native tribal governments; or (3) through compacting with IHS and assuming even greater control and autonomy for the provision of their own health care services. *See* 25 U.S.C. §§ 1601-1683; 25 U.S.C. §§ 450 et seq.

**Figure 1: Counties in the 12 IHS Areas**



Source: GAO-05-789 and GAO analysis of additional IHS information, as of June 2007.

Note: Some counties are included in more than one IHS area. This occurs in the IHS areas of Albuquerque, California, Navajo, Phoenix, and Tucson.

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**Table 1: IHS User Population by IHS Area**

IHS area	Estimated IHS area user population, 2006
Aberdeen	118,347
Alaska	130,682
Albuquerque	86,504
Bemidji	98,825
Billings	70,384
California	74,248
Nashville	47,379
Navajo	236,893
Oklahoma City	309,542
Phoenix	150,886
Portland	100,395
Tucson	24,164

Source: IHS.

For fiscal year 2006, Congress appropriated approximately \$2.7 billion to IHS to primarily provide direct care at IHS-funded facilities and to purchase care outside of IHS through contracts.<sup>12</sup> From this appropriation, IHS also funds public health nursing, health education, and other functions. In addition, in fiscal year 2006, IHS received reimbursements of \$681 million from Medicare, Medicaid, and private health insurance, with Medicare and Medicaid contributing almost 90 percent of those reimbursements. These reimbursements were for treatment at IHS-funded facilities of patients who were eligible for Medicare and Medicaid, in addition to IHS health care.<sup>13</sup> More than 50 percent of IHS's budget supports tribally operated facilities and around 1 percent supports UIHP facilities. Out of the total appropriated for services, approximately \$500 million was designated for contract health services.<sup>14</sup> For services

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<sup>12</sup>In addition, the appropriation included \$353 million for IHS for the construction, repair, maintenance, improvement, and equipment of health and related facilities.

<sup>13</sup>Tribally operated facilities are also permitted to bill Medicare, Medicaid, and private insurance for reimbursement for services provided. These facilities are generally allowed to retain reimbursements, without an offsetting reduction in their IHS funding, in order to fund health services. *See* 25 U.S.C. §§ 1621f, 1645.

<sup>14</sup>According to IHS, the final total amount appropriated for contract health services in fiscal year 2006 was about \$517 million, which includes funds appropriated for contract medical care and funds appropriated for the Indian Catastrophic Health Emergency Fund.

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that IHS-funded facilities cannot provide, the contract health services funding is used to purchase care for eligible American Indians and Alaska Natives through contracts with outside providers.<sup>15</sup> For example, contract health services money has been used to purchase specialty care that may not be available at a patient's local IHS-funded facility, such as behavioral health care. While IHS tracks the overall costs of providing health services, it does not itemize those costs by disease; therefore the agency does not track the cost for its facilities to provide HIV/AIDS prevention and treatment services.

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## HIV/AIDS Prevention Strategies

According to HHS, efforts are under way—primarily by CDC—to fund prevention programs to educate people at highest risk, as well as the general public, about HIV/AIDS and preventing or reducing their risk. CDC reports that HIV prevention programs can include strategies such as the following.<sup>16</sup>

**HIV testing and counseling.** According to CDC, individuals at risk for HIV should be offered testing and counseling so that they can be aware of their status and take steps to protect their own health and that of their partners. Testing is a key HIV prevention strategy because, as CDC estimates, more than half of HIV infections are transmitted by individuals who are unaware of their infection. Recently available HIV rapid test results are available the same day, in contrast to traditional lab-based testing that can take up to 2 weeks to provide results. Thus rapid testing can help ensure that individuals receive their test result. Moreover, because rapid tests do not require lab facilities or highly trained staff, this type of test can expand access to testing in both clinical and nonclinical settings; however, rapid tests are more expensive than lab-based tests. In addition to testing, counseling services offer patients ways to eliminate or reduce their risk for HIV infection.

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<sup>15</sup>To be eligible for contract care, an American Indian or Alaska Native generally must already be eligible for IHS direct services, reside within a county that is part of one of the 12 IHS areas, and either (1) reside on a reservation within the area or on certain traditional American Indian or Alaska Native lands, or (2) belong to or maintain close economic and social ties with a tribe based on such a reservation. Contract care funds may only be used to pay for services when patients are unable to obtain such services through other sources, including Medicare, Medicaid, or private insurance.

<sup>16</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *Comprehensive HIV Prevention: Essential Components of a Comprehensive Strategy to Prevent Domestic HIV 2006* (Atlanta, Ga: 2006).

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**Partner notification.** Sexual or needle-sharing partners of HIV-positive individuals have been exposed to HIV and may be infected. Partner notification services attempt to locate these individuals based on information provided by the patient to provide counseling, education, and other services to prevent infection or, if the individual is infected, provide referrals to care.

**Health education and risk reduction.** Health education provides individuals with the skills and information necessary to avoid or reduce behaviors that put them at risk for HIV infection. Health education services can include individual, group, school, and community interventions, as well as outreach to HIV-positive individuals and HIV-negative individuals at high risk. These services can also include health communication and public information programs for individuals at high risk and the general public. Risk reduction activities can include condom distribution and needle exchange programs.

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## HIV/AIDS Treatment Strategies and Barriers to Care

HHS issues guidelines for the medical management of HIV and issues surrounding HIV infection.<sup>17</sup> The guideline documents are periodically reviewed and updated by panels of HIV experts, because concepts relevant to management of HIV change rapidly. The recommended treatment for HIV is a combination of three or more drugs, called Highly Active Antiretroviral Therapy (HAART). HAART is used to slow the progression of HIV/AIDS and has reduced the number of HIV/AIDS deaths, but it may have side effects and requires adherence to complicated drug regimens. Additionally, although these drugs can treat HIV infection, HIV cannot be cured. A 2004 Kaiser Family Foundation report estimated the annual cost for providing these drugs was between \$10,000 and \$12,000 per patient.

Beyond drug regimens, patients with HIV/AIDS may require additional specialized care. According to CDC, proper management of HIV/AIDS involves a complex array of behavioral, psychosocial, and medical services, and therefore referral to a health care provider or facility experienced in caring for HIV-infected patients is advised. Treatment must be tailored to the patient's needs and may include mental health services, substance abuse services, and medical case management, including

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<sup>17</sup>These guidelines are available on HHS's AIDSInfo Web site, which provides information on HIV/AIDS prevention, treatment, and research, at <http://aidsinfo.nih.gov/Guidelines/Default.aspx?MenuItem=Guidelines> (downloaded September 27, 2007).

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treatment adherence services. Patients with HIV/AIDS may also require support services, such as housing or transportation assistance.

Patients with HIV/AIDS may face barriers to care. A 1998 study reported that patients with HIV/AIDS in both rural and urban areas experienced barriers to treatment services including a lack of knowledge about the disease, insufficient financial resources, and a lack of employment opportunities.<sup>18</sup> Moreover, the study found that patients with HIV/AIDS in rural areas—compared to their urban counterparts—reported significantly greater need to travel long distances to medical facilities and personnel; a shortage of adequately trained medical and mental health professionals; a lack of personal or public transportation; and community stigma toward people living with HIV.

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## American Indians and Alaska Natives and HIV/AIDS

American Indians and Alaska Natives suffer from HIV/AIDS at higher rates than whites and from a range of other medical conditions at higher rates than the general population. CDC estimated that in 2005, a total of 1,581 American Indians and Alaska Natives were living with AIDS in the 50 states and the District of Columbia. CDC's 2005 surveillance data also showed that of individuals diagnosed with AIDS from 1997 through 2004, American Indians and Alaska Natives died sooner after diagnosis than did individuals of all other races and ethnicities except blacks.<sup>19</sup> In addition, women accounted for 24 percent of the estimated numbers of American Indians and Alaska Natives living with AIDS in 2005, compared with 12.5 percent for whites. The data also showed that the 10 states with the highest number of American Indians and Alaska Natives living with AIDS in 2005 were: (1) California, (2) Arizona, (3) Oklahoma, (4) Washington, (5) New York, (6) Alaska, (7) North Carolina, (8) New Mexico, (9) Minnesota, and (10) Texas.<sup>20</sup> CDC's estimate of the number of American Indians and Alaska Natives living with AIDS in the 12 IHS areas, which do not cover the entire United States, was 872 in 2005 (see table 2).

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<sup>18</sup>Heckman et al., "Barriers to care among persons living with HIV/AIDS in urban and rural areas," *AIDS Care* 10 (1998): 365-375.

<sup>19</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States and Dependent Areas, 2005*, vol.17 (Atlanta, Ga: 2007).

<sup>20</sup>*Distribution of persons estimated to be living with AIDS by race/ethnicity at the end of 2005*, [www.statehealthfacts.org](http://www.statehealthfacts.org) (October 3, 2007). CDC provided these data to the Kaiser Family Foundation as a special request.

**Table 2: Estimated Number of American Indians and Alaska Natives Living with AIDS, by IHS Area**

<b>IHS area<sup>a</sup></b>	<b>Estimated number of American Indians and Alaska Natives living with AIDS, 2005<sup>b</sup></b>
Aberdeen	26
Alaska	78
Albuquerque	67
Bemidji	23
Billings	12
California	104
Nashville	56
Navajo	61
Oklahoma City	149
Phoenix	142
Portland	135
Tucson	19
<b>Total in IHS areas<sup>c</sup></b>	<b>872</b>

Source: CDC.

Notes: CDC assigned the cases of American Indians and Alaska Natives living with AIDS to IHS area by using county codes supplied by GAO. A county can only be included a single time in only one area; the national HIV/AIDS surveillance data cannot be analyzed at a lower geographic division than the county level. Therefore, CDC made some arbitrary decisions when counties were listed across areas. This occurred in the Albuquerque, California, Navajo, and Phoenix areas.

<sup>a</sup>The 12 IHS areas cover all or part of 35 states.

<sup>b</sup>CDC's estimated number of American Indians and Alaska Natives living with AIDS does not differentiate between IHS-eligible and non-IHS-eligible American Indians and Alaska Natives.

<sup>c</sup>CDC estimated that 1,581 American Indians and Alaska Natives were living with AIDS in the 50 states and the District of Columbia in 2005.

HIV/AIDS is one of many health concerns facing American Indians and Alaska Natives. While American Indians and Alaska Natives have the third highest rate of HIV/AIDS after blacks and Hispanics, the disease is not one of the top 10 leading causes of death for this population. Some of the major health concerns facing the population include diabetes; heart, liver, and cardiovascular diseases; cancer; unintentional injuries; obesity; substance abuse; and suicide. Given these numerous health concerns, as well as challenges related to poverty and unemployment, the National Alliance of State & Territorial AIDS Directors report that making HIV/AIDS a priority is often difficult for many American Indian and Alaska Native communities.

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Although HIV/AIDS is not among the major health concerns for the population, American Indians and Alaska Natives experience high rates of risk factors for HIV infection, such as sexually transmitted diseases and poverty-related conditions. According to 2005 CDC surveillance data by race or ethnicity, American Indians and Alaska Natives had the second highest rates of gonorrhea and chlamydia and the third highest rate of syphilis.<sup>21</sup> CDC notes that these rates suggest that the sexual behaviors that facilitate the spread of HIV are relatively common among American Indians and Alaska Natives.<sup>22</sup> In addition to sexually transmitted diseases, alcohol and drug abuse—which are prevalent in the American Indian and Alaska Native community—are risk factors for HIV transmission. Moreover, conditions related to poverty, such as lower levels of education and poorer access to health care, may increase the risk for HIV infection. During 2002 through 2004, approximately one quarter of American Indians and Alaska Natives—about twice the national average—were living in poverty.<sup>23</sup> American Indians and Alaska Natives also have poorer access to health care than other racial and ethnic groups, with 21 percent of American Indians and Alaska Natives lacking a usual source of medical care, compared to 18 percent of whites in 2004.<sup>24</sup>

Furthermore, American Indians and Alaska Natives may be less likely to be tested for HIV than persons of other racial and ethnic groups because of location and confidentiality concerns. For example, those who live in rural areas may be less likely to be tested for HIV because of limited access to testing. While access to preventive services, such as testing, is a problem for rural populations in general, more American Indians and Alaska Natives, compared with persons of other races and ethnicities, resided in rural areas at the time of their AIDS diagnosis.<sup>25</sup> Also, American Indians and Alaska Natives may be less likely to seek testing because of concerns about confidentiality in close-knit communities, where someone

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<sup>21</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *Sexually Transmitted Disease Surveillance 2005* (Atlanta, Ga: 2006).

<sup>22</sup>Sexual behaviors that facilitate the spread of HIV include having unprotected sex with men who have sex with men, multiple partners, or anonymous partners.

<sup>23</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS among American Indians and Alaska Natives* (Atlanta, Ga: 2007).

<sup>24</sup>National Center for Health Statistics, *Health, United States, 2006 With Chartbook on Trends in the Health of Americans* (Hyattsville, Md: 2006).

<sup>25</sup>U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS among American Indians and Alaska Natives* (Atlanta, Ga: 2007).

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who seeks testing is likely to encounter a friend, relative, or acquaintance at the local health care facility.

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### American Indians and Alaska Natives May Access Services outside of IHS

Many American Indians and Alaska Natives have health insurance coverage and may choose to access services outside of IHS. According to IHS, about 55 percent of the IHS user population has some form of public or private coverage. Of this, about 43 percent are eligible for Medicaid or Medicare. Depending on their eligibility and resources, American Indians and Alaska Natives may have access to health care at facilities available to the general population, such as public or private hospitals and community health centers.

For HIV/AIDS care, American Indians and Alaska Natives may also access services at Ryan White-funded facilities. The Ryan White Program provides funding to states, territories, metropolitan areas, and other public or private nonprofit entities to provide health care, medications, and support services to more than 500,000 medically underserved individuals and families affected by HIV or AIDS, including American Indians and Alaska Natives.<sup>26</sup> Specifically, services include outpatient medical and dental care, prescription drugs, case management, home health care, and hospice care.

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### IHS HIV/AIDS Prevention Services Generally Were Available, but Varied Across Areas

IHS area officials reported that HIV/AIDS prevention services were generally available in all 12 areas. HIV/AIDS education was available in every IHS area. Testing services were also available in every IHS area, though the type and extent of the services varied. In addition to education and testing services, officials in some areas mentioned that some facilities provided other services as part of their HIV/AIDS prevention activities, such as condom distribution and partner notification.

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### HIV/AIDS Education Was Provided in All Areas

Officials from IHS area offices reported that HIV/AIDS education services were offered in all 12 areas. Education was provided by a variety of staff, including practitioners, such as physicians and nurses, during medical appointments; tribal health educators; and community health

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<sup>26</sup>GAO has published several products on the Ryan White program. See Related GAO Products at the end of this report.

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representatives,<sup>27</sup> in various settings, including IHS-funded facilities, tribal health departments, schools, health fairs, and prisons. For example, one provider said that she held bingo nights at an UIHP facility, beginning the evening with an HIV education speaker or presentation. Two tribal health educators and an UIHP official said that they played quiz show games with youth to teach them about HIV/AIDS.

IHS officials and tribal health educators noted that HIV/AIDS education materials were available; however, there were challenges with using these materials. Officials in four areas—Albuquerque, Oklahoma City, Portland, and Tucson—noted concerns with the cultural appropriateness of HIV/AIDS education materials. Two tribal health educators reported using materials from sources outside of IHS, such as the American Red Cross and Advocates for Youth; however, they modified their presentations to make them more appropriate and easy to understand.<sup>28</sup> For example, the tribal educators mentioned that they modified the wording of an HIV prevention curriculum’s activity to make it more relevant to their groups. Additionally, one area official said that educators had to revise the materials to a reading level where they could be understood by the target audience. Despite these education efforts, some IHS officials and advocacy groups noted that misconceptions about HIV/AIDS remained among some in the American Indian and Alaska Native community—for example, that the disease could be contracted from a toilet seat or that only men who have sex with men could become infected.

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### Some HIV Testing Services Were Available in All Areas, but Type and Extent of Services Varied

According to IHS officials and service providers, HIV testing services were offered in all 12 IHS areas, but some officials said that services were not available at all facilities. Additionally, the type of testing that was available varied. IHS officials reported that HIV testing was offered primarily to pregnant women and those at high risk for HIV/AIDS. IHS HIV testing services included both lab-based and rapid tests, with officials in 9 IHS areas—Aberdeen, Alaska, Albuquerque, Billings, California, Nashville, Oklahoma City, Phoenix, and Portland—reporting that rapid testing was

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<sup>27</sup>The Community Health Representatives program is an IHS-funded and primarily tribally operated program of community-based health care workers who provide health promotion and disease prevention services in their communities.

<sup>28</sup>CDC notes that, to be effective, HIV/AIDS prevention interventions must be tailored to specific audiences. Each of the 562 federally recognized tribes has its own culture, beliefs, practices, and sometimes languages, making it challenging to create programs for each tribe.

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available in one or more of their facilities. IHS officials reported advantages to rapid testing, including the ability to test pregnant women who were in labor or patients presenting in emergency rooms, and to provide quick results to patients at high risk who are unlikely to return to the facility to receive the results from lab-based tests. Officials in three areas—Aberdeen, Phoenix, and Tucson—reported that some patients do not return to pick up their lab-based HIV test results. However, some IHS officials reported that cost was a barrier to adopting the more expensive rapid testing and that staff required additional training to administer the tests. To address this concern, one area reported providing funding for training on rapid HIV testing for clinical staff.

Although testing services were available to some extent in all areas, some IHS officials and advocacy groups expressed concern that some American Indians and Alaska Natives were not being tested for HIV. Officials in one area reported that some IHS health care providers may not feel comfortable discussing sexuality, and as a result they may not offer testing to patients in groups at high risk. An official in another area reported that, given more prevalent health concerns, providers did not always discuss HIV/AIDS. An official in a third area said that, while IHS-funded facilities offer testing, there was still a segment of the population who were not tested until they showed symptoms of HIV. In addition, according to IHS officials and advocacy groups, some American Indians and Alaska Natives did not seek or declined testing within IHS due to lack of awareness about the disease, confidentiality concerns, and stigma surrounding the disease. For example, one UIHP facility staff member said that she usually referred individuals to the county health department for HIV testing because the facility's clients were afraid that their test results would be revealed to IHS staff, many of whom the patients know. An official at one organization that provides case management to American Indians and Alaska Natives reported that some patients did not seek testing because there was a local belief that by being tested one was wishing the disease on oneself.

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## Other Prevention Services Were Provided

In addition to HIV testing and education services, IHS officials described some other services that were provided as part of their HIV/AIDS prevention activities. Some IHS officials mentioned that IHS facilities were involved in partner notification. For example, an official from one area said that public health nurses notified partners of patients with HIV and other sexually transmitted diseases, followed up with the partners about their testing needs, and provided additional counseling. In addition, officials in some areas mentioned that facilities in their areas distributed condoms as part of their HIV/AIDS prevention activities. For example, a

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provider in one area made condoms available in every exam room at the IHS facilities in the area so that patients were no longer ashamed or embarrassed about seeing, taking, or asking about condoms. Finally, officials in two areas mentioned that tribes in their area had a needle exchange program.

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### Some IHS Facilities Provided HIV/AIDS Treatment Services, but Most American Indians and Alaska Natives Received Services from Outside Providers for a Variety of Reasons

While some IHS facilities offered HIV/AIDS treatment services, area officials reported that most patients received treatment from providers at facilities outside of IHS. Five IHS-funded hospitals regularly treated patients and had staff dedicated to providing HIV/AIDS treatment. While other facilities provided limited HIV/AIDS treatment, most relied on outside providers, such as Ryan White-funded facilities or local hospitals. Area officials reported that some patients with HIV/AIDS may not access or continue treatment due to a variety of reasons, including lack of transportation.

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### Five IHS Facilities Regularly Treated Patients with HIV/AIDS

Of the more than 45 IHS-funded hospitals, officials from IHS headquarters and facilities identified 5 hospitals that regularly treated patients with HIV/AIDS. According to IHS headquarters, 3 facilities have committed the most resources to sustaining HIV/AIDS treatment services: the Alaska Native Medical Center in the Alaska area, the Gallup Indian Medical Center in the Navajo area, and the HIV Center of Excellence at the Phoenix Indian Medical Center in the Phoenix area. For example, the Phoenix Indian Medical Center had staff such as a physician experienced in treating HIV/AIDS and an HIV clinical pharmacist providing HIV/AIDS treatment services. IHS officials reported that treatment services were also regularly provided at 2 other IHS facilities: the Albuquerque Indian Hospital in the Albuquerque area and the W.W. Hastings Indian Medical Center in the Oklahoma City area. These 2 facilities each relied on one physician who regularly treated patients with HIV/AIDS. Both physicians reported seeing patients with HIV/AIDS for over 15 years and continue to provide services to patients.

Officials from all five of the facilities that regularly treated patients with HIV/AIDS said that some patients received HIV/AIDS services from outside providers. In some cases, the IHS facilities coordinated with outside providers for some HIV/AIDS services. For example, patients at the Gallup

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Indian Medical Center and the Albuquerque Indian Hospital received case management services outside of IHS. The Gallup Indian Medical Center worked with staff from the Navajo AIDS Network, an organization that provides case management services—including in the Navajo language—to American Indians and Alaska Natives with HIV/AIDS. In addition, the Phoenix Indian Medical Center’s HIV pharmacist arranged for Medicaid-eligible patients to receive their HIV drugs by mail through a pharmacy outside of IHS.

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### Other IHS Facilities Provided Limited HIV/AIDS Treatment, but Most Referred Patients to Outside Providers

Several area officials reported that some of the other IHS facilities provided limited HIV/AIDS treatment services, but most facilities referred patients to outside providers. For example, some facilities had physicians with experience treating HIV/AIDS or provided case management services to patients with HIV/AIDS. According to officials from five areas—Aberdeen, Alaska, Bemidji, Nashville, and Oklahoma City—the facilities that provided HIV/AIDS treatment services were generally larger IHS-funded facilities, particularly hospitals. For example, IHS reported that at least 13 physicians with experience treating HIV/AIDS worked at IHS hospitals other than the five facilities that regularly provided care. At some facilities that did not regularly offer HIV/AIDS treatment services, staff made efforts to provide care when needed. For example, officials in two areas—Albuquerque and Bemidji—reported that staff at a facility in their area had used a hotline to obtain HIV/AIDS treatment information. In addition, one UIHP facility in the California area, which has no IHS-funded hospitals, contracted with an HIV/AIDS specialist outside of IHS to provide treatment services at the facility once a week. However, officials reported that none of the other facilities in the area provided HIV/AIDS treatment services.

Officials from all 12 areas reported that some patients with HIV/AIDS were treated outside of IHS, citing a variety of settings. Officials in 8 areas—Aberdeen, Alaska, Albuquerque, Billings, Nashville, Oklahoma City, Phoenix, and Tucson—reported that patients in their areas received care from Ryan White-funded facilities. According to HRSA, in 2005 more than 950 of the 2,463 Ryan White-funded facilities across the United States provided services to one or more American Indians or Alaska Natives with HIV/AIDS. In addition, IHS officials noted that American Indians and Alaska Natives may receive HIV/AIDS treatment services from local hospitals or from physicians in private practice. Some patients who receive HIV/AIDS treatment outside of IHS may continue to receive other types of health care from IHS-funded facilities. For example, one IHS official reported that these patients might see a specialist quarterly or once

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a year for their HIV/AIDS treatment services and an IHS provider for routine care. An official for another area reported that of those patients referred to other providers for HIV/AIDS services, most stay with their IHS-funded facility for their other health care services.

IHS area officials noted several reasons why IHS-funded facilities in their areas did not provide HIV/AIDS treatment services.

**Too few patients and limited experience.** Officials for six areas—Albuquerque, Bemidji, California, Nashville, Oklahoma City, and Portland—reported that some facilities did not provide treatment because they did not have any patients known to have the disease. Officials for eight areas—Aberdeen, Albuquerque, Bemidji, Billings, Oklahoma City, Phoenix, Portland, and Tucson—reported that providers’ lack of training or experience related to HIV/AIDS were reasons why HIV/AIDS treatment was not provided at some facilities. Chief medical officers from four of the eight areas cited frequently changing HIV/AIDS treatment protocols as a reason why providers might not feel comfortable treating the disease.

**Allocation of limited resources.** Officials for 10 areas—Aberdeen, Albuquerque, Bemidji, Billings, California, Nashville, Oklahoma City, Phoenix, Portland, and Tucson—cited limited IHS resources, such as funding or staff, as a reason for referring patients outside IHS. Officials for 4 of the 10 areas said that, given IHS’s limited resources, including limited staff, and the availability of HIV/AIDS services outside of IHS, they preferred to refer patients to outside providers rather than provide HIV/AIDS treatment services in-house. In addition, officials in 4 of the 10 areas reported that their pharmacies do not provide HAART because of the high cost of the HIV/AIDS drugs or because too few patients seek those drugs from IHS.

**Other health concerns.** Officials in six areas—Alaska, Bemidji, Billings, Oklahoma City, Portland, and Tucson—mentioned that their areas have other health concerns that take precedence over HIV/AIDS. Among the other more prevalent health concerns mentioned were unintentional injuries and diabetes. Moreover, while area officials listed diabetes, accidents, and heart disease as some of the 10 leading causes of death in their area, only the California area officials listed HIV/AIDS as one of the 10 leading causes of death in their area. See appendix I for the reasons why IHS-funded facilities did not provide HIV/AIDS treatment services, by area.

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## Some American Indians and Alaska Natives with HIV/AIDS May Not Access or Continue Treatment

IHS area officials and facility providers noted that some American Indians and Alaska Natives with HIV/AIDS may not access or continue care, even if treatment is available, for reasons such as concerns about confidentiality and lack of transportation. Officials in the 12 IHS areas reported that patients' concerns with confidentiality and stigma in close-knit communities were reasons why some patients did not access care from IHS. Officials from 7 areas—Aberdeen, Alaska, Bemidji, California, Navajo, Oklahoma City, and Portland—reported that some patients with HIV/AIDS were concerned that their friends or relatives who work or access services at IHS would learn about their HIV status. For example, an official for one rural area said that in villages many people are related to IHS community health aides and other service providers, which increases patients' reluctance to disclose their HIV status and seek HIV/AIDS treatment services. Officials in 7 areas—Alaska, Albuquerque, Bemidji, Billings, Oklahoma City, Phoenix, and Tucson—mentioned that distance to HIV/AIDS treatment services or lack of transportation may affect American Indians' and Alaska Natives' ability to access care. Officials in one area reported knowing of an isolated region in one state in the area that had “clear unmet needs” because it was located 300 miles from any facilities—IHS or otherwise—with HIV/AIDS treatment services. In one urban area, an official reported that relying on public transportation was a barrier to treatment because it can be unreliable and unaffordable for many clients. Area officials in Albuquerque, Phoenix, and Navajo said that patients may not access treatment because of cultural reasons. One official noted that traditional healing practices may take priority over western medicine. In addition, this official noted that, in some communities, family obligations may also take priority over treatment. For example, he said that a patient may miss an appointment because he or she chose to be with a sick family member in another state.

Some area officials reported that there were other factors that could affect a patient's continuation of HIV/AIDS treatment, such as alcohol or drug abuse or lack of housing. Officials for five areas—Alaska, Albuquerque, Navajo, Phoenix, and Tucson—cited concerns with patients with HIV/AIDS adhering to their treatment programs, partly due to substance abuse. In addition, officials for two IHS-funded facilities noted that housing can be of concern. For example, one of the facility officials said that an HIV-positive patient from a small community moved to a nearby city because the patient's home lacked both heat and water, compromising the patient's health. See appendix I for the reasons why American Indians and Alaska Natives with HIV/AIDS did not access or continue HIV/AIDS treatment services, by area.

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## IHS Has HIV/AIDS Outreach and Planning, Capacity Building, and Surveillance Initiatives

IHS has undertaken outreach and planning, capacity building, and surveillance initiatives related to HIV/AIDS. These initiatives are overseen by national and area-level officials. IHS's outreach and planning initiatives include an HIV/AIDS program Web site, an HIV listserv, and a national HIV/AIDS administrative work plan. IHS has also carried out several initiatives aimed at building the capacity of its providers to offer HIV/AIDS-related prevention and treatment services, such as training of health care providers and implementation of an HIV-related data system. Additionally, IHS has undertaken initiatives related to improving the surveillance of HIV/AIDS in the American Indian and Alaska Native population by developing a prenatal HIV screening measure and an early detection surveillance system.

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## IHS HIV/AIDS Initiatives Oversight

IHS initiatives related to HIV/AIDS are overseen by a national IHS HIV/AIDS program official or by officials at the area level. The national program is coordinated by an HIV/AIDS principal consultant, the only full-time staff member dedicated to these initiatives. Program initiatives are often conducted in collaboration with other IHS personnel and are supported by IHS<sup>29</sup> and outside funding sources, such as the Minority AIDS Initiative.<sup>30</sup> These additional IHS personnel who support IHS's HIV/AIDS initiatives do so in addition to other full-time duties. At the area level, HIV/AIDS initiatives are often conducted as part of broader health promotion and disease prevention programs. Officials in five areas reported having staff who acted as area HIV/AIDS coordinators, but few of those staff worked full-time on HIV/AIDS and all had other duties, such as

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<sup>29</sup>The IHS headquarters budget includes funds for HIV/AIDS—about \$425,000 in fiscal year 2006. However, tribes have the option to take the HIV/AIDS program funds to directly provide HIV/AIDS services. Any funds not taken by the tribes are available for use by the headquarters HIV/AIDS program. The amount taken by the tribes varies from year to year. In fiscal year 2006, there was about \$13,000 left after tribal shares were used.

<sup>30</sup>The Minority AIDS Initiative was created in 1998 in response to growing concern about the effect of HIV/AIDS on racial and ethnic minorities in the United States. The initiative's principal goals are to improve HIV-related health outcomes for racial and ethnic minority communities disproportionately affected by HIV/AIDS and reduce HIV-related health disparities. It does this by providing new funding designed to strengthen organizational capacity and expand HIV-related services in minority communities. Administration of the Minority AIDS Initiative is decentralized across eight federal agencies and offices, primarily within HHS. IHS does not receive an annual budget assignment of Minority AIDS Initiative funds; instead, IHS submits annual proposals to HHS's Office of HIV/AIDS Policy in Washington, D.C. each November. The Minority AIDS Initiative office then grades the proposals and notifies the IHS HIV/AIDS principal consultant of the amount of funds to be distributed.

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providing behavioral health education or acting as a consultant for other diseases.

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## Outreach and Planning Initiatives

IHS has undertaken several outreach and planning initiatives, including an HIV/AIDS program Web site, an HIV listserv, and a national HIV/AIDS administrative work plan.

**Web site.** A public Web site, [www.ihs.gov/MedicalPrograms/HIVAIDS](http://www.ihs.gov/MedicalPrograms/HIVAIDS), contains information on American Indian and Alaska Native-related HIV/AIDS research, HIV/AIDS clinical treatment guidelines, and links to other relevant Web sites, including grant and funding resources. It was launched March 21, 2007, on the first National Native HIV/AIDS Awareness Day. As of July 2007, the Web site had more than 3,500 unique visitors, an average of 36 visits a day, according to an IHS official.

**Listserv.** The HIV/AIDS principal consultant operates an HIV listserv, which e-mails information of general interest to those working with American Indians and Alaska Natives with HIV/AIDS, such as HIV/AIDS-related news, recent research, and funding opportunities. An IHS official reported that the listserv included about 650 individuals, including American Indian and Alaska Native community members and officials from IHS, tribes, and American Indian and Alaska Native advocacy groups.

**HIV/AIDS administrative work plan.** According to IHS, as of September 2007, a national IHS HIV/AIDS administrative work plan was nearing completion. The plan is intended to integrate multiple activities to help improve IHS surveillance, information sharing, and data collection. The plan will determine HIV/AIDS intervention priority areas, describe the activities to be conducted within each priority area, and identify key personnel and organizations with responsibility for each activity. The plan is also intended to be a 3-year administrative blueprint for further development and progression of the HIV/AIDS program. As of September 2007, the plan was in draft form and being circulated both within and outside of IHS for comment. The HIV/AIDS principal consultant said that the work plan would be finalized and issued in the fall of 2007.

**Collaboration with other organizations.** IHS had signed or was developing memoranda of understanding with other organizations, including HRSA and the Substance Abuse and Mental Health Services

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Administration (SAMHSA), on various HIV/AIDS activities.<sup>31</sup> IHS and HRSA have signed a 3-year memorandum of understanding to collaborate on multiple HIV/AIDS initiatives in an effort to decrease duplication of services, increase awareness of common resources, and improve coordination and quality of services to American Indians and Alaska Natives. IHS and SAMHSA were developing a memorandum of understanding to train IHS staff to conduct HIV/AIDS rapid testing. The memorandum was expected to be implemented in early 2008. In addition, six areas reported working with local organizations on HIV/AIDS initiatives. For example, an official in the Aberdeen area reported that the area has an HIV/AIDS task force consisting of clinical providers, community health representatives, and HIV coordinators from state health departments in the Aberdeen area. The taskforce is initiating an HIV strategic plan for the area.

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## Capacity Building Initiatives

IHS also has carried out several initiatives aimed at building the capacity of providers to offer HIV/AIDS-related prevention and treatment services.

**HIV/AIDS collaborative training.** IHS provides HIV/AIDS training for IHS-funded staff in 2-and-1/2-day sessions funded by HHS's Minority AIDS Initiative. Since fiscal year 2005, the sessions have focused on HIV/AIDS behavioral health issues, capacity and partnership building, and related intervention strategies. Topics for training to be conducted during 2007 and 2008 include: reporting, data collection, best practice models, clinical practice issues, prevention policies and procedures, and culturally appropriate pre- and posttest counseling interview techniques. IHS also plans to use this funding to conduct a 1-day Traditional Healers Summit to discuss HIV/AIDS with traditional healers. IHS officials noted this would be the first training of this kind for any disease.

**Training IHS community health representatives.** IHS also received funding from the Minority AIDS Initiative to provide community health representatives with HIV/AIDS-related training.<sup>32</sup> These training sessions will be presented by health care professionals and will teach community health representatives about facts, fears, and public perceptions about

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<sup>31</sup>SAMHSA is the lead federal agency responsible for improving the quality and availability of prevention and treatment services for substance abuse and mental illness.

<sup>32</sup>Community health representatives provide health promotion and disease prevention services in their communities.

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sexually transmitted diseases, including HIV/AIDS. Community health representatives will also be coached on how to present this information on their reservations. These sessions were scheduled to take place in November 2007.

**Area-organized training and conferences.** In addition to training overseen by the IHS HIV/AIDS Program, officials from eight area offices reported offering HIV/AIDS regional training sessions or conferences to tribal leaders, clinical providers, and community members. For example, the Aberdeen area holds an annual conference on HIV/AIDS where attendees learn about local resources, funding resources, and possible partnership opportunities with IHS, the state, and tribes.

**HIV/AIDS telemedicine support network.** With Minority AIDS Initiative funding, the HIV Center of Excellence in the Phoenix Indian Medical Center created an HIV/AIDS telemedicine support network for health care providers in IHS-operated, tribally operated, and UIHP facilities to expand the quality and availability of HIV/AIDS communication, training, support, and expert consultation. An IHS official said that the goal of this network is to increase the availability of HIV/AIDS treatment by providing facilities with access to HIV/AIDS experts and consultants. The network is still in the developmental stages and, according to IHS, is initially being targeted to 16 IHS-funded facilities.

**HIV Management System.** In September 2006, IHS implemented its HIV Management System (HMS), a data system intended to help clinical providers and case managers provide quality care to HIV/AIDS patients and those at risk for the disease. When a facility enters its data into HMS, the system can generate quality-of-care audit reports or send reminders to providers when patients with HIV/AIDS need care. IHS officials could not estimate how many facilities will use HMS, noting that participation is voluntary. As of October 2007, staff from 12 facilities had been trained in how to use the system. HMS originally was funded by the Minority AIDS Initiative; however, IHS did not receive funding for fiscal year 2007 to continue this system. IHS officials said that despite the loss of funding they will continue to support HMS with IHS resources, but that some of their efforts, such as the evaluation of the program, will have to be curtailed. Officials said they plan to reapply for funding for fiscal year 2008.

**Increased HIV testing.** IHS also received funding in fiscal year 2007 from the Minority AIDS Initiative to continue to increase HIV screening at UIHP facilities. Seven awards of approximately \$45,000 will be issued to urban

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facilities in order to enhance HIV testing, including rapid testing and standard lab-based testing, and to provide a more targeted effort to address HIV/AIDS prevention in some of the largest urban American Indian and Alaska Native populations in the United States. This initiative is expected to expand services to patients, build IHS's testing capacity, and collect data about barriers to testing services.

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## Surveillance Initiatives

IHS has undertaken two initiatives to improve surveillance of HIV/AIDS in the American Indian and Alaska Native population.

**Prenatal HIV screening.** In 2005, IHS implemented a new Government Performance and Results Act measure<sup>33</sup> that examines the percentage of pregnant IHS patients screened for HIV in a year.<sup>34</sup> The 2006 target for this measure was 55 percent of IHS's pregnant patients screened for HIV within the last year; the actual percentage of patients screened was 65 percent. For 2007, IHS's target was to ensure that the proportion of pregnant female patients screened for HIV did not decrease more than 1 percent from the 2006 level. For 2007, the percentages of pregnant women screened by IHS ranged from 48 percent to 88 percent among the areas, with an overall screening rate of 74 percent.

**Early detection surveillance system.** With funding from the Minority AIDS Initiative, IHS is developing a national early warning system to detect increases in the rate of HIV infection for American Indian and Alaska Native populations at high risk. This initiative aims to enhance and improve screening for HIV in prenatal populations by examining a sample of IHS facilities from which data are collected electronically. From this sample, IHS wants to be able to detect any changes in the rates of HIV infection among pregnant women. In addition, the initiative includes

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<sup>33</sup>The Government Performance and Results Act of 1993 requires federal agencies to demonstrate that they are using their funds effectively toward meeting their missions. The law requires agencies to have a 5-year strategic plan in place and to submit annual performance plans and reports with their budget requests. *See* 5 U.S.C. § 306 (5-year strategic plan) and 31 U.S.C. § 1115 (annual performance plan). The annual performance plan must contain specific performance measures for that 1-year period. The Government Performance and Results Act year runs from July 1 through June 30.

<sup>34</sup>This measure represents the percentage of pregnant patients screened for HIV at IHS-funded facilities. However, because tribes are not required to report data, this measure reflects data from only those tribally operated facilities that choose to report to IHS. IHS estimates that about 85 percent of patients seen in tribally operated facilities were included in these measures.

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conducting a knowledge, attitude, and practice survey of health care professionals on CDC's new, broader HIV screening guidelines to identify misunderstandings and obstacles and accelerate the adoption of the new guidelines in IHS funded-facilities. An IHS official said that the survey was being developed and was expected to be completed by December 2007. The early surveillance initiative also seeks to analyze the rate of HIV screening among patients who have tested positive for a sexually transmitted disease, patients who have tested positive for other diseases that typically coexist with HIV/AIDS, and unique individuals screened for HIV in order to estimate the proportion of the IHS user population who are aware of their HIV status.

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## Agency Comments and Our Evaluation

We provided a draft of this report to HHS for comments from IHS, CDC, and HRSA. We received written comments from HHS. HHS substantially agreed with the findings of our report and offered technical comments to provide additional information or clarify specific findings, which we incorporated as appropriate. The letter included with HHS's comments is reprinted in appendix II.

Generally, HHS's technical comments requested that we provide additional context about IHS's capacity to provide HIV/AIDS prevention and treatment services. HHS commented that IHS is mainly a primary care system and generally relies on providers outside of IHS for HIV/AIDS treatment services. HHS stated that IHS generally refers patients with HIV/AIDS to outside providers as they do for other complex conditions, such as cancer and heart disease. In addition, HHS noted that the barriers to HIV/AIDS testing and misconceptions about the disease mentioned in this report are not unique to the American Indian and Alaska Native communities.

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We are sending copies of this report to the Secretary of Health and Human Services. We will also make copies available to others on request. In addition, the report will be available at no charge on GAO's Web site at <http://www.gao.gov>.

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If you or your staff have questions about this report, please contact me at (202) 512-7114 or [ekstrandl@gao.gov](mailto:ekstrandl@gao.gov). Contact points for our Office of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix III.



Laurie Ekstrand  
Director, Health Care

# Appendix I: Reasons Why Treatment Services May Not Be Offered or Accessed, as Reported by IHS Area Officials

IHS area	Reasons why some IHS-funded facilities did not offer services			Reasons why American Indians and Alaska Natives with HIV/AIDS may not access or continue treatment				
	No known patients with HIV/AIDS	Limited resources	Other health concerns	Confidentiality concerns	Distance or lack of transportation	Cultural reasons	Alcohol or drug abuse	Lack of housing
Aberdeen		✓		✓				
Alaska			✓	✓	✓		✓	
Albuquerque	✓	✓		✓	✓	✓	✓	
Bemidji	✓	✓	✓	✓	✓			
Billings		✓	✓	✓	✓			
California	✓	✓		✓				
Nashville	✓	✓		✓				
Navajo				✓		✓	✓	
Oklahoma City	✓	✓	✓	✓	✓			
Phoenix		✓		✓	✓	✓	✓	✓
Portland	✓	✓	✓	✓				
Tucson		✓	✓	✓	✓		✓	✓
<b>Total</b>	<b>6</b>	<b>10</b>	<b>6</b>	<b>12</b>	<b>7</b>	<b>3</b>	<b>5</b>	<b>2</b>

Source: GAO analysis of interviews with IHS officials in the 12 area offices.

Note: The reasons why HIV/AIDS treatment services were not offered, accessed, or continued were provided by IHS officials during our interviews with the 12 area offices and may not constitute an all-inclusive list.

# Appendix II: Comments from the Indian Health Service



DEPARTMENT OF HEALTH & HUMAN SERVICES

Office of the Assistant Secretary  
for Legislation

Washington, D.C. 20201

**NOV 14 2007**

Laurie E. Ekstrand  
Director, Health Care  
U.S. Government Accountability Office  
Washington, DC 20548

Dear Ms. Ekstrand:

Enclosed are the Department's comments on the U.S. Government Accountability Office's (GAO) draft report entitled, "Indian Health Service: HIV/AIDS Prevention and Treatment Services for American Indians and Alaska Natives" (GAO-08-90).

The Department substantially agrees with the findings and conclusions of the report. The Indian Health Service would like to offer the following comments and suggestions listed on Attachment A that will help clarify certain issues and provide additional information on specific findings.

The Department has provided several technical comments directly to your staff.

The Department appreciates the opportunity to review and comment on this draft before its publication.

Sincerely,

*Rebecca Himmelfarb*  
for Vincent J. Ventimiglia  
Assistant Secretary for Legislation

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# Appendix III: GAO Contact and Staff Acknowledgments

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## GAO Contact

Laurie Ekstrand at (202) 512-7114 or [ekstrandl@gao.gov](mailto:ekstrandl@gao.gov)

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## Acknowledgments

In addition to the contact named above, Karen Doran, Assistant Director; Catina Bradley; Adrienne Griffin; Christina Ritchie; Eden Savino; and Timothy Walker made key contributions to this report.

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# Related GAO Products

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*Ryan White CARE Act: Changes Needed to Improve the Distribution of Funding.* [GAO-06-703T](#). Washington, D.C.: April 27, 2006.

*Ryan White CARE Act: AIDS Drug Assistance Programs, Perinatal HIV Transmission, and Partner Notification.* [GAO-06-681T](#). Washington, D.C.: April 26, 2006.

*Ryan White CARE Act: Improved Oversight Needed to Ensure AIDS Drug Assistance Programs Obtain Best Prices for Drugs.* [GAO-06-646](#). Washington, D.C.: April 26, 2006.

*HIV/AIDS: Changes Needed to Improve the Distribution of Ryan White CARE Act and Housing Funds.* [GAO-06-332](#). Washington, D.C.: February 28, 2006.

*Indian Health Service: Health Care Services Are Not Always Available to Native Americans.* [GAO-05-789](#). Washington, D.C.: August 31, 2005.

*Ryan White CARE Act: Factors that Impact HIV and AIDS Funding and Client Coverage.* [GAO-05-841T](#). Washington, D.C.: June 23, 2005.

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