



**URBAN INDIAN  
HEALTH COMMISSION**

*Invisible Tribes: Urban Indians and  
Their Health in a Changing World*



**A Report Issued by the Urban Indian Health Commission  
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This report was produced by the Urban Indian Health Commission, a select group of leaders convened by the Robert Wood Johnson Foundation and the Seattle Indian Health Board's Urban Indian Health Institute to examine health care issues facing urban American Indians and Alaska Natives.

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This logo was designed by Roger Fernandez for the Urban Indian Health Commission. The front structure is a Northwest Coast plank house and it symbolizes the home, which is what the Urban Indian Health Organizations are to many urban Indians. The buildings and the teepee in the background remind us of the changing landscape urban Indians face in today's world.

The term "tribe" is often associated with American Indians today. We chose to use the term tribe in the title of this report not to imply that urban Indians are a tribe, but that Indians living in cities are forming communities to help them maintain their native customs and cultures. The pan-Indian nature of urban Indian communities speaks strongly to the vitality of American Indian tribal communities today, and the desires on the part of Indian people everywhere to assure that their cultures are preserved.

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## EXECUTIVE SUMMARY

During the last 30 years, more than 1 million American Indians and Alaska Natives have moved to metropolitan areas. These original inhabitants of the United States have left reservations and other areas, some by choice and some by force. This change in lifestyle has left many in dire circumstances and poor health. To many in the United States, this population is invisible, leaving an important problem unnoticed: the health of nearly 67 percent of the nation's 4.1 million self-identified American Indians and Alaska Natives.

This report focuses on and highlights this segment of our nation's population that many do not understand very well. Aside from the valiant, heroic efforts of our nation's urban Indian health care programs, American health care and America's leaders largely ignore these people. We know from the RAND national report card on quality that overall the quality of American health care remains mediocre for everyone. However, we also know that racial and ethnic minorities, including American Indians and Alaska Natives, are at an even greater risk of receiving mediocre or even poor quality care. Other than the few urban Indian health care programs sprinkled across the country, large-scale efforts to reduce these disparities in care often overlook the urban Indian population. The current urban Indian programs cannot do this job alone. So, although the federal government and various organizations have attempted to address this problem, there remains much to be done—and urgently—as urban Indians struggle to get the health care they deserve.

### BACKGROUND

Today, nearly seven out of every 10 American Indians and Alaska Natives—2.8 million—live in or near cities, and that number is growing. Some urban Indians are members of the 562 federally recognized tribes and are thus entitled to certain federal health care benefits, with the bulk of these services provided only on reservations, making access difficult for those in cities. Others are members of the 109 tribes that the government “terminated” in the 1950s. Without this federally recognized status, members of these tribes do not

qualify for federal Indian health aid provided by the IHS or tribally run hospitals and clinics. Legislation enacted and treaties signed during the last century guaranteed health care for American Indians and Alaska Natives, but for the most part, recent policies have stripped many of them of their rights to health care when they move to cities. Today's urban Indians are mostly the products of failed federal government policies that facilitated the urbanization of Indians, and the lack of sufficient aid to assure success with this transition has placed them at greater health risk. Competition for scarce resources further limits financial help to address the health problems faced by urban Indians.

Decades ago, tribes exchanged their land and its vast resources for federal promises of a better life and better health, but the government has not delivered on its promises. As a result, the health of urban Indians has suffered, especially compared to other Americans' health.

Today, there is no national, uniform policy regarding urban Indian health, and current federal executive policy aims to eliminate funding for urban Indian health within the Indian Health Service.

### THE FINDINGS

Urban Indians face several challenges when trying to access quality health care. According to one study, they face time constraints, transportation issues, distrust of government programs and the cost of traveling to receive government-provided health care. (Kaiser Family Foundation, 2004) Additionally, many of those seeking treatment at urban clinics are poor and uninsured, and Medicaid covers only part of their care.

A large proportion of urban Indians is living in or near poverty and thus faces multiple barriers to obtaining care. Half of all non-elderly American Indians and Alaska Natives are poor or near-poor, with family incomes below 200 percent of the federal poverty level. More than 25 percent of American Indians and Alaska Natives are eligible for Medicaid, yet only 17 percent report that they are covered by it or another public program. American Indians and Alaska Natives do not apply

for Medicaid for a variety of reasons, many of which could be addressed and resolved through greater awareness and an increased focus on this population's needs.

Urban Indians are much more likely to seek health care from urban Indian health organizations (UIHOs) than from non-Indian clinics. However, with only 1 percent of the Indian health budget allocated to urban programs and with this 1 percent under threat of elimination, these Indian-operated clinics must struggle to obtain and maintain the funding, resources and infrastructure needed to serve the growing urban Indian population. The vast majority of American Indians and Alaska Natives living in cities are ineligible for or unable to utilize health services offered through the Indian Health Service or tribes, so the urban Indian health organizations are a key lifeline for this group.

An additional challenge in addressing the needs of this population is the lack of data. Although federal, state and local public health institutions collect some urban Indian public health data, these data are rarely disaggregated, separately analyzed or reported. Existing data are replete with problems, including racial misclassification on official documents, inattentiveness on the part of public officials to collect data on urban Indians, small cell size in official studies that limits the use of officially collected data, inadequate numbers to allow for scientifically sound analysis, and a general lack of standardization and attention to data collection on urban Indians as a whole. Since many decisions about public support are based on data, those with little or no data can easily be overlooked.

Although public and private health institutions continue to struggle to collect data on the health care of American Indians and Alaska Natives, profiles of specific diseases that plague this population have emerged. Depression, diabetes and cardiovascular disease deserve special attention due to their alarming presence and frequent coexistence in this population.

These three diseases are closely linked as risk factors and co-morbidities in the American Indian and Alaska Native population. It is common for an urban Indian to suffer from more than one of these diseases, which interact with, amplify and perpetuate one another. Many of the underlying causes, markers and barriers to treatment of

these diseases are also shared—at above-average rates—by other diseases and afflictions suffered by American Indians and Alaska Natives.

## **Depression**

Researchers have collected little data on depression among urban Indians, although some studies have indicated that up to 30 percent of all American Indian and Alaska Native adults suffer from depression (SAMSHA, 1999) and there is a strong reason to believe the proportion may be even greater among those living in cities. Few urban Indian health organizations have sufficient funding to create useful and sustainable mental health programs. Few can afford to employ a mental health professional or manage the cost of additional space to treat patients in private. Many of their clients lack health insurance, and those who are insured might have policies imposing strict limits on mental health coverage.

National aggregate data, however, can offer an idea of the magnitude and distribution of depression among urban Indians. The data show that at the national level, American Indians and Alaska Natives suffer disproportionately from depression and substance abuse and, with the exception of private psychiatric hospitals, are overly represented in in-patient care relative to Caucasians. (OMH Web site, 2007) More than one-third of Indian Health Services patient-care contacts in 2006 were related to mental health, alcoholism or substance abuse.

In treating these patients, it is important for health care professionals to understand this population's culture and history. With few American Indian or Alaska Native health professionals, and with many primary caregivers lacking sufficient mental health training, urban Indians are not, in most cases, receiving adequate mental health care. To effectively treat urban Indians, health care professionals must understand, accept and work with urban Indians' unique cultural and historical perspectives.

## **Diabetes**

Compared to the general U.S. population, American Indians and Alaska Natives have a higher prevalence of diabetes, a greater mortality rate from diabetes and an earlier age of diabetes onset.

An estimated 15 percent of American Indians and Alaska Natives age 20 years or older who receive care from the Indian Health Service have type 2 diabetes. (CDC, 2005) This prevalence exceeds that of the nation as a whole (9.6 percent), as well as that of many other racial groups. A study of two urban Indian health clinics found that diabetes was among the top five reasons for health care visits. (Taylor, 1988) Diabetes kills roughly four times as many American Indians and Alaska Natives as it does members of the U.S. population at large. (IHS, 2000) In general, people are more likely to develop type 2 diabetes and die from its complications as they grow older (CDC, 2005), a pattern that is even more pronounced among American Indians and Alaska Natives. (IHS, 2000)

Between 1990 and 1999, diabetes was the fifth leading cause of death for American Indians and Alaska Natives living in counties served by urban Indian health organizations. Among this population, the diabetes death rate was 32 per 100,000 and significantly higher than that of the general urban population. In addition, between 1990 and 1999 diabetes-related mortality increased at a faster rate among American Indians and Alaska Natives than among the general urban population. (Urban Indian Health Institute, 2004)

A special initiative was started in 1999 to address diabetes among American Indians. Through improvements in education, prevention and treatment, the initiative has not only raised awareness, but it has likely prevented deaths and disabilities among patients. Urban Indian health organizations are a part of this initiative and have been successful in reaching urban Indians. Preliminary data for the period 2000 to 2005 show significant improvements in most urban areas. This initiative proves the value of targeted interventions and the ability of community-based organizations to better serve hard-to-reach populations like urban American Indians and Alaska Natives. But with many urban Indians already afflicted with diabetes, more steps must be taken.

## Cardiovascular Disease

Cardiovascular disease is the leading cause of death among American Indians and Alaska Natives. It kills more American Indians and Alaska Natives age 45

and older than cancer, diabetes and unintentional injuries—their second, third and fourth leading causes of death—combined. (IHS, Trends in Indian Health, 2000-2001) Diabetes raises the risk of stroke. The American Indian and Alaska Native stroke-related death rate due to diabetes is more than triple that of the general population. (Galloway, 2002) Perhaps even more troubling, obesity, physical inactivity and high blood pressure—all risk factors for cardiovascular disease—are growing problems among American Indian and Alaska Native youth.

Studies show that contrary to trends among other U.S. racial and ethnic groups, cardiovascular disease rates continued to rise among American Indians. (Howard et al., 1999) Up to 25 percent of American Indian men ages 45 to 74 have signs of heart disease. (Ali et al., 2001) New cases of coronary heart disease (chest pain and/or heart attack) among American Indians are nearly twice that of the general population. (Howard, et al., 1999)

Studies show that coronary heart disease, high blood pressure and stroke are disproportionately prevalent among American Indians and Alaska Natives. (AHA Statistics Committee and Stroke Statistics Subcommittee, 2007) They have substantially higher rates of coronary heart disease than whites and many other racial and ethnic groups. (Galloway, 2005)

Heart disease, like diabetes, is an expensive and time-consuming condition to treat. Often, heart disease accompanies diabetes, making treatment even more complicated and expensive. For urban Indians, access to both diagnostic tests and specialized cardiac care cannot be assured due to poverty, lack of insurance and the limitations of urban Indian health organization services. The current UIHO network is an incomplete system offering only preventative and primary health care, which limits the ability of urban Indians to receive adequate and timely treatment of cardiovascular problems.

## CONCLUSIONS AND RECOMMENDATIONS

These findings illustrate the depths of the urban Indian health crisis. Decades of neglect have placed urban Indians at greater risk of unnecessary death and disability. Although the United States continues to work to address racial and ethnic disparities in health care, American Indians and Alaska Natives

living in this country's cities have been mostly invisible in these strategies. Special attention must be paid to make sure they are included in future initiatives. Without informed dialogue and targeted action, the health of urban Indians will continue to decline. To that end, the Urban Indian Health Commission offers the following recommendations.

- **Demographics:** Although federal Indian policy favors resources for Indian tribes and those living on Indian reservations, shifts in populations and findings from health disparities research confirm that public and private sector efforts to improve health care quality and reduce disparities must assist and recognize Indians living cities.
- **Best Practices to Improve the Quality of Care and Reduce Disparities:** Build upon and implement interventions for improving urban Indian health care; expand the information technology capacity of Urban Indian Health Organizations (UIHOs) and others who provide care for urban American Indians to help improve clinical performance and serve as a platform for data collection; establish and support initiatives like the Special Diabetes Program for Indians for other conditions, such as cardiovascular disease, depression and other major health problems; help clinical systems employ tools like the Chronic Care Model, where applicable; and implement culturally specific best practice prevention interventions, such as the use of traditional healers, talking circles and community events, where applicable.
- **Data for Performance Measurement, Public Reporting, Quality Improvement and Research:** Ensure that urban American Indians and Alaska Natives are included in all data collection efforts to improve health care quality such as regional quality improvement collaboratives, regional and national private health plan initiatives and others so that this work measures the quality of care provided to urban American Indians and Alaska Natives, stratifies those measures by American Indian and Alaska Native race and ethnicity, and reports those stratified measures publicly; engage municipal, local, state and federal health officials to ensure that data on the urban Indian population are indeed available; examine new approaches to small population research that would meet scientific rigor and the needs of urban American Indians and Alaska Native people; support increased research activity by and for the urban American Indian and Alaska Native people; and consider the development of urban American Indian and Alaska Native Centers of Excellence.
- **Culturally Competent Quality Care:** Expand the number of Native health professionals by working with local colleges, universities and trade institutions to support Native students; encourage UIHOs to serve as training sites and facilitate collaborative relationships to support this educational role; and support the integration of traditional medicine in health care delivery.
- **Access to Quality Care and Health Services:** Provide technical assistance in building partnerships with local health providers for greater health service access; improve access to public and private health insurance to assure proper uses of health care when needed; educate health officials and policy-makers about the effects of eligibility requirements on insurance enrollment; and help reduce misunderstandings and perceived barriers for urban Indians.
- **Policy and Funding:** Support the Urban Indian Health Program through the Indian Health Service; include urban American Indians and Alaska Natives in national programs dealing with health disparities and minority health initiatives; and encourage efforts to enhance public and private partnerships that can help urban Indians build health access and service capacity.



## I. A Population in Crisis

Many Americans assume that nearly all American Indians and Alaska Natives live on vast rural reservations, where federal programs see to all their health care and basic needs. This could not be further from the truth.

Today, nearly seven out of 10 American Indians and Alaska Natives live in or near cities, and that number is growing. According to the U.S. Census Bureau, more than 1 million American Indians and Alaska Natives have moved to metropolitan areas during the past three decades. They now constitute roughly 67 percent of the nation's 4.1 million self-identified American Indians and Alaska Natives.

Many live in extreme poverty, poor health and cultural isolation. Many live far from federally mandated reservation-based health services, which are ill-equipped to increase the number of patients they treat. In one sense, these 2.8 million urban Indians are America's largest and most vulnerable tribe. Yet to many in their government and to many of their Indian and non-Indian fellow citizens, urban Indians are invisible.

Reliable health statistics on urban Indians are scarce because this demographic has been studied so little and its members are often misclassified on vital records as belonging to other races or ethnicities. But what we do know about urban Indians' health is enough to warrant immediate action.

The United States has a unique relationship with American Indians that places responsibility for their care on the government and the American people. Simply stated, tribes exchanged their land and its vast resources for federal promises of a better life and better health. Those promises are the main reason why we all live on what was once Indian land. Yet, these promises have not been fully kept.

In 2004, the first comprehensive national study on urban Indian health revealed a community in crisis. The study found that Urban Indians had multiple health risks, and when compared to the general population, urban Indians were found to have higher death rates due to alcohol-related causes, chronic

liver disease and cirrhosis, diabetes, and accidents. The findings of this study were later republished in 2006 in a peer-reviewed article in the American Journal of Public Health. (Findings from this study are presented in Appendix A, Tables 1 through 3.) (Castor et al. 2006)

American Indians and Alaska Natives living in cities face poverty, unemployment, disability and inadequate education at rates far above those of other Americans. These and other risk factors have contributed to a health crisis in this population despite an ongoing effort to eliminate health care disparities across all races and ethnicities.

Consider these facts:

- The infant mortality rate among urban American Indians and Alaska Natives is 33 percent higher than that of the general population.
- Their death rate due to accidents is 38 percent higher.
- Their death rate due to diabetes is 54 percent higher.
- Their death rate due to chronic liver disease and cirrhosis is 126 percent higher.
- Their rate of alcohol-related deaths is 178 percent higher.
- Some studies indicate that up to 30 percent of all American Indian and Alaska Native adults suffer from depression, and there is strong reason to believe the proportion is even greater among those living in cities.
- Cardiovascular disease (CVD) was virtually unheard of among American Indians and Alaska Natives as recently as 40 years ago. Now it is their leading cause of death.
- Diabetes can double to quadruple an American Indian or Alaska Native adult's risk of developing CVD.

Urban Indians have less access to health care than other Americans. Often, their living conditions are literally sickening. Persistent bias against them and

their mistrust of government keep many from getting the health care they need. Large-scale efforts to reduce racial and ethnic disparities in health care largely overlook them, concentrating instead on far larger underserved communities.

Meanwhile, political disagreements over national Indian policy have deprived urban and rural Indians alike of the funds they need to improve their health. The resulting lack of progress has led some in Washington to undervalue urban Indian health programs and regard them as ones that do not deserve further funding. Taxpayer dollars, they say, would be better spent on health programs that benefit all Americans.

To draw the country's attention to the unique needs of urban Indians, the Robert Wood Johnson Foundation funded the creation of the Urban Indian Health Commission. Through this report, the Commission seeks to raise the visibility of the plight of urban Indians. The Commission hopes to identify and promote practices that can elevate urban Indians to health care parity with national averages.

The Commission is comprised of 11 members and two advisors from the fields of education, public policy, Indian affairs, medicine, research, business, industry, government, and the community and nonprofit sectors.

This report focuses on the challenges to improving urban Indian health and offers a detailed examination of urban Indian health today based on the best data available, with a special focus on three large, growing and often intertwined diseases: depression, diabetes and cardiovascular disease. The depression section sets the stage by exploring recurrent themes, such as the woeful state of urban Indian health data, the frequent disconnect between native and Western philosophies of wellness and healing, the lack of cultural competency in the medical workforce, and, perhaps most pointedly, the insidious effects that racial discrimination has had on Indians for generations. The report concludes with accounts of model programs that are making high-quality health care more accessible to the growing number of American Indians and Alaska Natives living in cities.

## II. Urban Indian Access to Health Care

Under Title V of IHCA, the Indian Health Service contracts with private Indian-controlled nonprofit corporations to run urban Indian health organizations (UIHOs). Today, there are 34 urban Indian health organizations. In fiscal year 2006, Congress spent \$32.7 million on the program, or about 1 percent of IHS's \$3 billion annual budget. The 34 organizations served roughly 100,000 Indian people in 2005.

Many urban Indian health organizations are the glue that holds their communities together. Indians have a well-founded distrust of government programs and are far more likely to seek health care from Indian-operated clinics than from others. These organizations are more sensitive to Indian cultural needs and have a better understanding of historic discrimination experiences that can thwart appropriate health care. Urban Indian health organizations also create opportunities for urban Indians to practice their traditions and explore their cultures, which benefit their health profoundly. These organizations also help clients obtain and keep government-sponsored health coverage; guide them through social service bureaucracies; and connect them to jobs, educational opportunities and support services.

However, today many U.S. cities with sizeable American Indian and Alaska Native populations lack access to an urban Indian health organization. Many urban Indians live long distances from reservation-based IHS or tribal health services. California, for example, has more American Indians and Alaska Natives than any other state, and just 10 percent have access to IHS clinical services. (Seals et al., 2006) There, as in other states, urban Indians who must move to reservations for health care might have to wait months to reestablish residency, and then might spend even more time on a waiting list before getting treatment. Many become sicker and some even die before reaching the top of the list.

Even among the urban Indian health organizations, not all are able to provide the full spectrum of health services needed by urban Indians. In addition, none are connected to a hospital and few are connected to specialty care services, both of which are needed by the urban Indian community.

With federal funding inadequate and uncertain, urban Indian health organizations have begun turning to philanthropies and other non-federal funding sources. For example, the N.A.T.I.V.E. Project in Spokane, Wash., recently raised \$3.9 million from state, community and charitable sources to expand its facilities. Such victories are rare, however.

Even when urban Indian health organizations manage to secure grants, they often come with strings attached. For example, grantmakers might insist on research-based treatments or a strict focus on patient outcomes. Reliance on evidence-based treatments is virtually impossible for an urban Indian population that has rarely been the subject of a randomized trial. Grant conditions such as these are well-meaning and might make sense for other populations, but in the urban Indian context, they erect barriers to funding and the care it finances. In addition, non-IHS-recognized urban Indian programs may provide the services due to the dysfunction that fluctuating federal funding has caused to the urban Indian program.

Inadequate funding is hardly the only barrier to improving health care for urban Indians.

For example, surveys and anecdotes reveal that urban Indians are a very itinerant population. Many migrate between reservations and cities, within and among cities, and even among states. Urban Indian health organization staff members say it is common



Grand opening of the new facility of the N.A.T.I.V.E. Project in Spokane, Wash.

for a client's record to show multiple addresses in a given year. Officials at the North American Indian Center of Boston report that they have "regular"



**South Dakota Urban Indian Health Center staff in front of the Aberdeen Area Indian Health Service tele-digital mammography van. The van provides an opportunity for women to receive their annual mammograms and bone density testing on-site.**

clients from as far away as Arizona, California and New Mexico. Half of the service recipients during the early stages of Denver's Native American Cancer Research Native Sister Initiative moved to new homes every 18 months.

This high degree of movement obviously makes it challenging to treat urban Indians with chronic conditions. Several

urban Indian health organizations have developed innovative solutions to the problem. The South Dakota Urban Indian Health Center, for example, created a network of clinics in Pierre, Sioux Falls and Aberdeen, S.D., to better serve clients who move frequently. New York City's American Indian Community House opened HIV/AIDS satellite programs in Buffalo, Syracuse and Hogsburg, N.Y., to better serve its clients.

In addition to urban Indian health organizations, there are several entities that affect urban Indians' access to care. Each faces its own set of challenges.

### **Indian Health Service**

The Indian Health Service is an agency of the U.S. Department of Health and Human Services through which health services are provided to some American Indians and Alaska Natives. (Indian Health Service Web site, 2006) Many urban Indians are ineligible for care at IHS and tribal facilities on reservations, and for all practical purposes that care is unavailable to many who are eligible. Additionally, the urban Indian health organization network's limited capacity reduces its reach.

Even Indians living on reservations find it increasingly difficult to obtain proper health care. As a discretionary domestic program, IHS must compete for federal dollars with a multitude of other programs and interests. Just under half of all uninsured American Indians and Alaska Natives identify IHS as a source of coverage and care. IHS is not now, nor has it ever been, health insurance, and yet urban Indians are told that they should identify IHS as insurance on health care applications. Many cannot access it because of time and the cost of traveling to receive it. As a result, many forego health care. (Kaiser Family Foundation (KFF), 2004)

Financial pressures are also forcing tribal leaders to make tough decisions about limiting access to tribally managed health care. Their priority is to provide care for local tribal members living on reservations. Therefore, those living in urban areas are often restricted from accessing tribally managed care, and are mainly channeled to the already overstretched urban Indian health organization system. Many of those seeking treatment at urban clinics are likely to be poor and uninsured, and, as explained below, Medicaid covers only part of the cost of their care.

### **Private Insurance**

As a result, private health insurance and federal health care entitlements have become vital to the urban American Indian and Alaska Native population. But 35 percent of all American Indians and Alaska Natives and 48 percent of those with low incomes are uninsured, largely reflecting their low rates of job-based health coverage. (KFF, 2004)

### **Medicaid and Medicare**

Many urban Indians living in or near poverty face multiple barriers to obtaining care under Medicaid, which is jointly funded by the federal and state governments and managed by the states.

Half of all nonelderly American Indians and Alaska Natives are poor or near-poor, with family incomes below 200 percent of the federal poverty level. More than 25 percent of American Indians and Alaska

Natives are eligible for Medicaid, but only 17 percent report that they are covered by it or other public programs.

Some American Indians and Alaska Natives do not apply for Medicaid because they do not understand the enrollment process. Many are incorrectly told that they are not eligible for Medicaid due to misunderstandings of eligibility rules. Others do not apply because of transportation difficulties or literacy and language barriers. For example, many cite concerns that their property will be seized or their assets confiscated. Some do not apply because past injustices against Indians make them fear or distrust the government. (Langwell et al., 2003) Many other urban Indians in poverty are childless adults and do not qualify for Medicaid. In most states, adults between 21 and 65 who are not disabled or pregnant or do not have a dependent child are ineligible. (Centers for Medicare and Medicaid Services Web site)

On the positive side, Medicare, federally funded health care for the elderly and disabled, has benefited older urban Indians enormously.

In 1997, Congress created the State Children's Health Insurance Program (SCHIP) to provide subsidized health insurance for children from families with incomes too high to qualify for Medicaid but too low to afford private health insurance. Insurance premiums and co-payments were waived for American Indian and Alaska Native children in 2000. This move was partially intended to help urban Indian families, as many take their children to non-Indian health care providers. However, many of these families and many providers are not aware that the waiver exists. (Satter, 2002)

IHS and tribal health facilities receive 100 percent federal reimbursement for Medicaid and Medicare services provided to qualified American Indians and Alaska Natives. Urban Indian health organizations, in contrast, receive only partial reimbursement. Nineteen of the 34 UIHOs have been designated Federally Qualified Health Centers (FQHCs) and, as

such, their "prospective payment" reimbursements for services are based on predetermined, fixed amounts. Under a complex set of rules, those repayments currently run at between 85 percent and 90 percent of actual costs. The 15 other non-FQHC organizations are reimbursed under even less generous fee-for-service systems that vary by state. Many states believe that Indian health is a federal responsibility and do not include urban Indian health organizations in their provider networks. This misunderstanding often limits urban Indian health organizations' reimbursement for covered services. In addition, as states consider adding premiums and cost-sharing arrangements to their Medicaid programs, urban Indian health organizations will be subject to these requirements.



Urban Indian youth celebrating their physical fitness climbing activities in Oakland, Calif.

## Community Health Centers

Some poor and near-poor urban Indians in cities without urban Indian health organizations rely on community health centers for care. However, these centers are under increasing strain as growing numbers of middle-class Americans who have lost their employer-sponsored insurance turn to them for help. In addition, these centers do not always provide culturally appropriate services for urban Indians. These same concerns apply to urban Indians' use of hospital emergency rooms for primary care services.

### III. Challenges in Data Collection

Data increasingly drive public health spending decisions. If data on a community is not counted, its health needs go unrecognized and health care dollars go elsewhere.

There is no formal public health surveillance system for urban Indians. Federal, state and local public health institutions might collect such data, but they are rarely disaggregated or separately analyzed. Many standard federal health surveys cannot report accurately on urban Indians, in part because they lack adequate racial designations. In an effort to address some of these gaps, the Urban Indian Health Institute was created as a division of the Seattle Indian Health Board to unify data from the urban Indian health organizations and use the data to address urban American Indian and Alaska Native health needs and clarify health disparities. (Tualii et al., 2006) The majority of current urban American Indian and Alaska Native health data available is the work of the Urban Indian Health Institute.

The nature of urban Indian communities also makes it difficult to quantify their health conditions. Their numbers are small, making it hard to create sufficiently large statistical samples. Also, unlike other urban minority groups, urban Indian communities tend to be widely dispersed across metropolitan areas. They frequently encompass many tribes and widely varying levels of experience with urban life. The lack of historic records makes it difficult to trace their health patterns over time.

Simply obtaining existing data on urban Indians is another major challenge. Privacy rules, for example, may prevent access to data when sample sizes and response rates are too low for general and stratum-specific analysis.

Generally, there is a paucity of information on urban Indian health. PubMed, the U.S. National Library of Medicine's comprehensive Web-based health archive, indexes about 2,300 scientific articles with either "American Indian(s)" or "Alaska Native(s)" in their titles. Adding the word "urban" to the search drops the number to just 63.

There is strong reason to believe that the few studies that do exist grossly underestimate the true extent of the problem. Urban Indians are frequently misclassified on vital records used to determine health statistics. Many have mixed racial backgrounds and European or Hispanic surnames. Fear of discrimination causes others to misstate their heritage on official documents.

The quality of a health surveillance system depends on the quality of its data. If data are not accessible, they might as well not exist. And unfortunately, health statistics on urban Indians are generally of poor quality and largely inaccessible. The situation perpetuates their invisibility to the nation.

Examination of data sources has found that only six out of 15 major federal health data sets can provide acceptable levels of accuracy on American Indians and Alaska Natives. Two can be used for simple distributions only and the remaining seven are unusable because their samples are too small. (Appendix A, Table 5) (Unpublished UIHI analysis using data from Waksberg 2000)

## IV. Depression Among Urban Indians

Depression, diabetes and cardiovascular disease are far from the only diseases or health conditions that afflict American Indians and Alaska Natives in disproportionate numbers. However, these conditions deserve heightened attention due to their alarming prevalence and frequent coexistence in this population. Moreover, some of the underlying causes and markers of these three diseases are shared by other diseases and afflictions suffered by American Indians and Alaska Natives at above-average rates. Many of their barriers to treatment are also common to other conditions.

It is common for an urban Indian to suffer from more than one of these diseases, which interact with, amplify and perpetuate one another. For example, research shows that the lifetime risk of depression is doubled if a person develops diabetes. (Anderson, 2001) Likewise, a study of Northern Plains American Indians has found that those with major depression are more likely than those without it to report having cardiovascular disease. (Sawchuck, 2005) Similarly, type 2 diabetes is a strong risk factor for the development of cardiovascular disease among American Indians and Alaska Natives age 20 and older. (Galloway, 2005) Diabetes and cardiovascular disease, both formerly rare, are now among the leading causes of death for American Indians and Alaska Natives.

Indeed, it is useful to view the triad of depression, diabetes and cardiovascular disease among urban Indians as a single scourge. An urban Indian might respond to depression, for example, by engaging in unhealthy behavior such as poor diet, smoking and alcohol abuse. Those factors, in turn, can contribute to the onset of diabetes, heart disease or both, causing even worse depression, more unhealthy behavior and premature death.

### Depression Among Urban Indians

The following discussion of urban Indians' struggle with depression serves as an example of how culture, discrimination, health workforce preparation and health data collection affect the state of urban Indian health. These issues similarly affect

American Indians' struggle with diabetes and cardiovascular disease, as well as other health conditions.

Mental health is a national priority, as evidenced by its inclusion as a focus area of Healthy People 2010. (Healthy People 2010 Web site) Health professionals also acknowledge that mental health and depression, specifically, are endemic problems in Indian country.

Nonetheless, depression among urban Indians has received scant attention from researchers. Little is known about its rates and characteristics, and there is no uniform protocol to examine the issue. No aggregate data exist, and there is no plan to gather such data. The federal government has done little to

**G**ordon S.\* is a 60-year-old Blackfoot from Montana. He was taken from his family at a young age and treated cruelly in boarding schools. Gordon now faces mental health issues and was diagnosed with diabetes. In addition, he struggles with alcoholism, which has complicated his disease management. Before receiving treatment at the urban Indian health clinic, when he drank heavily, he would stop taking his insulin. Understanding the complex nature of Gordon's health issues, providers at the clinic were able to devise a treatment plan that took into consideration Gordon's multifaceted needs. Even though Gordon has engaged in heavy drinking since completion of treatment, he takes his insulin daily and has not experienced any critical lows. Thanks to the care and counseling that he received, he understands the importance of managing his diabetes and is aware that every percentage point that he reduces his A1c lowers his risk of complications by 35 percent. His last A1c in November was 7.9, down from 9.7 in June.

\* Names have been changed to protect patient privacy.

acknowledge the subject and the dearth of research makes it challenging to describe its extent.

Some small studies, however, indicate that up to 30 percent of all American Indian and Alaska Native adults suffer from depression (Substance Abuse and Mental Health Services Administration (SAMHSA) Web site), and there is strong reason to believe the proportion might be even greater among those living in cities.

Many American Indians and Alaska Natives suffer “historical trauma” (Brave Heart, 2004), an emotional reliving of wrongs against one’s people that is described in greater detail below. Both conditions frequently manifest themselves as depression. Whatever its source, depression puts people at increased risk for suicide (Lynch & Clarke, 2006), substance abuse (Dapice, 2006; Rao, 2006), and a host of other health problems.

As previously described, nearly half of all urban Indians live in extreme poverty. Researchers have recently discovered that poverty can “get under the skin” and make one sick. (Taylor, 1997) They have linked it to biologic pathways that produce excess cortisol, inflammation, oxidative stress and gene methylation, which are associated with increased risk of coronary heart disease, diabetes, some cancers and other chronic diseases. (Seeman, 1997)

Few urban Indian health programs have sufficient funding to create useful and sustainable mental health programs. Few can afford to employ a mental health professional or manage the cost of additional space to treat patients in private. Many of their clients lack health insurance, and those who are insured might have policies imposing strict limits on mental health coverage. There is no specific allocation for mental health in the miniscule federal urban Indian health budget.

Significant sums, however, are being spent on social problems such as violence, alcoholism and substance abuse that are frequently linked to depression. The misguided assumption appears to be that if bad behavior is stopped, the related mental health issue will somehow take care of itself. Resources should also be spent on treating this debilitating disease.

## Historical Trauma

“We still have sorrows that are passed to us from early generations, those to handle besides our own, and cruelties lodged where we cannot forget. We have the need to forget. I don’t know if we stopped the fever of forgetting yet. We are always walking on oblivion’s edge.”

—Louise Erdrich, *The Painted Drum*

Mental health researchers have recently advanced a theory of “historical trauma.” It suggests that genocide, mass expulsion, forced assimilation and other cruelties against groups shatter the lives and health not only of direct victims but those of their descendants. Much of the pioneering work in this field focuses on American Indians.

Historical trauma combines with poverty and ongoing discrimination to produce profound feelings of sadness, anxiety, depression, anger and estrangement. In American Indians it generates fear and mistrust of whites. (Whitbeck et al, 2004) There is a sense of re-experiencing past wrongs, grief over lost languages and traditions and reduced self-esteem. Loss of access to sacred sites for therapeutic spiritual renewal and traditional food gathering is particularly traumatic. (Wilson, 2003) Individuals pay less attention to their health and well being (Vernon, 2001) and act out through substance use and violence. (Brave Heart & DeBruyn, 1998)

## The Challenges of Urban Indian Depression Data

It is almost impossible to obtain an accurate picture of depression among urban Indians. Urban Indian health programs collect limited information on the extent of emotional ill health in their communities and have a difficult time separating out patients’ coexisting mental health conditions. National data on the prevalence and characteristics of urban Indian mental health typically come from federal data sets that combine information collected from vastly different reservation, rural and urban populations. Sample sizes are frequently small, many Native people do not seek help for depression,



and the condition is often studied in tandem with substance abuse or violence.

National aggregate data, however, can offer an idea of the magnitude and distribution of depression among urban Indians. The data show that at the national level American Indians and Alaska Natives suffer disproportionately from depression and substance abuse and, with the exception of private psychiatric hospitals, are overly represented in in-patient care relative to whites. (Centers for Disease Control and Prevention (CDC), Office of Minority Health (OMH) Web site) More than one-third of IHS patient-care contacts in 2006 were related to mental health, alcoholism and substance abuse. As previously noted, some small studies indicate that up to 30 percent of adult American Indians and Alaska Natives suffer from depression. (SAMSHA Web site)

The Healthy People 2010 Midcourse Review has 17 mental health objectives. Only one objective—for suicide—includes data for American Indians and Alaska Natives, and their rate is higher than that of most other groups. Without more data, this population and the challenges it faces will continue to go largely unnoticed.

### Culturally Competent Care

“The last patient of the day is a tribal leader. Her daughter just committed suicide that morning, left two little kids behind and her husband. . . . She couldn’t say a word. There was no point in interviewing her. I just held her in my arms and sang her one of my traditional songs, and prayed hard. . . . No, they don’t teach that in medical school.”

—A Native family physician

The past two generations have witnessed a renaissance of traditional American Indian and Alaska Native culture on reservations and in cities, with salutatory effects on Native mental health. At the same time, urban Indians have developed a distinct pan-Native culture of their own. Whether urban or rural, Native culture is probably unfamiliar to most non-Native health professionals. Cultural

competency is clearly vital to delivering high-quality care in these communities. The medical profession, however, has no cultural competency mandates, only guidelines (National Office of Minority Health, 2001), and many non-Native medical trainees feel unprepared to treat such patients.

There are few American Indian or Alaska Native health professionals overall, and even fewer mental health specialists. In 1996, there were just 29 psychiatrists of Native American heritage in the entire United States. The ratio of Native American mental health professionals to Native Americans is about 10 per 10,000; the ratio for whites is nearly double, at about 17 per 10,000. (SAMSHA Web site) From 2002 to 2006, less than 1 percent of the country’s medical students were American Indian or Alaska Native (Association of American Medical Colleges, 2006), and federal funds to recruit more into the field have been targeted for elimination. Staff turnover in urban Indian health clinics appears to be high, making it very hard to establish trust with people seeking mental health care.

Family physicians provide the bulk of mental health care in America (Subramanian 2003), but many lack adequate training in the screening and diagnosis of depression. (Bell, 2005) In addition, 25 percent of resident trainees in primary care feel unprepared to care for people with beliefs at odds with Western medicine, who mistrust the medical system or who use alternative medicine. (Weissman, 2005) Only one of the country’s 34 urban Indian health organizations sponsors a postgraduate residency training program for family physicians serving American Indians or Alaska Natives.

It would be extremely difficult for a non-Native mental health professional to treat urban Indians effectively without understanding, accepting and working with their unique cultures. For example, it is important for health professionals treating this population to understand that inter-tribal cultural events give urban Indians a sense of belonging and healing and make them feel good about their identity, values, ceremonies and beliefs. Likewise, they should know that coming-of-age ceremonies enhance urban Indian teens’ knowledge of and pride in their culture, which in turn promotes healthy living. (Kulis et al, 2002)



Urban Indian youth exemplify the merging of cultures.

Mental health professionals also need to understand the high esteem Native people have for their elders and their roles as counselors and teachers. (Mala personal communication, 2007; Marbella, 1998) Those engaged in family counseling, in particular, must understand that the entire community and an individual's extended clan are considered parts of that person's family and should have roles in their care.

emotional and spiritual. Some believe health has a social component as well.

All components must be balanced for total body wellness. If one component has been neglected or is "ill," it is impossible to achieve overall health. For example, a person who does not maintain a respectful and active spiritual relationship with the Creator cannot attain wellness. Mental health is thought of in a similar manner. Ignorance of tradition, inability to practice tradition, and the often impossible challenge of balancing mainstream and Native values leads to "dis-ease." Many urban Indians choose to combine both Native and Western approaches to healing.

### Holistic Approach to Life and Health

"One day I was at sweat lodge and after every sweat we had the feast, and I was finally familiar enough with these people that I put my guard down and started letting out some of that pain. I actually started crying a couple of times in [the] sweat lodge simply because I was so hot, so miserable. And yet when I got out of that, I felt refreshed. . . . I was going through depression workshops and all of a sudden I didn't feel depressed no more."

—Tobias Martinez, Mescalero Apache,  
Native American Cancer Research

Finally, and perhaps most importantly, mental health professionals need to understand, respect and work within the bounds of the Native philosophies of life and health.

Native people have a holistic philosophy of life that emphasizes and reveres the connections between all animate and inanimate things. They also have a holistic view of health. Many tribes believe that health has four basic components: physical, mental,



Totem pole at the Native American Rehabilitation Association of the Northwest in Portland, Ore.

## V. Type 2 Diabetes Among Urban Indians

The alarmingly high prevalence of diabetes among American Indians and Alaska Natives correlates to federal policies that made them a predominantly urban people. In the past they hunted, fished, and grew their own traditional, healthy foods. Some researchers believe that centuries of feast-and-famine cycles geared their bodies to store fat during times of plenty. Now, genetics have combined with sedentary urban life and a steady but unhealthy diet to create disease where none existed before.

As previously noted, studies have linked depression with diabetes and diabetes, in turn, with cardiovascular disease, as examined more fully below. An estimated 10 percent to 30 percent of people of all races with diabetes also have depression, raising their risk of complications, disability, hospitalization; added health care expense; and a worse quality of life. (Anderson et al., 2001)

Diabetes is chronic and for many people fatal. The body either does not produce insulin (type 1 diabetes) or initially fails to use it properly and then gradually ceases its production (type 2 diabetes). There are two other types of the disease: gestational diabetes (glucose intolerance during pregnancy) and pre-diabetes (excessive blood glucose levels). While all forms of diabetes exist in American Indians and Alaska Natives, this report focuses on type 2.

Type 2 diabetes, which is believed to be caused by an interplay of genetic and environmental factors, was once virtually unknown among American Indians and Alaska Natives. It now afflicts a higher percentage of American Indian and Alaska Native adults than adults in nearly all other racial or ethnic groups in the United States (CDC, National Diabetes fact sheet, 2005) and is the fourth leading cause of their death. (IHS, Trends in Indian Health 2000-2001) American Indians and Alaska Natives are more than twice as likely as whites to have the disease (CDC, National Diabetes fact sheet, 2005) and have a death rate from diabetes nearly four times that of the general population. (IHS, Trends in Indian Health, 2000-2001)

An estimated 15 percent of American Indians and Alaska Natives age 20 years or older who receive care from the Indian Health Service have type 2 diabetes. (CDC, National Diabetes fact sheet, 2005) This prevalence exceeds that of the national average (9.6 percent) as well as that of many other racial groups. A study of two urban Indian health clinics found that diabetes was among the top five reasons for health care visits. (Taylor, 1988)

Urban-specific data suggest that American Indians and Alaska Natives also tend to develop diabetes at an earlier age than whites and other race populations. (CDC, BRFSS data, 1998-2003) Once considered an adult onset disease, type 2 diabetes now afflicts a larger share of American Indian and

**R**ichard T.\* is a 71 year old man who moved to New York City when he was 18 years old with his grandfather. He smiles proudly when he talks of what a hard worker his grandfather was as an iron worker in the city. He fell in love with the city, yet felt a loss for his home and family on the reservation. In 1995, Richard was diagnosed with diabetes and has since made great improvements in managing his illness. He is a regular member of the diabetes support group. Although he faces many additional health challenges, such as a hip replacement, Richard is dedicated to controlling his diabetes and has made a special effort to implement the lessons he has learned regarding food choices, home testing of blood sugars, and creative ways of increasing his activity level. Thanks to the care and support that he received, Richard reports feeling much better and is able to spend quality time with his kids, grandkids, and wife.

\* Names have been changed to protect patient privacy.

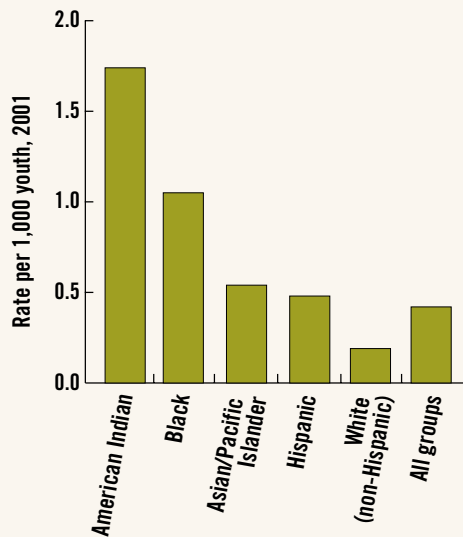
Alaska Native youth ages 10 to 19 than any other race. In fact, a recent national study estimated that 1.74 per 1,000 American Indian and Alaska Native 10-to-19-year-olds have type 2 diabetes, compared with 0.42 per 1,000 among all races. (SEARCH for Diabetes in Youth Study Group, 2006) (See Figure 1.) This huge gap is of grave concern because it places American Indian and Alaska Native youth disproportionately at risk for cardiovascular disease, which is already the No. 1 killer of their people.

Diabetes kills roughly four times as many American Indians and Alaska Natives as it does members of the U.S. population at large. (IHS, Trends in Indian Health, 2000-2001) In general, people are more likely to develop type 2 diabetes and die from its complications as they grow older (CDC, National Diabetes fact sheet, 2005), a pattern that is even more pronounced among American Indians and Alaska Natives. (IHS, Trends in Indian Health, 2000-2001)

Between 1990 and 1999, diabetes was the fifth leading cause of death for American Indians and Alaska Natives living in counties served by urban Indian health organizations. Among this population, the diabetes death rate was 32 per 100,000 and significantly higher than that of the general urban population. (See Figure 2.) In addition, between 1990 and 1999 diabetes-related mortality increased at a faster rate among American Indians and Alaska Natives than among the general urban population. (Urban Indian Health Institute (UIHI), 2004) (See Figure 3.)

In addition to causing premature death, type 2 diabetes can lead to serious and life-threatening complications, including heart disease and stroke, high blood pressure, colon and other types of cancer, blindness, kidney disease, nerve damage, dental disease, and depression. Many people do not know they have type 2 diabetes until the symptoms of complications appear.

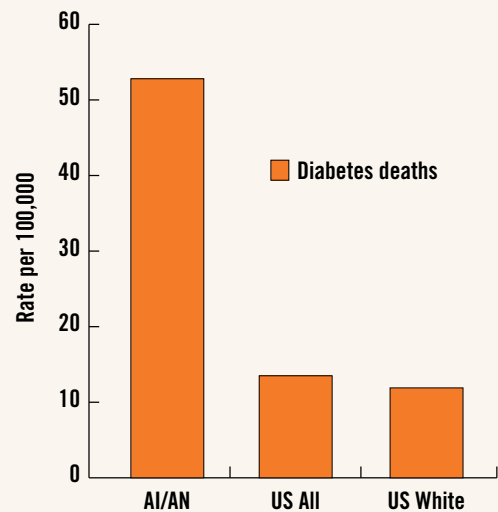
**Figure 1. Estimated Prevalence of Type 2 Diabetes by Race/Ethnicity, Ages 10–19**



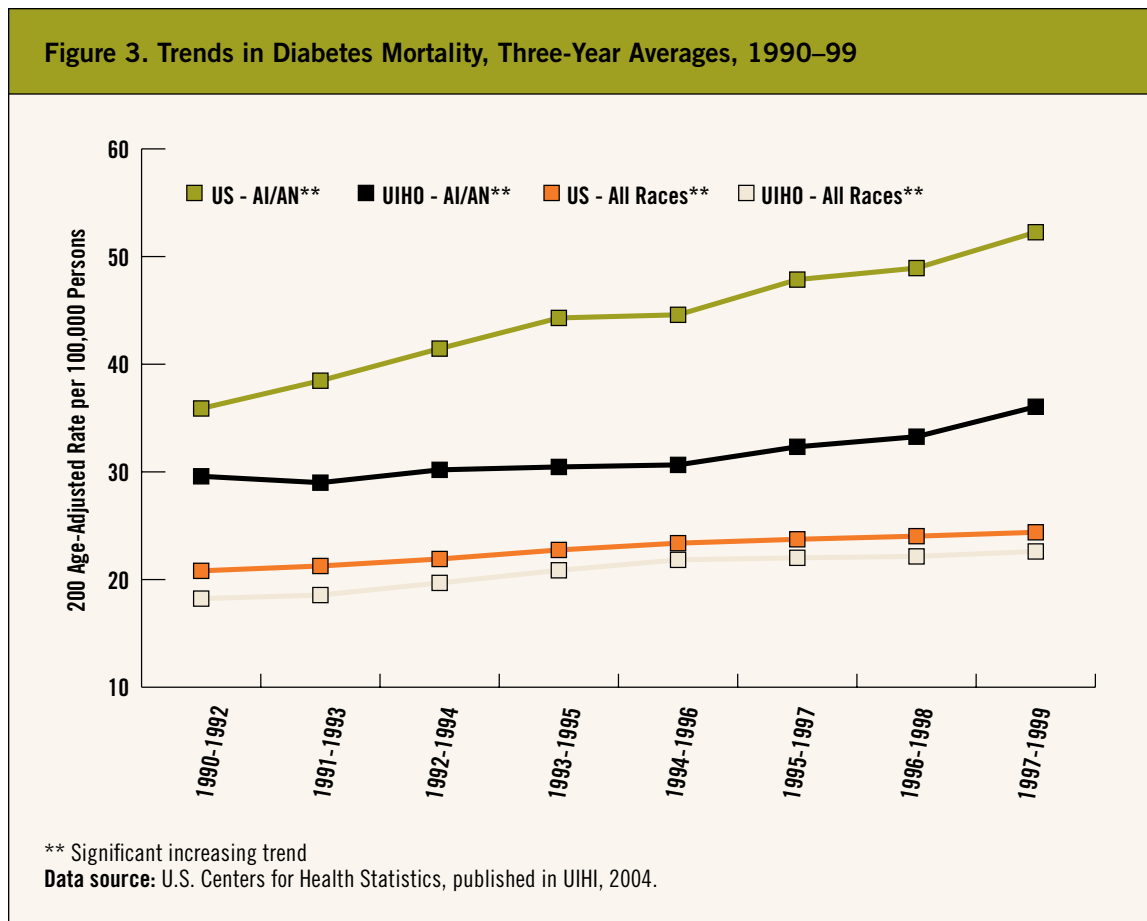
Source: SEARCH for Diabetes in Youth Study Group, 2006, p. 1513

**Figure 2. Death Rate From Diabetes Among American Indians/Alaska Natives in IHS**

Service Areas 1996–98 and U.S. All Races and White, 1997, Age-Adjusted



Source: IHS, Trends in Indian Health, 2000-2001, pp. 69 and 133.



Some complications from diabetes affect American Indians and Alaska Natives more than other groups. For example, American Indians with diabetes are six times more likely than the general population to have kidney disease and between three to four times more likely to require lower-limb amputations. (American Diabetes Association Web site) In this way, diabetes not only contributes to early mortality but it is among one of the leading causes of disability, contributing to unemployment and poverty.

Gestational diabetes is also of great concern and is noted to occur more frequently among American Indian and Alaska Native women than women in other minority groups. Women who experience gestational diabetes have a 20 percent to 50 percent chance of developing type 2 diabetes in five to 10 years after pregnancy. (CDC, National Diabetes fact sheet, 2005) Children whose mothers had diabetes during pregnancy are at increased risk of developing type 2 diabetes themselves. (Dabelea and Knowler, 2000)

## VI. Cardiovascular Disease Among Urban Indians

Cardiovascular disease (CVD) encompasses high blood pressure (hypertension), chest pain (angina pectoris), heart attack (myocardial infarction), stroke, and other heart and circulatory system disorders. Its connection with diabetes is even stronger and often more deadly than the link between diabetes and depression. Having diabetes can double to quadruple an American Indian or Alaska Native adult's risk of developing CVD. (Howard et al., 1999) It is their single greatest risk factor for contracting heart and circulatory system diseases.

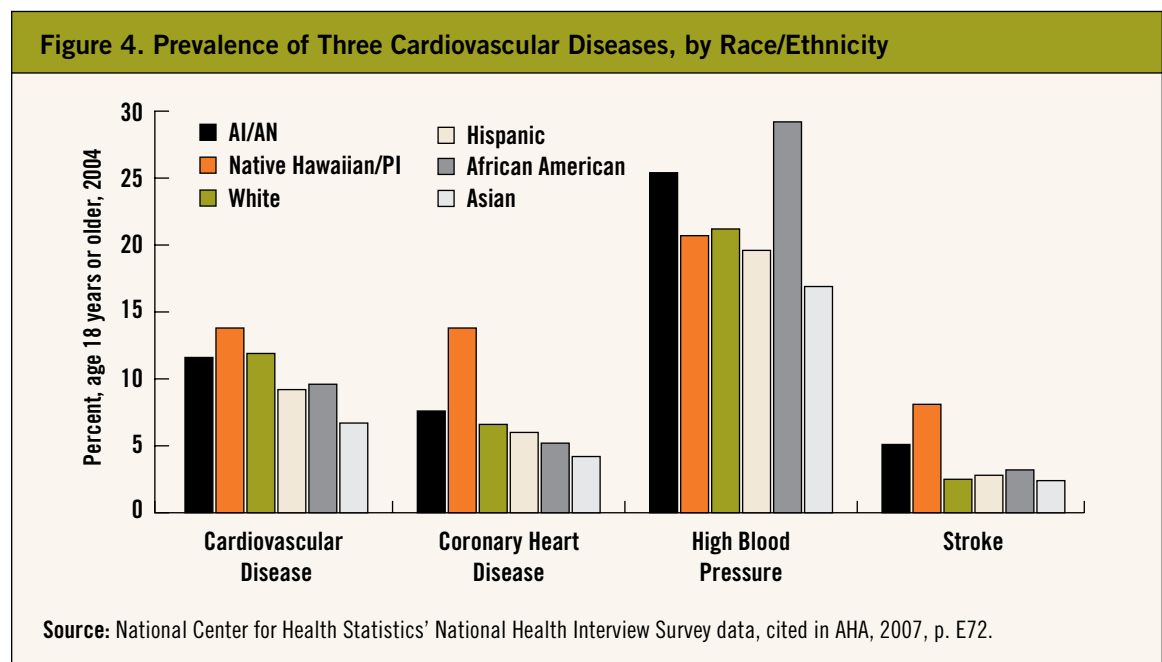
Like diabetes, CVD was once rare among American Indians and Alaska Natives. Now it is their leading cause of death. It kills more American Indians and Alaska Natives age 45 and older than cancer, diabetes and unintentional injuries—their second, third and fourth leading causes of death—combined. (IHS, Trends in Indian Health, 2000-2001) Diabetes raises the risk of stroke. The American Indian and Alaska Native stroke-related death rate due to diabetes is more than triple that of the general population. (Galloway, 2002) Perhaps even more troubling, obesity, physical inactivity and high blood pressure—all risk factors for CVD—are growing problems among American Indian and Alaska Native youth.

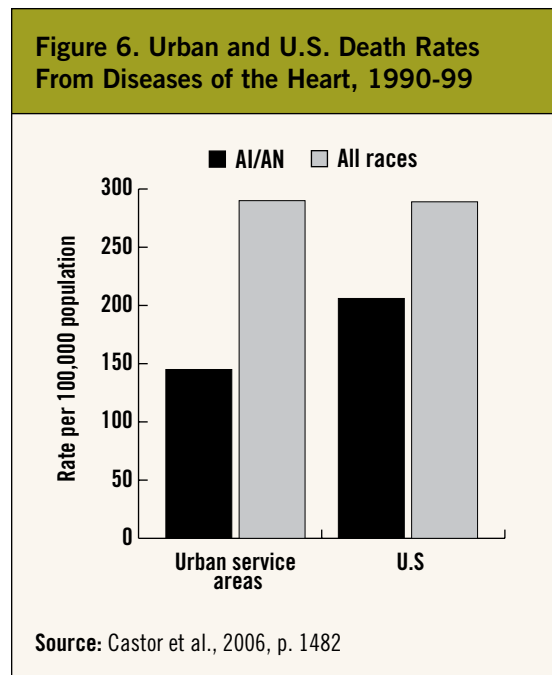
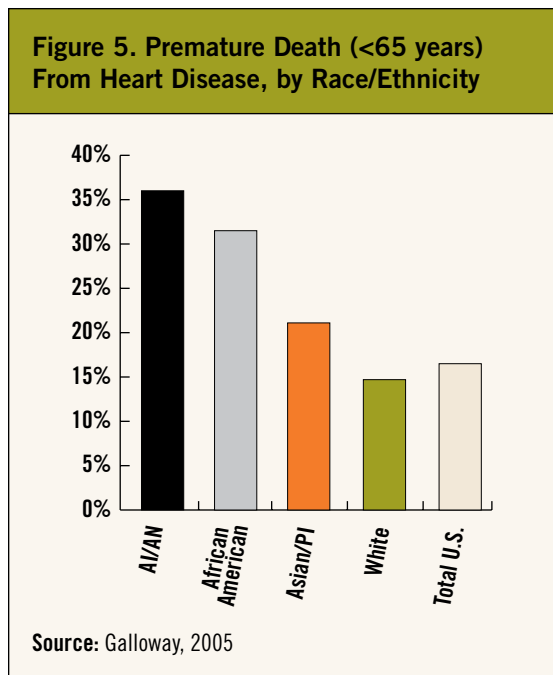
Studies show that contrary to trends for other U.S. racial and ethnic groups, CVD rates have been rising among American Indians. (Howard et al., 1999) Up to 25 percent of American Indian men ages 45 to 74 have signs of heart disease. (Ali et al., 2001) New cases of coronary heart disease (i.e., chest pain and/or heart attack) among American Indians are nearly twice that of the general population. (Howard et al., 1999)

Other studies show that coronary heart disease, high blood pressure and stroke are disproportionately prevalent among American Indians and Alaska Natives. (American Heart Association (AHA), 2007) (See Figure 4.)

Studies of premature death (death before age 65) disclose higher heart disease mortality rates among American Indians and Alaska Natives than among other racial and ethnic groups. (Harwell et al., 2005; Galloway, 2005) (See Figure 5.) Other studies also suggest that if racial misclassification on vital records were corrected, the American Indian and Alaska Native CVD death rate for those under 65 would be even more alarming. (Rhoades, 2005)

Heart disease is the leading cause of death among urban Indians living in the 34 urban Indian health

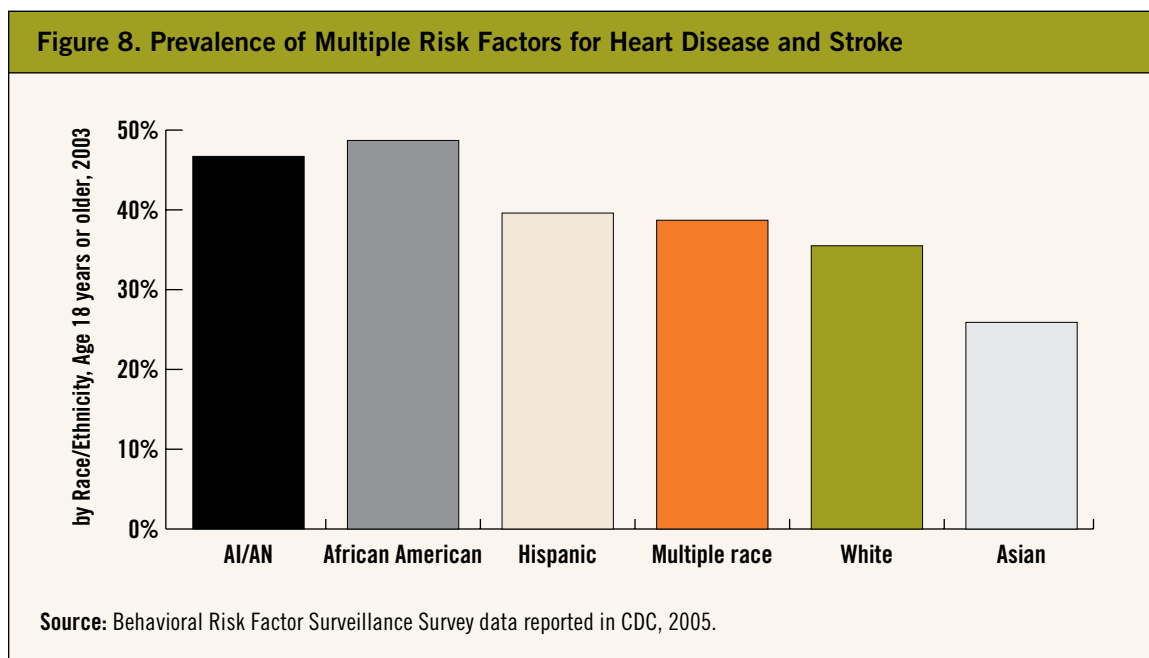




organizations' service areas. Their death rate from diseases of the heart is 145 per 100,000. (Castor et al., 2006) (See Figure 6.)

Having multiple risk factors for CVD magnifies the risk of heart disease and stroke. The 2003

Behavioral Risk Factor Surveillance Survey found that nearly half of American Indians and Alaska Natives had two or more risk factors for CVD, ranking them second only to African Americans. (CDC, 2005) (See Figure 8.)



In addition to diabetes, other risk factors for CVD include:

- **Obesity:** Studies show the American Indian and Alaska Native adult obesity rate is double that of the general population. (Galloway, 2002) Another study found that young urban Indians are two to three times as likely as their peers in the general population to either be obese or be at risk of becoming obese. (Smith and Rinderknecht, 2003)
- **Cigarette Smoking:** Cigarette smokers have two to four times the risk of coronary heart disease as nonsmokers. (US DHHS, 1989) With a rate of 32 percent, a larger percentage of American Indian and Alaska Native adults smoke than any other racial or ethnic group. (CDC, 2006)
- **High Blood Pressure:** High blood pressure is considered both a form of CVD and a risk factor for other forms of CVD. Once uncommon among American Indians and Alaska Natives, it is now highly prevalent. Hypertension among American Indian tribes in Arizona, North Dakota, South Dakota and Oklahoma ranges from 21 percent to 41 percent. (Welty, et al., 2002) Overweight American Indian and Alaska Native youth also have significantly higher blood pressure than other youth. (Smith and Rinderknecht, 2003)
- **Cholesterol:** Elevated blood cholesterol levels raise the risk of coronary heart disease. The 1997 Behavioral Risk Factor Surveillance Survey found higher rates of high cholesterol among American Indians and Alaska Natives than among other racial and ethnic groups in three states. Several studies indicate that low-density lipoprotein (LDL) cholesterol (i.e., the “bad” cholesterol) is more strongly related to cardiovascular disease among American Indians and Alaska Natives than in the general population. (Galloway, 2002; Howard, et al., 2000; Welty, et al., 2002)
- **Post-Traumatic Stress Disorder:** As previously described, many American Indians and Alaska Natives suffer from post-traumatic stress disorder. A study found that American Indians and Alaska Natives with PTSD have nearly twice the prevalence of CVD as those without the disorder. (Sawchuck et al., 2005)

Relatively little is known about CVD risk factors among urban Indians specifically. The literature review for this report identified only one study of CVD risk factors among urban Indians, and it was conducted nearly 25 years ago. It found that those living in Minneapolis had an extremely high prevalence of diabetes, cigarette smoking and obesity and a moderately high prevalence of high blood pressure and blood cholesterol. (Gillum et al., 1984)



## VII. Models of Success

Despite the challenges discussed above, high quality care is being provided through several innovative programs, many of which are offered by urban Indian health organizations. These programs offer the best possible care for their patients because they understand and address the specific needs and concerns of American Indians and Alaska Natives. Their cultural sensitivity encourages urban Indians to seek care when they need it and adopt healthier lifestyles. These programs serve as models, which can be replicated and built upon. The following examples highlight the variety of ways that urban Indian health organizations and other health care providers and researchers meet the needs of the urban population they serve.

- The American Indian Community House in New York City promotes urban Indian wellness, not just clinically but by giving American Indians a place to share and celebrate their identity in an often impersonal city. It hosts community events in “the Circle,” a vast gathering space with hardwood floors and natural lighting. Its contemporary art gallery and performing arts department promote American Indian and Alaska Native artists.
- The Indian Walk-In Center in Salt Lake City hosts health fairs with traditional Native American dancing, basketball tournaments and a diabetes awareness “fun run.” It refers clients to three local health clinics that it has business partnerships with and that collect data on patient outcomes for future study.



**Martin Waukazoo, CEO of the Native American Health Center in Oakland, Calif., speaks passionately about the needs of the urban Indian community.**

- In addition to its community health center, the Seattle Indian Health Board in Seattle operates a family medicine residency-training program and manages the Urban Indian Health Institute. Also focusing on preventive medicine, the Seattle Indian Health Board runs a statewide urban Indian tobacco education and cessation program under contract with the state health department.
- The Native American Health Center in Oakland, Calif., has housing projects for the poor and homeless.



**Ground breaking ceremonies for the Hunter Health Center located in Wichita, Kan.**

- The Hunter Health Center in Wichita, Kan., was originally an urban Indian health organization but has evolved into one of the largest health centers serving the general public in the state.
- The Native American Rehabilitation Association of the Northwest in Portland, Ore., was initially a drug treatment center but has evolved into a medical clinic. It now hosts a major suicide prevention effort.
- The Urban Inter-Tribal Center of Texas in Dallas has partnered with shoe manufacturer Nike, Inc., to provide custom-made orthopedic shoes to Native people with diabetes.
- The Native American Cancer Research Corp. (NACR) in Denver partnered with local urban Indian groups and the American Indian Clinic in Los Angeles to develop, test and implement programs that train female urban Indian volunteers (“Native Sisters”) to guide others through the often bewildering medical

bureaucracy. Early phases of the project focused on cancer education and improving mammography rates. It has since been expanded to cover other chronic diseases and conditions. Research conducted in conjunction with the project has expanded knowledge about urban Indian health tremendously. NACR also developed a culturally appropriate American Indian tobacco education and cessation program in the Denver region, hosts an annual “wellness event” and powwow honoring local Native American cancer survivors, sponsors weekly weekend “health walks” at Denver public parks, and has launched a community obesity-prevention initiative.

- The Alaska Native Medical Center in Anchorage offers patients traditional healing services and counseling by elders upon referral from a staff clinician. More than 90 percent of visits to the traditional healing clinic are for counseling or pain-related complaints. (Mala, personal communication, 2007) Likewise, the Veteran’s Administration Medical Center in Phoenix provides traditional healing methods for Navajo veterans for a variety of emotional disorders.
- A decade-old national initiative to combat diabetes among American Indians and Alaska Natives illustrates how adequate financial resources can yield significant improvements in health. In 1997, the Indian Health Service and



**The South Dakota Urban Indian Health, Inc. “Bike to Book” program provides new or refurbished bikes plus helmets to elementary school-age children so that they can ride to school for exercise and get there on time.**

other government agencies created the Special Diabetes Program for Indians (SDPI) to help prevent and treat diabetes among American Indians and Alaska Natives living on reservations, in rural areas and in cities. Data collected

by the SDPI can provide crucial insights on urban Indians, who typically are excluded from routine health surveillance systems. According to the American Diabetes Association,

diabetes prevention efforts made possible by SDPI—including increased physical activity programs in schools, wellness programs and increased nutrition education—have contributed to significant increases in the availability of diabetes prevention, treatment services and care for targeted populations.

- The Urban Indian Health Institute of the Seattle Indian Health Board has successfully retrieved national urban Indian health data from three sources: the U.S. census, the National Center for Health Statistics’ vital statistics records, and the Centers for Disease Control and Prevention’s Youth Risk Behavioral Survey. It also has completed or is working on analyses using data from these and other sources.
- The Strong Heart Study (SHS) has been tracking CVD among American Indians on reservations since 1988 and is widely considered the most comprehensive resource on the subject. The largest epidemiological study ever of American Indians, the SHS offers the advantage of including multiple communities (13 tribes in three geographic areas) and continuing over many years. The SHS incorporates extensive physical measurements, interviews regarding risk behavior and dietary intake, and recent genetic sequencing. Information gathered will contribute to our overall understanding of disease pathways and genetics of CVD, and has added to the growing body of literature demonstrating the critical importance of CVD among American Indians today. The SHS is also the largest longitudinal study in the United States looking at CVD in people with diabetes. (Strong Heart Study Web site)
- Native American Cancer Research works with the Colorado Department of Public Health and Environment to help increase data collection within Denver—where 43 percent of the Indian populations resides—and with the Ute Mountain Ute Reservation. Through the use of convenience sample data collection, they provided needs assessment data for more than 300 American Indians in 2006-2007 as compared to almost no similar urban Indian data collected prior to that initiative.

## VIII. Conclusion

The findings outlined in this report illustrate the depths of the urban Indian health crisis. Decades of neglect have placed urban Indians at greater risk of unnecessary death and disability. Although the United States continues to work to address racial and ethnic disparities in health care, urban American Indians and Alaska Natives have been mostly missed in the efforts, and special attention must be paid to make sure they are included in future initiatives. Most important, in the short term, data collection and access to services must be

addressed to provide the high-quality care that this population deserves.

The United States has promised to care for this population's health. Yet, without informed dialogue and targeted action, the health of urban Indians will continue to decline and promises will continue to be broken. The evidence cries for greater attention, and we hope that this report helps assure that urban Indians are not allowed to remain an invisible tribe.

## Appendix A: A History of Broken Promises

It would be difficult, if not impossible, to fully appreciate the health crisis that afflicts urban Indians without understanding the historic forces that reshaped it from a predominantly rural to an urban population. This appendix provides a history of federal relations with American Indians and Alaska Natives, with an emphasis on the policies, practices and events that fueled their migration away from rural areas and into cities.

### The History of American Indian and Alaska Native Urbanization

Many American Indians, from the Mound Builders of the Midwest to the Pueblo tribes of the Southwest, have a long tradition of living in urban areas. For centuries, American Indians lived in villages of varying sizes in every part of the country.

European colonization, however, altered American Indian and Alaska Native living conditions forever. Newcomers often forcibly removed Indians from their lands or created conditions whereby tribes uprooted themselves.

The federal government originally considered tribes sovereign foreign nations and dealt with them through formal treaties. (O'Callaghan, 1855) In a series of landmark legal cases in the early 1800s, the U.S. Supreme Court redefined Indian tribes as "domestic dependent nations," to whom the government had a trust obligation comparable to those of a legal guardian to a ward. Many of those obligations arose from treaties, many of which promised tribes health care providers and medical supplies. Congress, the court ruled, possessed plenary authority over Indian affairs under the U.S. Constitution and, with it, a duty to ensure Indians a life of health and decency.

However, Congress and the executive branch largely ignored those rulings, and with the passage of the American Indian Removal Act of 1830 began to forcibly expel thousands from the East to the trans-Mississippi West. The colonization of those Western lands fueled conflict between tribes and settlers. In the 1850s, the government began forcing many Indians to move off their lands to designated areas called reservations.

The pace of Indian migration to cities accelerated after 1886, when Congress passed the General Allotment Act, also known as the Dawes Act. This law took millions of acres out of Indian hands by dividing reservations among their inhabitants into homesteads ranging from 160 acres to as little as five acres. "Excess" lands were at first sold or given away to non-Indians, and later non-Indians were allowed to buy Indian allotments. This one-time division of land permanently harmed American Indians, as Indian families were forced to subdivide their plots again and again from one generation to the next. In a short time, the descendants lacked sufficient land to farm, ranch or bequeath to their heirs. Millions of acres fell out of Indian ownership, causing extreme economic hardship. As conditions on reservations deteriorated, government officials encouraged Indians to move to nearby towns and villages to work as farm hands, laborers and domestics.

Meanwhile, epidemics of smallpox, measles, whooping cough, pneumonia, trachoma and tuberculosis swept through reservations in the 1890s and 1900s, killing entire families. Sometimes these diseases were introduced by sick children who were sent home from government-sponsored mission, boarding and trade schools where officials expected they would be assimilated into mainstream culture. Many of their parents loathed doing so, but sent them nonetheless as a means to escape starvation and disease. Other children were forcibly sent against their and their families' will. By 1900, forced removal, wars, disease and poverty had reduced the American Indian population to less than 300,000. This situation fit neatly into the general perception that Indians were "vanishing," making it easier for their needs and dire situation to be overlooked.

When the United States declared war on Germany in 1917, thousands of Indians joined the armed forces, bought war bonds and took jobs in defense plants. Congress recognized their patriotism in 1924 by passing a law granting all American Indians U.S. citizenship. Many states, however, refused to recognize Indians as state citizens, some failing to until 1965. The federal government, meanwhile, did little else to ease poverty on reservations, and in the

years following World War I many Indians chose to remain in cities rather than return to impoverished conditions on reservations.

The reservation system was disastrous for American Indians. It destroyed traditional Native economies and led to abject poverty, environmental degradation, poor housing, malnutrition, unemployment, and ill health. To keep from starving, Indians began seeking day labor jobs in non-Native towns and cities.

Conditions on reservations remained dire into the 1920s, and religious missionaries and others pressed Congress to act. It responded by sponsoring a national study conducted by Lewis Meriam of the Institute of Government Research. Released in 1928, the Meriam Report's main conclusions remain as relevant now as they did then. The "overwhelming majority of the Indians are poor, even extremely poor," it found. It was difficult to measure the depth of their plight due to inadequate and inaccurate statistics and vital records, "one of the most essential tools in the promotion of public health and the control of preventable disease." Due to inadequate funding, the performance of the federal office then responsible for Indian health fell "markedly below" standards maintained by the U.S. Public Health Service as well as military and veteran health agencies. (Brookings Institution, 1928)

Congress then passed the Indian Reorganization Act of 1934, which was expected to improve conditions on reservations by giving tribal leaders more control over local affairs. The country, however, was still reeling from the Great Depression, and, despite new services that helped reduce Indian deaths due to infectious diseases, federal funding for Indian health remained inadequate.

The Hoover Commission Report of 1948 on federal government restructuring declared the Indian Reorganization Act a failure and called for a new direction in Indian policy. Thus began one of the most profoundly damaging episodes in recent American Indian history. Some members of Congress and the executive branch concluded that the only solution to America's centuries-old "Indian problem" was for Indians to cease being Indian. They launched a policy of assimilation that would transplant thousands from rural reservations into the urban American mainstream and declare that

many thousands more were no longer "American Indians" to whom promises were owed, but simply "Americans."

In the 1950s, the U.S. Bureau of Indian Affairs (BIA) began a formal national rural-to-urban relocation program that promised occupational training and jobs to Indians who moved to cities. Job placement centers were created in Denver, Salt Lake City and Los Angeles. By 1957, nearly 7,000 Indians had been relocated. Many were completely unprepared for city life and quickly slipped into poverty and poor health.

Congress, meanwhile, directed the BIA to compile a list of tribes that it deemed economically stable enough to be released from federal wardship. In 1953, it passed a nonbinding resolution expressing its belief that all tribes in California, Florida, New York and Texas and specific tribes in six other states should "at the earliest possible time ... be freed from federal supervision and control." (House Concurrent Resolution 108) Congress also passed a law that year that undercut tribal sovereignty by giving many states jurisdiction over most criminal and civil matters on reservations within their bounds. Over the next several years, Congress officially terminated federal recognition of 109 Indian tribes, absolving itself of obligations owed to more than 36,000 Indians. Indian lands were sold, with the proceeds going to the dissolved tribes. But those sums did not come close to compensating for the value of abrogated trust obligations or the pain of being told that, in the government's eyes, they were no longer Indian.

Termination was yet another disastrous policy for Indian tribes, as evidenced by the rapid financial decline of the Menominees of Wisconsin. State and local regulation of the tribe's lumber industry forced the closure of its mill, and the tribe's previously stable economy crashed. According to the 2000 census, Menominee County, which was created in the wake of the tribe's dissolution and whose boundaries are coterminous with that of its former reservation, had a 25 percent poverty rate, more than eight times that of the Wisconsin county with the lowest rate. Many other terminated tribes across America have suffered similar hardship. In 1977, the American Indian Policy Commission called for the reinstatement of most tribes, but the majority remain dissolved.

The general public became much more aware of the Indians' story during the 1960s. Some urban Indian communities began opening free storefront health clinics staffed by volunteers. Young Indians, meanwhile, founded the American Indian Movement in Minneapolis to address police brutality against their people and demand their long-ignored rights. Television coverage of the occupation of Alcatraz Island in 1969 and the violent exchange at Wounded Knee, S.D., in 1973 exposed millions of Americans for the first time to the desperate conditions in rural and urban Indian country. Those uprisings also galvanized many Indians, both on and off reservations. After centuries of erosion, Indians began to reconstruct their national identity.

In 1970, President Richard Nixon sent Congress an unprecedented "special message" on Indian affairs urging a decisive break with past failed policies. Assimilating Indians by terminating their tribes, he said, was morally and legally indefensible and clearly worsened their standard of living. He asked Congress to repudiate the policy formally, to pledge to carry out its treaty and trustee obligations, and to grant Indians control over Indian programs whenever their leaders requested such authority. The policy came to be known as "self-determination without termination." It has been reconfirmed by every succeeding president and remains the guiding principle of contemporary federal Indian policy. Nixon's message also singled out Indian health and the growing urban Indian population as issues requiring special attention. His nearly 40-year-old observations on those subjects, like those of the Meriam Report issued almost a half-century earlier, remain depressingly relevant. Indian health, he said, lagged decades behind that of the general population. Many officials had no idea that more Indians lived in towns and cities than on reservations, with three-fourths of them living in poverty. The "biggest barrier" to serving urban Indians was simply locating and identifying them. They were, Nixon said, the "most deprived and least understood segment of the urban population." (Nixon's Special Message to Congress, July 8, 1970)

The growing American Indian civil rights movement and Nixon's call for a new policy direction finally inspired Congress to pass the Indian Health Care Improvement Act (IHCA). The law explicitly acknowledges that "the health status of Indians is

far below that of the general population" and that the government's "special responsibilities and legal obligations to the American Indian people" require it to provide "all resources necessary" to improve the health of all Indians—and urban Indians specifically—"to the highest possible level."

### **The Basis of the Federal Role in Urban Indian Health**

The U.S. Constitution, adopted in 1787, gave Congress sole authority to regulate commerce with Indian tribes and gave presidents the power to make treaties with them. For the better part of the next century, presidents negotiated and Senates ratified hundreds of such treaties, many of which explicitly obliged the government to provide doctors, medicines, hospitals and other health services to Indians in exchange for land and peace. Most of those pacts remain valid, yet unfulfilled.

Treaty negotiations were essentially an executive action with Senate approval. However, Indian affairs had evolved as a domestic issue, leaving out the House of Representatives. To reflect this reality, in 1871 Congress passed legislation that shifted the basis of Indian relations from treaties to laws. During the next half-century, Congress appropriated funds for Indians on an ad hoc basis with little oversight. Indian aid was frequently diverted to other purposes, and their health suffered.

The situation improved marginally with the passage of the Snyder Act of 1921. It formally made the BIA the hub of federal appropriations "for the benefit, care, and assistance of the Indians throughout the United States" and specifically for their "conservation of health." (The Snyder Act, Public Law 67-85, November 2, 1921) In 1954, Congress transferred responsibility for Indian health from the BIA to the U.S. Indian Health Service (IHS), a new branch of the Department of Health, Education, and Welfare's Public Health Service. The change occurred during the height of the termination and relocation era, and many tribes viewed it with deep apprehension.

The first formal federal effort to address urban Indian health was launched in 1968 when IHS director Dr. Emery Johnson persuaded Congress to allocate \$300,000 for a clinic in Rapid City, S.D.

Meanwhile, local Indian leaders in Seattle opened a free clinic the following year and brought the idea of helping urban Indians to the attention of Senator Henry M. Jackson, then chair of the Senate Interior Committee. This led to the drafting of the Indian Health Care Improvement Act of 1976. (Indian Health Care Improvement Act, Public Law 94-437, September 30, 1976).

### Urban Indian Health Organizations

The Reagan administration broke precedents set by the Nixon, Ford and Carter administrations and sought to eliminate urban Indian health funding. Congress resisted, but in 1983 the administration succeeded in cutting the IHS budget in half. The number of urban Indian health organizations fell from 43 to 34, and the urban Indian health system has never fully recovered.

In February 2006, the George W. Bush administration proposed eliminating the urban Indian health program, arguing that urban Indian health organization clients could use federally supported community health centers that serve the general public. No funding increase for community health centers was included to offset the additional expense of new Indian patients or to provide community health center staff members with relevant cultural competency training. The lack of advance consultation with urban Indian health

professionals led to a national outcry. Prominent American Indian and Alaska Native organizations testified before Congress against the cuts and reminded Congress that the federal government's responsibility does not end at the reservation border.

Without IHS funding, the UIHO would not be able to provide the same quality care currently required by the urban American Indian and Alaska Native population. UIHOs offer special medical, psychological and cultural services that specifically target urban American Indians and Alaska Natives. Recently, one UIHO reported, "We have a lot of patients who won't go anywhere else. They worry about finances, what they see as racism, and they're intimidated by the health care system."

Challenges to the legitimacy of urban Indian financing have arisen in recent years. During hearings regarding legislation to reauthorize the 1976 Indian Health Care Improvement Act, the Department of Justice raised concerns about health programs exclusively for urban Indians as possibly violating the equal protections clause of the 14th Amendment to the Constitution. While federal officials have occasionally raised this challenge over the 30 years of the urban Indian health program, legal reviews and Congressional scholars have repeatedly clarified that the Congress, with its plenary authority over Indian affairs, can and has repeatedly legislated on behalf of urban Indians and such actions do not violate the 14th Amendment.

## Appendix B: Acronyms Used in the Report

<b>AAMC</b>	Association of American Medical Colleges
<b>AHA</b>	American Heart Association
<b>AHRQ</b>	Agency for Healthcare Research and Quality
<b>AIAN</b>	American Indian and Alaska Native
<b>BIA</b>	Bureau of Indian Affairs
<b>BRFSS</b>	Behavioral Risk Factor Surveillance System
<b>CDC</b>	Centers for Disease Control
<b>CHC</b>	Community Health Centers
<b>CMS</b>	Centers for Medicare & Medicaid Services
<b>CRIHB</b>	California Rural Indian Health Board
<b>CVD</b>	Cardiovascular Disease
<b>DHEW</b>	Department of Health, Education and Welfare
<b>DHHS</b>	Department of Health and Human Services
<b>FQHC</b>	Federally Qualified Health Center
<b>HCFA</b>	Health Care Financing Administration
<b>IHCIA</b>	Indian Health Care Improvement Act
<b>IHS</b>	Indian Health Service
<b>LDL</b>	Low-Density Lipoprotein
<b>MCH</b>	Maternal and Child Health
<b>NACR</b>	Native American Cancer Research
<b>NCES</b>	National Center for Education Statistics
<b>NCHS</b>	National Center for Health Statistics
<b>OMH</b>	Office of Minority Health
<b>PTSD</b>	Post Traumatic Stress Disorder
<b>SAMHSA</b>	Substance Abuse and Mental Health Services Administration
<b>SCHIP</b>	State Children's Health Insurance Program
<b>SDPI</b>	Special Diabetes Program for Indians
<b>SHS</b>	Strong Heart Study
<b>SIHB</b>	Seattle Indian Health Board
<b>UIHC</b>	Urban Indian Health Commission
<b>UIHI</b>	Urban Indian Health Institute
<b>UIHO</b>	Urban Indian Health Organization
<b>YRBS</b>	Youth Risk Behavior Survey



## Appendix C: Tables

**TABLE 1**

Socioeconomic Characteristics Among Urban American Indians and Alaska Natives, 2000

Socioeconomic Characteristics	UIHO Service Area Populations		Nationwide Populations	
	AIAN %	General %	AIAN %	General %
Below 100% of federal poverty level	24.1	13.5	25.7	12.4
Below 200% of federal poverty level	48.2	42.7	51.4	46.0
Adults (age>18) below 100% of federal poverty level	21.2	5.5	22.7	5.0
Children (age<18) below 100% of federal poverty level	30.1	18.4	31.6	16.6
Older than 25 years with a high school diploma or GED	70.4	79.6	70.9	80.4
Older than 25 years with a 4 year college degree	13.0	28.9	11.5	24.4
Unemployed	11.5	6.3	12.3	5.7
Single parent household	46.1	31.0	43.5	29.2
With disability	23.9	19.1	24.3	19.3

AIAN=American Indian/Alaska Native; UIHO=Urban Indian Health Organization

Source: Castor et al., 2006

**TABLE 2**  
 Poor Birth Outcomes/Risk Factors and Factors Associated  
 with Infant Death Among American Indians and Alaska Natives

	UIHO Service Area Populations				Nationwide Populations			
	AIAN		General		AIAN		General	
	%	95% CI	%	95% CI	%	95% CI	%	95% CI
<b>Poor Birth Outcomes/Risk Factors (1991-2000)</b>								
Low birth weight (<2,500 grams)	6.8	(6.6-7.0)	7.3	(7.2-7.3)	6.6	(6.5-6.7)	7.4	(7.4-7.4)
Premature birth	12.2*	(12.0-12.5)	10.8	(10.8-10.9)	12.1*	(12.0-12.3)	11.1	(11.0-11.1)
Mother's age <18	8.2*	(8.0-8.4)	4.6	(4.5-4.6)	8.2*	(8.2-8.3)	4.8	(4.8-4.9)
Mother unmarried	60.3*	(59.8-60.8)	34.8	(34.7-34.8)	57.4*	(57.2-57.7)	31.9	(31.9-31.9)
Received late or no prenatal care	7.4*	(7.2-7.6)	3.4	(3.4-3.5)	7.3*	(7.2-7.4)	3.0	(3.0-3.0)
Smoked during pregnancy	17.2*	(16.9-17.5)	10.7	(10.7-10.7)	21.1*	(21.0-21.3)	14.3	(14.3-14.3)
Alcohol use during pregnancy	0.3	(0.3-0.4)	0.3	(0.3-0.3)	0.3	(0.3-0.4)	0.3	(0.3-0.3)
<b>Factors Associated with Infant Deaths (1995-2000)</b>								
Mother unmarried	70.0	(61.4-79.5)	49.5	(48.8-50.2)	65.6	(62.1-69.1)	47.2	(46.9-47.5)
Low birth weight (<2,500 grams)	54.2	(46.6-62.6)	65.5	(64.7-66.3)	49.7	(46.7-52.8)	65.2	(64.8-65.6)
Premature birth	53.7	(45.5-62.8)	64.5	(63.7-65.4)	50.1	(46.9-53.6)	64.5	(64.1-64.9)
Smoked during pregnancy	25.2	(19.4-32.2)	15.5	(15.0-16.0)	29.8	(27.3-32.5)	19.5	(19.3-19.7)
Mother's age <18	11.2	(7.9-15.4)	7.0	(6.8-7.3)	10.2	(8.9-11.6)	7.6	(7.4-7.7)
Alcohol use during pregnancy	9.2	(5.8-13.9)	2.2	(2.0-2.4)	7.4	(6.2-8.9)	2.3	(2.2-2.4)
Received late or no prenatal care	7.4	(4.7-11.1)	3.0	(2.8-3.2)	7.1	(5.9-8.4)	2.7	(2.6-2.7)

AIAN=American Indian/Alaska Native; UIHO=Urban Indian Health Organization; CI=confidence interval

\*Significantly higher for AIAN compared to the general population

Source: Castor et al., 2006

**TABLE 3**  
**Poor Mortality Rates Among American Indians and Alaska Natives, 1990–1999**

Overall and Cause Specific	UIHO Service Area Populations				Nationwide Populations			
	AIAN		General		AIAN		General	
	Rate per 100,000	95% CI	Rate per 100,000	95% CI	Rate per 100,000	95% CI	Rate per 100,000	95% CI
Infant mortality	8.8 <sup>^*</sup>	(7.9-9.8)	6.6 <sup>^</sup>	(6.5-6.7)	8.9*	(8.5-9.3)	7.1	(7.0-7.1)
SIDS	1.8 <sup>^*</sup>	(1.4-2.2)	0.7 <sup>^</sup>	(0.7-0.7)	1.6*	(1.5-1.8)	0.8	(0.7-0.8)
All Ages/All Causes	573.9	(564.4-583.7)	883.2	(882.4-884.0)	769.0	(763.7-774.4)	902.1	(901.7-902.4)
Heart disease	145.0	(139.8-150.3)	290.0	(289.6-290.5)	206.0	(203.0-208.9)	289.0	(288.8-289.2)
Cancer	98.0	(94.0-102.2)	201.8	(201.5-202.2)	137.3	(135.0-139.6)	210.0	(209.9-210.2)
Accidents	42.7*	(40.7-44.9)	30.9	(30.8-31.1)	60.4*	(59.2-61.6)	35.5	(35.4-35.5)
Chronic liver disease and cirrhosis	27.5*	(25.9-29.3)	12.2	(12.1-12.3)	25.5*	(24.7-26.3)	10.4	(10.3-10.4)
Diabetes	32.0*	(29.7-34.4)	20.8	(20.7-20.9)	44.7*	(43.4-46.0)	22.9	(22.8-22.9)
Cerebrovascular diseases	34.5	(32.0-37.2)	61.2	(61.0-61.5)	48.8	(47.4-50.3)	65.4	(65.3-65.5)
Assault (homicide)	9.0	(8.3-9.9)	11.4	(11.3-11.5)	9.5*	(9.1-9.9)	8.2	(8.2-8.2)
Suicide	8.1	(7.3-8.9)	11.2	(11.1-11.3)	10.9	(10.5-11.4)	11.6	(11.6-11.7)
Chronic lower respiratory diseases	21.8	(19.9-24.0)	39.8	(39.7-40.0)	30.0	28.9-31.1)	42.1	(42.0-42.2)
Influenza and pneumonia	20.6	(18.6-22.8)	26.5	(26.3-26.6)	25.1*	(24.0-26.2)	23.8	(23.7-23.8)
Alcohol-related	28.1*	(26.5-29.9)	10.1	(10.0-10.2)	26.6*	(25.8-27.4)	7.3	(7.3-7.4)
Drug-related	9.0	(8.2-9.9)	9.4	(9.4-9.5)	10.5	(10.1-10.9)	12.9	(12.9-13.0)
Injury by firearms	8.0	(7.2-8.8)	14.0	(13.0-14.1)	6.0	(5.7-6.3)	6.2	(6.2-6.2)

Note. Cause-specific mortality rates for all ages are listed in rank order based on total numbers of deaths.

**AIAN=American Indian/Alaska Native; UIHO=Urban Indian Health Organization; CI=confidence interval**

<sup>^</sup>Rate calculated only for counties with populations greater than 250,000 based on 1990 census

\*Significantly higher for AIAN compared to the general population

Source: Castor et al., 2006

**TABLE 4**  
Highest Increased Rates of Risk Behaviors in Urban AI/AN versus White Youth

<b>Behavior</b>	<b>AI/AN</b>	<b>Whites</b>	<b>AI/AN Increase</b>
Ever been forced to have unwanted sex	16.4%	6.6%	Two-Fold
Physically hurt by a boy/girlfriend*	17.0%	8.0%	
Ever been pregnant or gotten someone pregnant	10.6%	3.6%	
Had sexual intercourse for the first time before age 13	12.4%	4.4%	
Ever used heroin	7.4%	2.6%	
Ever used injected drugs	5.1%	1.9%	
Tried marijuana for the first time before age 13	17.5%	8.7%	
Used marijuana on school property †	15.3%	5.5%	
Used cocaine one or more times †	8.7%	3.6%	
Carried a weapon on school property †	14.4%	6.0%	
Threatened or injured with a weapon on school property*	17.5%	7.4%	
Carried a gun †	12.7%	4.3%	Three-Fold
Attempted suicide	20.7%	6.8%	
Did not go to school because of feeling unsafe†	12.6%	3.7%	
Medical treatment from a fight*	10.8%	3.1%	Nearly Five-fold
Medical treatment from a suicide attempt	10.5%	1.9%	

Source: Youth Risk Behavior Survey Data (1997-2003), reported in UIHI 2007.

**TABLE 5**  
Adequacy of databases for provision of data with acceptable precision

<b>Federal Dataset</b>	<b>Adequacy for AI/AN Analyses</b>
<b>Census</b>	
Census 2000	A
American Community Survey	A
Current Population Survey – March	B
Current Population Survey – Monthly	B
Survey of Income and Program Participation	B
<b>NCHS/CDC</b>	
National Health Interview Survey	C
National Survey of Family Growth	C
National Immunization Survey	C
National Health and Nutrition Examination Survey	D
<b>AHRQ</b>	
Medical Expenditure Panel Survey	D
<b>HCFA</b>	
Medicare Current Beneficiary Survey	D
<b>SAMHSA</b>	
National Household Survey on Drug Abuse	D
<b>NCES</b>	
National Household Education Survey	B
Early Childhood Longitudinal Survey – Birth Cohort	D
Early Childhood Longitudinal Survey – Kindergarten Cohort	D

\* Level of detail possible that can be attained with adequate precision effective sample sizes

A Detailed cross-classification possible 4,000 or more

B Some limited cross-classification 1,000 to 3,999

C Only simple distributions 200 to 999

D Analysis not possible Under 200

Source: Unpublished UIHI analysis using data from Waksberg 2000

## Appendix D: Commission Information

### The Urban Indian Health Commission



Pictured from left to right (top row) Linda Burhansstipanov, Jennie Joe, Eve Slater, Theresa Maresca (bottom row) Jeffrey A Henderson, Michael Bird, Michael Trujillo, Clifford Trafzer, Jarrett Clinton

Not pictured: Philip Lee, Andy Schneider, Martin Waukazoo, Charles Wilson

The Urban Indian Health Commission is a select group of leaders convened by the Robert Wood Johnson Foundation and the Seattle Indian Health Board's Urban Indian Health Institute to examine health care issues facing urban American Indians and Alaska Natives.

**Commissioners:** Michael Bird, Linda Burhansstipanov, Jarrett Clinton, Jeffrey A. Henderson, Jennie Joe, Theresa Maresca, Eve Slater, Clifford Trafzer, Michael Trujillo, Martin Waukazoo, Charles Wilson

**Senior Advisors:** Philip Lee, Andy Schneider

**Robert Wood Johnson Foundation Senior Program Officers:** Michael Painter, Debra Pérez

**Seattle Indian Health Board Staff:** Ralph Forquera, Maile Taualii, Jessica Folkman

## About the Commissioners



**Michael Bird, M.P.H., M.S.W. (Santa Domingo/San Juan Pueblo)** – Mr.

Bird was most recently employed as the Native American director region 6 for Valueoptions New Mexico, a private mental health consulting firm. From 2001 to 2005, Mr. Bird was executive director for the National Native American AIDS Prevention Center in Oakland, Calif. In 1999, he was the first American Indian elected as president of the American Public Health Association. He holds a Master of Social Work from the University of Utah and a Master of Public Health degree from the University of California, Berkeley.



**Linda Burhansstipanov, Dr.P.H., M.S.P.H., C.H.E.S. (Cherokee Nation of Oklahoma)** – Linda B, as she is called, is grants director for the

Native American Cancer Research (NACR) and president of both NACR and Native American Cancer Initiatives in Pine, Colo. received her M.S.P.H. and Dr.P.H. from the University of California, Los Angeles. has authored more than 90 peer-reviewed scholarly articles and received multiple honors including the Susan G. Komen for the Cure Survivorship Professor award in 2006.



**Jarrett Clinton, M.D., M.P.H.** –

Dr. Clinton is a professor in the Department of Global Health at the College of Public Health at the University of South Florida and affiliate professor in the Department of Internal Medicine at the University of South Florida, College of Medicine. Until 2004, Dr. Clinton was a regional health administrator for the Department of Health and Human Services. He was a senior fellow at the JFK School of Government at Harvard, received his Master of Public Health at Johns Hopkins University, and earned his medical degree from Kansas University School of Medicine. He has a current appointment as advisor for the Center for Public Health Preparedness at the School of Public Health, University of South Carolina



**Jeffrey A. Henderson, M.D., M.P.H. (Cheyenne River Sioux)** – Dr.

Henderson is the president and CEO for the Black Hills Center for American Indian Health in Rapid City, S.D. He received his medical degree from the University of California, San Diego and his Master of Public Health from the University of Washington. He completed a residency in primary care internal medicine at the University of Washington and practiced with the Indian Health Service as a primary care internist for more than five years.

In 1998, Dr. Henderson founded the Black Hills Center for American Indian Health, a community-based, nonprofit organization whose mission is to enhance the wellness of American Indians living on the Northern Plains through research, service, education and philanthropy. He is a principal site investigator for the Stop Atherosclerosis in Native Diabetics Study (SANDS), co-investigator on the prominent Strong Heart Study and an assistant professor with the Native Elder Research Center at the University of Colorado at Denver Health Sciences Center.

*It is my hope that the work of this Commission will shine a bright and focused light upon urban Indian health issues and disparities that can then be effectively addressed by legislators, policymakers, Tribal and business leaders, and other committed individuals in both the public and private sectors. I also hope that our findings will spur an increased research interest and funding for urban Indian health research. It would be especially gratifying if our work eventually inspires a new generation of American Indians to pursue health-related education with the goal of helping to address the issue of urban Indian health. — Jeffrey Henderson*



**Jennie R. Joe, Ph.D., M.P.H., M.A. (Navajo)** – Dr. Joe is a professor

in the Department of Family and Community Medicine and the director of the Native American Research and Training Center in the

College of Medicine at the University of Arizona. She also serves on faculty in the university's American Indian Studies. Dr. Joe received her M.A., M.P.H. and Ph.D. from the University of California, Berkeley. She is a fellow in the Society of Applied Anthropology and is on a number of national and international committees and organizations. She is a major contributor to the body of health-related work on American Indians.

*I am a member of the Urban Indian Health Commission because we all need to advocate for access to quality health care for those who are often disenfranchised like Indians living in the cities. My background in health-related research and lifelong work with urban and tribal communities enables me to understand and witness first-hand the growing disparity in the health status of American Indians and Alaska Natives. Such experiences and perspectives are needed to make this Commission's work meaningful. It is my hope that the Commission's efforts will not only highlight these growing health disparities but will rally policy-makers and other advocates to search for more effective ways to address these disparities. — Jennie Joe*



**Theresa Maresca, M.D. (Mohawk)**

— Dr. Maresca is clinical associate professor at the University of Washington School of Medicine, Department of Family Medicine and the director of the Native

American Center of Excellence at the University of Washington. is a graduate of Vassar College and the Albert Einstein College of Medicine in New York. Maresca has served as a clinician in numerous rural and urban Indian settings in Arizona, South Dakota and Washington, and continues her practice with the Snoqualmie Tribe of western Washington. has been involved in American Indian medical education and is the former site director for the Seattle Indian Health Board's family practice residency program. 1999, she received the Distinguished Service Award for teaching excellence from the University of Washington.

*My background as a practicing primary care physician within American Indian health settings enables me to contribute perspective of patients and their families and a view of the complexity of health issues my people face on a day-to-day basis. I also bring experience*

*with the health systems challenges urban clinicians face in the field and concern for the continuation and development of the Native health workforce of tomorrow. My hope for the Commission's work is that urban Indian health issues will receive appropriate and consistent national attention, with funding to our level of need. — Theresa Maresca*



**Eve Slater, M.D.** — Dr. Slater is senior vice president-worldwide policy for Pfizer Inc and associate clinical professor of medicine at Columbia University College of Physicians and Surgeons. She received her M.D.

from Columbia University's College of Physicians and Surgeons. Dr. Slater was the first woman chief resident in medicine at Massachusetts General Hospital, served as chief of the Hypertension Unit at MGH, and served as assistant professor of medicine at Harvard Medical School. She worked at the Merck Research Laboratories in biochemical endocrinology and later in clinical regulatory development, working on HIV/AIDS treatments. Dr. Slater was named by President George W. Bush as assistant secretary for health shortly after the September 11, 2001, attack on the United States. Dr. Slater serves on the Board of Visitors of the New England Conservatory of Music and was a director of Vertex Pharmaceuticals (Cambridge, Mass.), AnorMED, Inc. (Langley B.C.), Phase Forward (Waltham, Mass.), VaxGen (Brisbane, Calif.) and Theravance (South San Francisco, Calif.). She is an accomplished flutist, having soloed with Arthur Fiedler and the Boston Pops.



**Clifford E. Trafzer, Ph.D. (Wyandot)**

— Dr. Trafzer is professor of history and ethnic studies, director of American Indian studies and director of the Costo Native American Research Center at the

University of California, Riverside. He was recently named the Rupert Costo Chair in American Indian Affairs at the university. He received his B.A. and M.A. from the University of Northern Arizona and his Ph.D. from Oklahoma State University. Dr. Trafzer has authored a number of award-winning books and recently co-edited "Native Universe," a book accompanying the opening of the National Museum of the American Indian in Washington D.C.





**Michael H. Trujillo, M.D., M.S., M.P.H. (Laguna Pueblo) – Dr.**

Trujillo is the executive director for program development and community outreach at the Translational Genomics Research

Institute (TGen) in Phoenix. He manages a unique initiative for a cutting-edge research institute to engage communities in the development of studies according to identified needs and disease risks. Previously, Dr. Trujillo served as associate professor in the Department of Family/Community Medicine and associate director for minority and community programs and outreach for the Regional Cancer Research and Treatment Center at the School of Medicine at the University of New Mexico. In 1994, he was appointed by President William J. Clinton as director for the Indian Health Service, becoming the first full-blood American Indian to serve in that office. He completed two four-year terms, retiring in 2002 as an assistant surgeon general/rear admiral in the U. S. Public Health Service. Dr Trujillo holds appointments at Arizona State University as clinical professor at the Center of Metabolic Biology and as professor of practice at the School of Public Affairs. He remains active in numerous local, regional and national committees and advisory boards dealing with American Indian and Native Alaskan issues, underserved populations, health disparities and health manpower issues. He has been recognized numerous times for his leadership and efforts to improve American Indian and Native Alaskan health care.



**Martin Waukazoo (Rosebud Sioux)**

– Martin Waukazoo is the CEO for the Native American Health Center in Oakland, Calif., a position he has held for more than 20 years. Mr. Waukazoo is a graduate of Black

Hills State University. He was an all-American high

school basketball player. Mr. Waukazoo moved to the San Francisco Bay Area after graduating from college, working in various Native organizations before becoming associate director and then executive director for the Native American Health Center. He is now actively involved in the Seven Directions Project, a mixed-use housing and community development project in the Bay Area.

*I am a member of the Urban Indian Health Commission because I firmly believe that my fellow Commission members have the experience, knowledge and expertise to ensure that urban Indian health programs continue on for the next generation. My 25 years working as the administrator for an urban clinic has enabled me to contribute to the Commission's work the perspective of the challenges, problems and obstacles in meeting the health needs of Indians living in urban areas. It is my hope that the Commission's efforts will create awareness among the greater population of the needs of American Indians living in urban areas that have resulted since the relocation of Indian people to urban areas. — Martin Waukazoo*



**Charles B. Wilson, M.D., M.S.H.A., Sc.D. (Cherokee) – Dr.**

Wilson is senior advisor at the University of California, San Francisco Global Health Sciences. He co-founded the Global AIDS Interfaith Alliance

in 2000 and serves as chairman of its board of trustees. He received his M.D. and neurosurgery training at Tulane University and his M.S.H.A. from the School of Business at the University of Colorado. He founded the Brain Tumor Research Center at UCSF and served as director until 1997. He served as a senior fellow at the Institute for the Future in Menlo Park. In 2001, he became senior advisor with the Health Technology Center, an organization in San Francisco that forecasts the short- and long-range future of medical and information technology.

## About the Advisors



**Philip R. Lee, M.D., M.S.** — Dr. Lee is senior scholar at the Institute for Health Policy Studies and professor emeritus of social medicine in the Department of Medicine, School of Medicine at the University of

California, San Francisco. From July 1993 to January 1997, Dr. Lee served as assistant secretary for health, U.S. Department of Health and Human Services, a role he held previously in the Johnson administration. In that position, he spearheaded a series of “listening sessions” in Indian Country to elicit issues and problems being faced by American Indians and Alaska Natives. Among those offering testimony were members of the often-overlooked urban American Indian population. Dr. Lee received his M.D. from Stanford and his M.S. from the University of Minnesota.



**Andy Schneider, J.D.** — Mr. Schneider is a principal with Medicaid Policy LLC, a corporation he founded in January of 2000 offering assistance on Medicaid issues to state agencies, providers, managed

care organizations and Indian tribes. He is adjunct associate professor of health policy at George Washington University School of Public Health & Health Services. Mr. Schneider spent 17 years on Capitol Hill. From 1979 to 1994, he served as counsel to the Subcommittee on Health and the Environment of the House Commerce Committee, then chaired by Representative Henry Waxman (D-Calif.). He was instrumental in the passage of the 1980, 1988, 1990 and 1992 amendments to the Indian Health Care Improvement Act (P.L. 94–437). A current client is the Kaiser Commission on Medicaid and the Uninsured. He has co-authored a number of Medicaid policy analyses, including *The Medicaid Resource Book* (July 2002), a widely used reference.

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