

Taking Action: Health Promotion and Outreach with American Indians and Alaska Natives

Literature Review

September 1, 2006 (historical)

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Introduction

Healthy People 2010, the national health-planning roadmap, “is firmly dedicated to the principle that—regardless of age, gender, race or ethnicity, income, education, geographic location, disability, and sexual orientation—every person in every community across the Nation deserves equal access to comprehensive, culturally competent, community-based health care systems that are committed to serving the needs of the individual and promoting community health.” *The National Institutes of Health Strategic Plan to Reduce and Ultimately Eliminate Health Disparities* focuses on three overarching goals: research, research infrastructure, and public information and community outreach.

Although the health status of most Americans has steadily improved, the improvement for American Indians and Alaska Natives has not kept pace. Health disparities still exist in areas such as:

- Alcohol and substance abuse
- Chronic diseases such as cardiovascular disease, diabetes, asthma, obesity, cirrhosis and liver disease, and arthritis
- Cancer
- Environmental hazards
- Injury
- Child health
- Mental health
- Violence
- Suicide
- Tuberculosis
- HIV/AIDS.

American Indian and Alaska Native populations are culturally distinctive and diverse. In spite of the multiplicity of American Indian and Alaska Native groups, there are striking cultural similarities and concepts that can be used in the design and implementation of public health programs. These similarities include tribal values such as the importance of family and community, cooperation, sharing, harmony with nature, and an oral tradition that incorporates the lessons learned and values of the tribe in the form of storytelling and respect for others.³⁴

Most tribes appreciate the importance of research to their preservation and sustainability. At the same time, most have reasonable concern about researchers’ tribal knowledge and cultural sensitivity. Research should include several key strategies, including attention to the cultural competence of the research team, planning for research with tribal communities, increasing local capacity, sharing results first with the community, and implementing a study in Indian country.^{34,54}

Methodology

As part of the planning process for the trans-NIH conference, Taking Action: Health Promotion and Outreach with American Indians and Alaska Natives, a literature search was undertaken to identify published reports that discussed peer-reviewed health education and/or outreach efforts focused on American Indians and Alaska Natives. The following databases were searched: PubMed, PsycINFO, Web of Science, Health and Psychosocial Instruments, and CINAHL. Population search criteria used were American Indian or Native American or First Nation or Alaska Native or Inuit. Content search criteria included outreach and health promotion to American Indians and Alaska Natives, cultural values, communicating with American Indian and Alaska Native, health issues/concerns, accessing care, early

diagnosis, and treatment. Where possible, the search was limited to the last 3 years. Abstracts returned were classified as research or review.

Members of the conference planning committee forwarded lists of peer-reviewed literature and fugitive literature, and where possible copies of these materials were obtained and reviewed. In addition, the Web sites of each of the four sponsoring institutes from the National Institutes of Health—Arthritis, Musculoskeletal and Skin Diseases; Dental and Craniofacial Disorders; Child Health and Human Development; and Aging—and the Web sites of the Indian Health Service (IHS), U.S. Department of Health and Human Services (DHHS), the DHHS Office of Minority Health, Association of American Indian Physicians, and Centers for Disease Control and Prevention were searched for reports describing health education and/or outreach programs focused on the populations of interest. Preference for inclusion was given to peer-reviewed articles and documents, with fugitive literature used to fill in gaps as warranted, particularly in the section focusing on health education/outreach programs.

Documents were divided into groups, based on titles and abstracts. The segments corresponded to those in the half-day conference planned for November: demographics; health status; language, culture, values, and attitudes; health beliefs, behaviors, and status; and health care providers and systems. Within those segments, particularly for the language, health beliefs, and providers sections, articles and fugitive literature were grouped by emphasis on a particular health focus, such as arthritis, diabetes, or heart disease. In addition, emphasis was given to articles focusing on topics covered by the four sponsoring institutes. Background information for each of the sections was selected based on repetition in more than one article or document, although generally, only one document was cited for any particular item.

For the latter three sections of the review, documents were scanned for case studies on potential model interventions or programs that were developed using social marketing principles. Model studies/interventions were included, to the extent possible, when steps for developing, implementing, and evaluating the study/intervention were included in the documentation. In instances where cases were not found on topics specific to the sponsoring institutes, cases that appeared to have a potential for adaptation and application on a range of topics were selected and highlighted. In addition to the initial search for documents, case studies included in the Centers for Disease Control and Prevention's series of CDCynergy editions, particularly the Social Marketing and American Indian/Alaska Native Diabetes editions, were also reviewed.

Demographics of the American Indian and Alaska Native Populations in the United States

The American Indian and Alaska Native populations are culturally diverse, geographically dispersed, and educationally and economically disadvantaged. According to the 2000 U.S. Census, 4.1 million individuals—approximately 1.5 percent of the U.S. population—identify themselves as American Indians or Alaska Natives.⁵⁵ This number includes 2.5 million who reported only American Indian or Alaska Native heritage, and 1.6 million who reported one or more other races as well.⁵⁵ Since 1990, the American Indian and Alaska Native population has grown at twice the rate of the U.S. population.⁵⁵ This growth, coupled with a higher mortality rate, has resulted in American Indians and Alaska Natives being an average of 5 years younger than the general population.^{49,30,56}

The American Indian and Alaska Native population is far from being a homogeneous group; it comprises 562 different tribes with unique cultures, histories, languages, and geography.^{12,37} Of the people who described themselves in the 2000 U.S. Census as American Indian, 79 percent specified a tribe. The four tribes with the most members reported were Cherokee, Navajo, Latin American Indian, and Choctaw. The four largest Alaska Native tribal groupings were Eskimo, Tlingit-Haida, Alaska Athabaskan, and Aleut.⁵⁵ Unlike other minority populations in the United States, the tribes are sovereign governments with inherent rights described in the U.S. Constitution and from treaties that govern their relationship with the United States.^{37,30}

Most American Indians live in Western states (43 percent), while 31 percent live in the South, 17 percent in the Midwest, and 9 percent in the Northeast.⁵⁵ In 2000, the three states with the largest American Indian populations were California, Oklahoma, and Arizona, and the cities with the largest American Indian populations were New York and Los Angeles.⁵⁵ Contrary to popular belief, a minority (34 percent) of American Indians and Alaska Natives live in American Indian areas.⁵⁶

Although the majority of American Indians and Alaska Natives speak English as their main language (72 percent), it is estimated that 200 Native languages are spoken at present.¹⁷ In the 2000 census, 18 percent of American Indian and Alaska Native respondents said that they spoke a language other than English at home but spoke English “very well,” and 10 percent reported that they did not speak English very well.⁵⁶

The educational attainments of American Indians and Alaska Natives are below the national average and vary by place of residence.⁵⁶ Approximately 71 percent of Native peoples are high school graduates, compared with 84 percent of the White population, but educational attainment varied considerably among tribal groupings.⁵⁶ American Indians and Alaska Natives are less than half as likely as Whites to have obtained a bachelors degree or higher.^{12,14,56} However, the number of tribal colleges, which weave native culture throughout the curriculum, has increased from 1 in 1968 to 32 in 2001. Tribal colleges are now located in 11 states and serve 30,000 American Indian students from more than 250 nations.¹ These institutions provide experiences in sharp contrast to those of older American Indians who were often educated at U.S. Bureau of Indian Affairs (BIA) boarding schools that sought to assimilate Indian children into the dominant culture.³⁷ During the 1930s and 1940s, approximately half of Indian children were sent to BIA boarding schools.³⁰

Educational achievement and income are closely related. American Indians and Alaska Natives are one of the most economically depressed groups in the United States, with one out of every four American Indians and one out of every five Alaska Natives living in poverty.^{11,56} This is approximately three times higher than the number of Whites who live in poverty in the United States.¹¹ The unemployment rate for American Indians and Alaska Natives is 2.5 times higher than the general population.³⁰ American Indians and Alaska Natives who participated in the labor workforce were less likely to have management or professional jobs (24 percent versus 33 percent for the whole population).⁵⁶ In addition, salaries for American Indians and Alaska Natives who worked full time and year round were substantially lower (\$28,900 for men and \$22,800 for women) than those of the whole population (\$37,100 for men and \$27,200 for women).⁵⁶ Higher proportions of American Indians and Alaska Natives worked in the service, construction, transportation, farming, fishing, and forestry industries.⁵⁶

While rural and urban communities in the United States are increasing their access to advanced telecommunications, American Indian and Alaska Native communities lag far behind. In 1999, a report from the U.S. Commerce Department stated that only 76 percent of rural Native American households have a telephone, compared to 94 percent of the general population.¹³ Significant variation occurs, however. On some reservations, such as the Navajo Reservation in New Mexico and the San Carlos Reservation in Arizona, fewer than 20 percent of households have telephones.⁹ Many tribes lack 911 service, which puts them at risk individually and as communities during crises.³ Even in areas with basic telecommunications infrastructure, the high cost of phone connections and service prevent many American Indians and Alaska Natives from having telephone service. In 1999, the average cost for basic telephone service on a reservation was \$100 per month.³

American Indians and Alaska Natives also have limited access to computers. The number of rural Native Americans with a household computer is much lower than the national average (27 percent versus 42 percent), as is access to the Internet (19 percent versus 26 percent).^{9,13} However, American Indians and Alaska Natives living on reservations have access to technology in some community facilities, and are the most likely to access the Internet at schools and libraries of any racial group.³ Lack of access to the Internet further exacerbates what analysts have called the “digital divide,” which prevents full participation in educational, economic, and healthcare opportunities and widens the gap between those with access to digital technology and those without.

Telephones and computers are not the only technologies in short supply on Native lands. Many American Indian and Alaska Native communities lack basic infrastructure such as roads, utilities, and adequate housing. The number of American Indians and Alaska Natives living in overcrowded conditions (15 percent) is 2.5 times the rate for the overall population.³⁷ Twelve percent of American Indian households do not have electricity.⁹ Lack of access to basic and advanced infrastructure and technologies limit American Indians and Alaska Natives' economic development, educational attainment, workforce training, and access to appropriate healthcare.^{3,13}

Health Status

Compared to other Americans, American Indians and Alaska Natives are disadvantaged at each stage of the lifespan, with disparities in infant mortality, life expectancy, mortality from chronic diseases, and access to and quality of care.⁴⁸ One in three American Indians and Alaska Natives is uninsured, and more than one-third report having no access to regular health care.^{18,72} The life expectancy for American Indians and Alaska Natives is 70 years compared with 75 years for the general population.⁴⁶ American Indians die at higher rates than other Americans from alcoholism (770 percent), tuberculosis (750 percent), diabetes mellitus (420 percent), accidents (280 percent), homicide (210 percent), and suicide (190 percent).³⁰ The leading causes of death for American Indians and Alaska Natives of all ages in 2002 were heart disease, cancer, accidents, diabetes, and cerebrovascular disease.⁴⁷ In some tribes, type 2 diabetes has become an epidemic, with rates as high as 50 percent.²² Moreover, native peoples are more likely than any other racial group in the United States to rate their health as fair to poor.⁴⁷

For American Indians and Alaska Natives, health disparities begin at birth. The infant mortality rate, an accurate indicator of the health of a population, is nearly 1.5 times higher among American Indians and Alaska Natives than most other ethnic groups.⁴⁷ Although high rates of neonatal deaths occur in areas served by the Indian Health Service (21 percent higher than Whites), some urban areas have neonatal death rates that are considerable higher.³¹ American Indian and Alaska Native babies are 3.2 times more likely to die from Sudden Infant Death Syndrome (SIDS) than are White babies. In fact, SIDS is the second leading cause of death of American Indian and Alaska Native infants.² Factors that contribute to infant mortality are tobacco use, alcohol use, lack of education on safe sleep practices, and inadequate prenatal care.^{2,58,31}

In addition, the health status of American Indian and Alaska Native children is lower than that of most children in the United States.³¹ A recent study of more than 11,000 children living on 12 reservations found that 47 percent of 5-year-old American Indian boys were overweight, compared to 26 percent of the general population. Almost half of American Indian children ages 5 to 17 are overweight, putting them at increased risk of diabetes, heart disease, and stroke.⁷¹ Despite the risks, these children often do not get adequate preventive care. One major study found that only half of the adolescent American Indians studied had received any form of preventive health care in the previous 2 years.⁴ American Indian and Alaska Native children have a higher risk than other racial groups for homicide and mental health problems such as depression, substance abuse, and suicide.⁴ The leading cause of death in American Indian and Alaska Native youth ages 1 to 20 is unintentional injury, and alcohol is involved in one-third of these deaths.⁴

The majority of American Indian and Alaska Native children have tooth decay (79 percent of children 2 to 5 years old), and the prevalence of tooth decay increases with age (91 percent of 15 to 19 year olds).³⁶ Compared with the general U.S. population, American Indian and Alaska Native children, adolescents, and adults experience three times more oral disease.²⁶ Most American Indian and Alaska Native adults and elders (98 percent) have lost teeth from dental decay, oral trauma, or periodontal disease.³⁶ Furthermore, American Indians and Alaska Natives with risk factors such as diabetes, tobacco use, substance abuse, and HIV/AIDS have a even higher rate of oral cancer, tooth decay, periodontal disease, and tooth loss.^{36,26}

American Indian and Alaska Native adults are plagued by an excess burden of preventable diseases, some of which are caused by smoking. The rate of cigarette, pipe, and cigar smoking is higher among American Indians than other groups, including a high rate of smoking by women of childbearing age.¹⁵

While cigarette smoking by adults in the United States has been decreasing since the 1960s, smoking by American Indians continues to increase, although prevalence varies greatly among tribal groups.^{64,53} A study of American Indians in Oklahoma found that 43 percent of men and 38 percent of women were current smokers. An additional 14 percent of American Indian men in Oklahoma reported use of smokeless tobacco.¹⁵ American Indians in the Southwest have a low smoking rate (19 percent of men and 10 percent of women), but about half of Northern Plains American Indians smoke.⁵³ In comparison, the U.S. median rate of smoking is 21 percent. Some studies report that many American Indians begin smoking before the age of 11.^{15,43} Smoking is a major risk factor for lung and other cancers, chronic obstructive lung disease, cardiovascular disease, and stroke; use of chewing tobacco increases the risk for mouth, throat, and esophageal cancers.^{15,43,66} According to the Indian Health Service, two of every five American Indian deaths in the United States are caused by smoking.⁴³

The prevalence of many diseases is increasing in American Indian and Alaska Native communities. Diabetes is twice as common as in the general population (15.3 percent compared with 7.3 percent), and it is steadily increasing. Approximately 30 percent of American Indians and Alaska Natives more than 55 years old have been diagnosed with diabetes.¹⁰ Cardiovascular disease is the leading cause of death in American Indians and Alaska Natives, and it also appears to be increasing.^{47,33} Cardiovascular disease is associated with common illnesses in Native communities, such as diabetes, cigarette smoking, and obesity.⁶⁷ Obesity begins early in Native American youth and continues throughout adulthood. Considerably more adult American Indians are overweight or obese than adults in the general U.S. population.⁷ This poses significant short- and long-term health risks because both type 2 diabetes mellitus and cardiovascular disease can be consequences of obesity.⁷¹

Cancer is the second leading cause of death of American Indians and Alaska Natives.⁴⁷ In the 1990s, deaths from lung cancer declined for African Americans, Hispanics, Whites, and Asians, but climbed by 28 percent for American Indians and Alaska Natives.⁶⁶ Deaths from stomach and oral cancers have increased in both male and female American Indian and Alaska Natives while decreasing in almost all other racial groups in the United States. Since 1992, breast cancer rates in American Indian and Alaska Native women have decreased, but only 46 percent survive 5 years, compared to 76 percent of White women. Disparities in survival rates are caused in part by cancer diagnosis at a late stage and the quality of treatment.^{40,25}

Studies suggest that American Indians and Alaska Natives experience a higher frequency of mental distress and mental illnesses, such as alcohol dependence and posttraumatic stress disorder, than do other Americans.⁵ The suicide rate of 15- to 24-year-old American Indian and Alaska Natives is 2.5 times greater than for this age group in the general U.S. population.⁶⁵ Suicide is the fifth leading cause of death for male American Indians and Alaska Natives of all ages and the tenth leading cause of female death.⁵⁹ Alcohol abuse is common in American Indians, with daily drinking less common than occasional binge drinking.⁵¹ The extremely high death rate of American Indians and Alaska Natives is due in part to alcohol-related events including accidents, homicide, and suicide, and physical illnesses such as liver disease.⁴¹

Because of the political, social, cultural, and spiritual diversity among the hundreds of different American Indian and Alaska Native nations, mental illness has different meanings for different groups. However, there is widespread stigma in Native communities against seeking help for mental illness. In addition, staffing of mental health programs for American Indians and Alaska Natives is less than 50 percent of what is needed for minimally adequate care, and not all providers are culturally competent. These factors prolong illnesses that could be prevented or treated.²⁹ Compared to the general population, American Indians have fewer available mental health services, have higher dropout rates, are less likely to respond to treatment, and have negative opinions of non-Indian mental health care providers.³⁰ For mental distress, American Indians are more likely to seek the help of traditional healers than non-Indian mental health care providers.⁵

Arthritis is also a major chronic health problem for American Indian and Alaska Native elders. The American Indian and Alaska Native populations have the highest estimated prevalence of arthritis among all U.S. races.⁶⁰ Almost half of Native peoples older than 65 report having arthritis, and 16 percent of

elders report having rheumatism. American Indians also have a higher prevalence of inflammatory diseases, including rheumatoid arthritis, systemic lupus erythematosus, and scleroderma than does the general population.⁴⁴ In particular tribes, up to 7 percent of adults have rheumatoid arthritis with features that differ from the general population, including younger age at onset, more severe disease, and family members with the disease.^{39,16} Northern Plains tribes have a high prevalence of systemic lupus erythematosus, often with increased severity of disease.³⁹ Although little research has been done on rheumatic diseases in American Indian children, one report suggests that juvenile rheumatoid arthritis may be five times more common in American Indian children than in Whites.³⁹

Chronic diseases such as arthritis and diabetes that are widespread in American Indian and Alaska Native communities often result in difficulties with basic functions such as walking, climbing stairs, and lifting. A recent national study of functional limitations among American Indian and Alaska Native elders found that 19 percent of those ages 45 to 49 years and 67 percent of those aged 85 or older had functional disabilities. Overall, more than one-fourth of American Indians and Alaska Natives older than age 45 had a functional limitation. Elders living below the poverty level were the most disabled, yet only 12 percent were receiving public assistance.²⁰

A large body of research shows that health disparities continue to persist for American Indians and Native Americans compared with other ethnic and racial groups in the United States. A 2003 Institute of Medicine report confirmed that health disparities for U.S. minorities are pervasive and are associated with worse outcomes in many cases, and it described historical and contemporary inequality in medical care for minority populations.³⁸

Culture, Values, Attitudes, and Language

Hallmarks of traditional Native American culture include community values and spirit, permanence, patience, and humor during periods of dissonance. American Indian and Alaska Native culture is marked by strong organizations, networks, and community ties as well as a sense of tribal purpose and solidarity, despite vast differences among and within tribal groups.⁵⁰

In many American Indian and Alaska Native cultures, interactions on all levels contain the fundamental element of respect. Respect is how one presents himself or herself to the world and how one behaves. Respect is tied to being Indian and Native, and encompasses how individuals treat one another, focusing on treatment of every individual as equal and good.³⁴

The presence of elders is critical to the impact and the quality of culturally competent services. Elders can share knowledge about how to understand, solve, and prevent problems, as well as knowledge about treatment methods that have been used for generations. Elders speak strongly about cultural values and rules on how to conduct oneself within the family and community. Through elders, wisdom becomes a living, oral knowledge applied to current contexts.⁵⁰

American Indian culture is maintained through the telling of stories, particularly because it is a culture based on oral as opposed to written tradition. The spoken word is what gives life and meaning to Indian history and customs. Songs, chants, curing rites, prayers, lullabies, jokes, personal narratives, and stories most importantly are the means by which Indians transmit the heritage of their most significant lessons from one generation to the next.⁶³

Health Beliefs, Behaviors, and Status

Traditional American Indian and Alaska Native healing systems (Traditional Indian Medicine) focus on balancing mind, body, and spirit within the community context. Contrary to the Western approach to health and healing, American Indian and Alaska Native people find it peculiar to isolate one part of a person and only try to heal that part. Native American groups have practiced a holistic approach to healing for thousands of years. Traditional American Indian and Alaska Native healing practices center on

benefits to the emotional, spiritual, psychological, and cultural aspects of the tribal group. Practices of ceremony, prevention, and healing are embedded in the fabric of traditional Native life.⁵⁰

There are numerous health beliefs and practices within the various American Indian and Alaska Native tribes. Many tribes continue to practice traditional ceremonies that are tied to maintaining balance and well-being. The use of medicine men/women, traditional healers, and herbal remedies and medicines is a continued practice in many rural and urban areas.³⁴

The leading causes of death for American Indians and Alaska Natives of all ages in 2002 were heart disease, cancer, accidents, diabetes, and cardiovascular disease.^{47,52} Native peoples have significantly higher prevalence estimates of alcoholism, tuberculosis, diabetes mellitus, pneumonia/influenza, liver disease, suicide, and SIDS.¹⁸

The prevalence of smoking among American Indians is twice the rate of that reported for the general population. The rates of smoking among Indian women of childbearing age (18–44 years) are very high (43 percent). In some Northern Plain states, 45 to 52 percent of adult Indians smoke cigarettes, while Southwest tribes have much lower rates. Two out of five Indian deaths are attributable to smoking.^{27,34}

For centuries, many American Indian and Alaska Native tribes have viewed tobacco as a sacred plant with powerful properties, and in these tribes tobacco has been an integral part of many ceremonies and prayers. The Northern Plains tribal group, in particular, bases a large part of their spiritual philosophy around the concept of the “sacred pipe.” The challenge for many tribal communities is to establish effective tobacco control and prevention policies and activities, while remaining respectful of the historical and contemporary roles of traditional tobacco use, which have had and continue to have significant cultural and spiritual meaning.⁵³

Alcoholism among American Indians has reached epidemic proportions and has been described as the number one health problem among Indians. The Federal Government reports that the Indian alcoholism death rate is more than five times greater than that reported for all U.S. races.³⁴

Recent reports show that cancer is now the second leading cause of death in American Indian women over the age of 45. Among Alaska Natives, cancer ranks as the second leading cause of death. Although cancer incidence, mortality, and survival rates vary according to location and tribe, the 5-year survival rate for easily treatable cancers such as cervical cancer is poorer for American Indian and Alaska Native women than for any other ethnic group. This is due, in part, to inadequate screening and followup care. Native women often delay seeking medical treatment to attend to the needs of their nuclear and extended families. Although this behavior is not unique to Indians, the consequences for this population are especially harmful.³⁴ In addition, fewer American Indians and Alaska Natives participate in clinical trials that can potentially be beneficial.⁶⁷

Regarding care for arthritis and rheumatic diseases, American Indians most frequently endure the discomfort of chronic pain and episodic flares. American Indians generally do not readily ask for help, discuss pain, or disclose the intensity of a painful episode. Those with inflammatory arthritis may be more likely to discuss the functional impact of the condition than the painful aspects. American Indians with inflammatory pain who discontinued taking prescribed medications because of side effects tended to not pursue alternative therapies with their physicians. Therefore, researchers have concluded that chronic joint pain is generally undertreated in the American Indian population and that clinicians should be aware that American Indian patients do not emphasize pain symptoms. American Indians are overwhelmingly interested in arthritis self-help classes to learn more about the condition and ways to manage chronic arthritis.^{44,45}

Health Care Providers and Systems

Treaties govern the relationship of the tribes with the U.S. Government and provide for ongoing Government services to the American Indian and Alaska Native people as part of the payment for the

lands they surrendered to the U.S. Government. Both the Government agency responsible for providing health and education services and the relationship between American Indian and Alaska Native and that agency have changed over time. Federal health care for American Indian and Alaska Native evolved from military physicians providing health care to Indians who lived close to forts in the early 1800s, to immunization programs, and to systems for providing physicians and medications to tribes. The relationship was paternal rather than a partnership. The health status of American Indians remained poor.³⁷

The responsibility for Indian health was transferred from the War Department to the Department of the Interior and, in 1954, to the Surgeon General of the U.S. Public Health Service as IHS.³⁷

In 1957, a seminal report, "Health Services for American Indians," set out a new vision recognizing:

- The need for a substantial Federal Indian health program
- That all community health resources should be developed in cooperation with Indians communities on a reservation-by-reservation bases
- That Federal Indian health programs should be planned in each community and include State and local programs for certain service delivery components
- That efforts should be made to recognize obligations and responsibilities to Indian residents.³⁷

During the 1950s and 1960s, IHS focused on both providing primary health care services and on improving housing and sanitation conditions. Later, the focus evolved to building management skills and training in health professions for American Indians and Alaska Natives. During the later 1960s, a training center was started to train Indian community members as community health representatives to bridge the gap between the patients needing services and the health care professionals providing services. In 1975, Congress enacted the Indian Self-Determination and Education Assistance Act. This formed the legal foundation authorizing tribes to plan and deliver services appropriate to their diverse demographic, economic, and institutional needs. During the 1980s, additional funding to build modern health facilities and greater tribal involvement characterized the relationship between tribes and IHS. In the 1990s, legislation supported a pilot program allowing tribes to contract for services within the Bureau of Indian Affairs and IHS. The success of the pilot program resulted in making this authority permanent. Three models currently exist:

- Tribes operate and manage health services programs for their communities
- IHS manages the health care delivery services for American Indians and Alaska Natives living in geographic areas
- Urban Indian health programs that are not managed by American Indian and Alaska Native communities or by IHS but that received significant funding from IHS.³⁷

IHS includes 12 administrative units called area offices. These area offices are further divided into 150 service units, 84 of which are operated and managed by tribes. Included in the 12 area offices are 37 hospitals, 61 health centers, 4 school health centers and 48 health stations.³⁸ There are 34 urban programs, generally operated by local nongovernmental and nontribal organizations.⁵⁰

In 1999, urban programs served an estimated 130,000 urban Indians—with the majority providing medical services and the remainder offering only referral services or other services such as alcohol and substance abuse treatment. In 2001, urban programs received 1.15 percent of IHS funding, for a total urban budget just under \$3 million.¹⁸

In 2005, IHS provided personal health care services to more than 1.4 million American Indians and Alaska Natives, 42 percent more than in 1955. In addition, more than 200,000 Indians not personally receiving medical care from IHS or tribal programs live in or near Indian communities that benefit from IHS environmental, sanitation, and community public health programs.³⁷

Contrary to popular opinion, not all American Indian and Alaska Native are covered by IHS programs; instead there is a high number of uninsured individuals. Nationally, 24 percent of American Indians and Alaska Natives younger than 65 years were uninsured in 1998, compared with 14 percent of Whites.¹⁹

About half (49 percent) of American Indians and Alaska Natives younger than 65 have job-based or private coverage. An estimated 17 percent of American Indian and Alaska Native populations have coverage through Medicaid or other public programs.⁴⁸ Tribal clinics are legally required to provide care without charge, regardless of a patient's potential coverage. However, at the same time, IHS regulations require clinics to pursue "alternate resources" before using Federal resources.¹⁹

A recent General Accounting Office report found that the availability of primary health care—medical, dental, and vision—was largely dependent on the extent to which American Indians and Alaska Natives living in IHS areas were able to access the services at IHS-funded facilities. Other barriers to health care included travel distances, time between making an appointment and the service delivery, lack of transportation, gaps in services offered by the facilities, and difficulty in recruitment and retention of health care providers in frontier areas. Facilities are required to pay for outside providers' services from their operating budgets, which could lead to rationing of outside care. Those facilities with multiple funding streams, including IHS, other health care programs, and tribal funds, were better able to provide a variety of services.³⁵

Research Implications

Research calls for developing health research strategies and interventions that are consistent with American Indian and Alaska Native community and cultural values to decrease health disparities. To resolve some of the tensions between Western research methodologies and cultural American Indian and Alaska Native values, a compilation of studies suggests the following themes:

- Partner with local American Indian and Alaska Native people and organizations for assessment, planning, and implementation
- Use traditional and religious consultants
- Invite and support the community and tribal control of programs
- Pay attention to language
- Allow ample time to build trust and respectful relationships
- Use ongoing evaluation and be ready to make changes in the program
- Incorporate traditional, visual, and participatory activities into the intervention
- Seek tribal organization support⁶¹
- Move beyond identification of barriers
- Modify funding systems so that projects can evolve at a pace within the comfort zone of the community
- Develop programs that address mentoring new health professionals and community health workers
- Provide greater emphasis and documentation for evaluation and peer review of interventions with American Indian and Alaska Native populations
- Use a continuous stream of communication, before, during, and after research is concluded, paying special attention to obtaining appropriate permissions and tribal clearance, and support for research results, especially where publications are an issue.

Model Studies/Interventions

Language, Culture, and Values

American Indian Women's Talking Circle (AIWTC)—This pilot study was designed to assist the American Cancer Society in revising the Circle of Life breast health program for American Indians and Alaska Natives. In developing materials for AIWTC, it was recognized that in American Indian and Alaska Native cultures, education was traditionally provided through the telling of tribal stories by storytellers who were respected members of the tribal community. This was the preferred way of educating the young and refreshing the memories of older tribal members on how to do things, as they say, "in the people's way." Traditional tribal tales,

storytelling, and the use of respected members of the Indian communities became important features of AIWTC educational curriculum design. It was important that the educational material be presented in a familiar, comfortable, and culturally acceptable style. The talking circle format met all of these needs. Talking circles are designed to incorporate the spirit of Indian life into discussions about health by merging the tradition of oral storytelling with a contemporary education program about cervical cancer prevention, treatment, and control.³⁴

Participatory Action Research (PAR)—This community-based research project resulted in a series of five subprojects within the Indian Family Stories Project. The project focused on identifying community needs and designing action plans in partnership with individual communities. PAR provides a way of conducting research in a way that respects community knowledge and expertise, a core aspect of Indian culture. The PAR framework involves research that is community-based, action-oriented, and collaborative.²¹

Indian Family Wellness (IFW)—This research project focused on a culturally grounded, family-centered preventive intervention resulting in a model that includes a set of four mechanisms for designing culturally appropriate research and outreach. Those mechanisms, comprising the Tribal Participatory Research Model, include tribal oversight, use of a facilitator, training and employing community members as project staff, and culturally specific intervention and assessment. Although IFW was designed for use by a specific tribe, the four mechanisms have clear applicability to family-centered prevention research.¹⁷

Community Readiness Model in Native Communities—This pilot project resulted in development of a workshop and practical manual to provide communities with the tools and instruments to assess their community strengths, resources, needs, and barriers for use in development of effective and culturally specific alcohol and drug abuse prevention strategies. The Community Readiness Model was developed using two research traditions: psychological readiness for treatment and community development. Although the Community Readiness Model was developed specifically for alcohol and drug abuse prevention, it was created with a broader aim of assessing readiness for a gamut of problems. These range from health and nutrition issues to environmental issues, social issues, and personal problems. The model can therefore be applied to many kinds of community-based prevention initiatives.⁴²

Health Beliefs, Behavior, and Status

Health Perceptions among Older Urban American Indians—This study focused on how urbanized older American Indians perceived their health and how they managed their health problems.³²

Tribal Efforts Against Lead—This was a university /tribal partnership using lay health advisors (LHAs) to prevent lead poisoning among Native American children in northeastern Oklahoma, the site of one of the world's largest lead and zinc mining operations. The mines are no longer open; however, mine tailings have been used in building and road construction in the area, and as a result, the soil of several small communities around the mining area is contaminated. LHAs engaged in more than 3,600 education and/or outreach activities over the course of the intervention.⁴³

Pathways—This was a multicentered, randomized trial designed to test the effectiveness of school and family-based interventions for the primary prevention of obesity in American Indian students. The intervention had four major components: (1) a food service intervention that modified foods served in the school cafeteria, (2) a physical education component that increased physical activity at school, (3) a classroom curriculum that focused on knowledge and practices related to healthy eating and lifestyle habits, and (4) and a family component aimed at actively involving parents of children participating in the program to create a positive and supportive environment for modifying dietary practices and physical activity. The 3-year intervention program included 1,704 American Indian third- and fifth-grade students from 41 schools in 7 American

Indian communities. This culturally appropriate school intervention, which included both family and school environmental components, promoted positive changes in knowledge, cultural identity, and self-reported healthful eating and physical activity among American Indian children and environmental changes in the school food service.^{8,23,24,26,68–70}

It's Your Life—It's Our Future—This was a smoking cessation project based in 18 American Indian outpatient clinics in northern California. The project consisted of five phases: (1) working with the Indian community to identify needs and barriers related to smoking cessation, (2) designing or revising quit-smoking materials, (3) conducting the prevalence survey, and (4) implementing the program, and (5) evaluating the program. The project succeeded in two ways. First, it provided important information for Indian leaders and health planners because it documented that smoking is a very serious problem in American Indian communities. Second, it served as a model for implementing a culturally sensitive smoking cessation program.⁶⁴

Clinical Trials Education for Native Americans—This was a culturally specific clinical trials education curriculum that evolved from the National Cancer Institute–supported Clinical Trials Education for Colorado Providers. A multicultural team revised the curriculum using a collaborative process. Important lessons learned included allocating enough time and resources to tailor presentations to the target audience, addressing barriers to participation via culturally appropriate strategies, providing adequate information to enable participants to make informed decisions, and writing the curriculum as a team to enrich both examples and interactive experiences.⁶

Health Care Providers and Systems

Wisconsin Intertribal Managed Care Demonstration Project—This project provided tribal benefits counselors to increase the number of patients with public and private insurance coverage, to expand the range of health care options available to tribal members, and to increase third-party revenues for tribal clinics. In a 2-year trial, 6 Wisconsin tribal sites experienced a 78-percent increase in Healthy Start enrollments (Wisconsin's Medicaid program for pregnant women and children), compared with a 26-percent increase statewide. The participating tribes showed increased participation in the State Children's Health Insurance Program, called BadgerCare, at a rate on par with the statewide rate.¹⁹

Improving Health Insurance Coverage for American Indian Children and Families Under Healthy Families (SCHIP)—This study examined the policy and implementation barriers for American Indian and Alaska Native children to obtain Healthy Families (SCHIP) coverage in California, which has more American Indian and Alaska Native residents than any other single state in the United States. In 2000, Federal regulations were amended to exempt American Indian and Alaska Native children from any SCHIP cost sharing.⁶²

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