



National Eye Health  
Education Program

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American Indian  
and Alaska Native

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Diabetic Eye Disease  
Communication Plan



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
National Eye Institute

## Development of a Diabetic Eye Disease Program for American Indians and Alaska Natives

Eye health awareness and annual dilated eye exams are important to detect diabetic eye disease and preserve visual health among people with diabetes. The NEI's National Eye Health Education Program (NEHEP) sought to address this need among the American Indian and Alaska Native population by developing a culturally-specific diabetic eye disease education program. The NEHEP convened an American Indian Alaska Native Outreach Work Group in June 2002 to begin development of a communication plan to increase awareness of eye health among this population. The NEHEP invited representatives from various tribes, the IHS, and other national organizations. Following this first meeting, focus groups and key informant interviews were conducted at various sites. The resulting information provided the foundation for the development of this communication plan. One year later, in September 2003, the NEHEP reconvened the Work Group to share results and invite feedback on the plan. This communication plan is intended to serve as a guide for planning a national diabetic eye disease education program for the American Indian and Alaska Native population by providing:

- an understanding of what information on diabetic eye disease would be helpful for American Indian and Alaska Native communities
- suggestions for how to present the information in a culturally appropriate way
- methods for creating effective messages
- insight into appropriate materials development and available dissemination channels.

This plan is not all-encompassing, but serves as a beginning for a joint venture with American Indian and Alaska Native organizations, communities and programs to improve the eye health of American Indians and Alaska Natives with diabetes.

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## **I. INTRODUCTION**

### **Diabetes in the United States**

Approximately 11 million Americans are diagnosed with diabetes (CDC, 2002), and about 40 to 45 percent of all people with diabetes have at least mild signs of diabetic retinopathy (Klein et al., 1984), the most common ocular complication of diabetes. Other ocular complications include cataract and glaucoma. Diabetic retinopathy accounts for 12 percent of all new cases of blindness in working age adults (National Society to Prevent Blindness, 1980). People with diabetes are at significantly higher risk of blindness than the general population (Howie and Drury, 1978).

### **Diabetes Among American Indians and Alaska Natives**

Diabetes is common among American Indians and Alaska Natives and has increased substantially over the years. The age-adjusted prevalence of diabetes among American Indians and Alaska Natives is almost three times that of U.S. non-Hispanic whites (CDC, 1998). Although diabetes was rarely reported among American Indians and Alaska Natives 50 years ago, it is now a major cause of morbidity (Gohdes, 1995). Information from the Indian Health Service (IHS) national outpatient database shows that between 1990 and 1997 the prevalence of diagnosed diabetes increased by 29 percent. The increase in prevalence between 1990 and 1997 ranged from 16 percent in the Northern Plains region to 76 percent in the Alaska region (Burrows et al., 2000). Other researchers have also reported diabetes rates between 40 and 50 percent in some American Indian and Alaska Native communities (Lee et al., 1995; Will et al., 1997).

### **National Eye Institute**

Eye disease, a major public health problem in the United States, causes significant suffering, disability, loss of productivity, and diminished quality of life for millions of people. Convinced that visual disorders constituted a national problem that could be solved only by greater emphasis on vision research, Congress authorized the establishment of the National Eye Institute (NEI) in 1968 as part of the National Institutes of Health (NIH), U.S. Department of Health and Human Services. The Institute's mission is to find new ways to prevent, diagnose, and treat diseases of the eye and visual system, thus preventing, reducing, and possibly even eliminating blindness. The NEI is addressing this public health problem through programs of biomedical research, disease prevention, and health promotion.

## **National Eye Health Education Program Overview and Goals**

In 1991, the NEI established the National Eye Health Education Program (NEHEP), which it coordinates in partnership with an array of public and private organizations that conduct eye health education programs. The NEHEP's primary goal is to prevent vision loss and blindness by educating the public and health professionals about sight-threatening eye diseases and ensuring that the results of eye and vision research benefit everyone. The NEHEP emphasizes public, patient, and professional education on the importance of early detection and treatment of eye diseases and disorders and the appropriate treatment for low vision. Increasing public awareness and knowledge of diabetic eye disease, its risks, and what to do about this blinding eye disease is another major goal of the National Eye Health Education Program.

An essential component of the NEHEP's success is its Partnership, with close to 70 public and private organizations interested in eye health education. The Partnership represents national organizations that are interested in eye health education and/or represent key audiences for NEHEP programs. Members include professional associations, voluntary health organizations, civic and fraternal organizations, and other government agencies. Through this network, the NEHEP has the opportunity to multiply its efforts in disseminating information to Americans at risk for glaucoma and diabetic eye disease, and to those who can benefit from vision rehabilitation. NEHEP staff provides technical assistance to the Partnership in developing community-based education efforts.

### **Importance of Early Detection and Timely Treatment**

American Indians and Alaska Natives have the highest prevalence of diabetes in the United States, in some groups exceeding 50 percent of adults (IHS, 2001). Compared with all U.S. races, American Indians and Alaska Natives have higher rates of diabetes-related complications such as blindness, kidney disease, amputations, and heart disease (Parker et al., 2002; Moy & Bartman, 1995).

Diabetic eye disease (DED) is the leading cause of new blindness in the United States for people age 20 to 74 (CDC, 1994). People with diabetes have a 25 times greater likelihood of becoming blind than do those without diabetes (CDC, 1991). The American Academy of Ophthalmology, the American Optometric Association, and the American Diabetes Association recommend that people with diabetes have dilated eye exams every year.

Although diabetic eye disease cannot be prevented totally, its risk can be greatly reduced. The Diabetes Control and Complications Trial (DCCT, 1993) showed that better control of blood sugar level slows the onset and progression of retinopathy caused by diabetes and lessens the need for laser surgery for severe retinopathy. The

Early Treatment of Diabetic Retinopathy Study (ETDRS, 1987) showed that laser treatment is highly effective in preventing visual loss from diabetic eye disease. Since diabetic eye disease often presents no symptoms, finding it early through annual dilated eye exams and treating it are the best ways to control this disease.

## **Outline of Plan**

The first section of this communication plan for educating American Indians and Alaska Natives with diabetes about diabetic eye disease presents the need for the Program, Program objectives, target audiences, and target audience analysis. The subsequent sections cover messages, channels, and materials. The final section discusses evaluation. In implementing the plan, the NEHEP will actively seek opportunities to work in partnership with other interested organizations. The tasks outlined here for the diabetic eye disease communication program will be prioritized according to need, opportunities for collaboration, and potential impact in order to use the NEHEP's resources most effectively.

## **II. BACKGROUND**

In June 2002, the NEI formed an ad hoc working group on American Indian and Alaska Native Outreach, with representation from diverse regions, tribes, eye care professionals, and national organizations including NEHEP partners. The goal of the meeting was to obtain input and guidance on developing a diabetic eye disease education and outreach program for American Indians and Alaska Natives. This document outlines the communication plan for the American Indian and Alaska Native diabetic eye disease education program formulated as a result of (1) recommendations from the working group, and (2) formative research including focus groups with the target audience and key informant interviews with community leaders and health program staff in the fall of 2002 and winter of 2003. The plan describes the development of a public education program for the primary target audience: all American Indians and Alaska Natives with diabetes.

Formative research with American Indians and Alaska Natives was conducted to gain a better understanding of the knowledge, awareness, and approaches related to DED among these populations and their communities. From the findings of this research, the work group felt it would be in a better position to develop a communication plan for a DED education program. The work group established the DED education program's primary target audience as American Indians and Alaska Natives already diagnosed with diabetes. The secondary audiences include people who are in a position to influence or support the health practices of individuals at risk, such as tribal leaders and providers, family members, health professionals, and community health representatives.

## **Program Need**

Despite the lack of published statistics on American Indians and Alaska Natives and diabetic eye disease, prevalence rates of diabetic retinopathy among American Indian and Alaska Native populations with diabetes are available. Studies have reported the prevalence of diabetic retinopathy among Sioux<sup>1</sup> Indians with diabetes (South Dakota) as 45 percent; 24 percent among Comanches, Kiowas, Seminoles, and Creeks (Oklahoma) with diabetes; between 24 and 49 percent among Cheyenne-Arapaho Indians with diabetes (Oklahoma); and 18 percent among Pima Indians with diabetes (Arizona) (Berinstein et al., 1997).

## **Program Objectives**

The specific objectives of the National Eye Health Education Program will be to:

- Increase awareness of diabetic eye disease, particularly diabetic retinopathy, among American Indians and Alaska Natives with diabetes.
- Increase knowledge of diabetic retinopathy among American Indians and Alaska Natives with diabetes, stressing the fact that the disease does not present symptoms during its early stages and that it can lead to blindness.
- Increase knowledge that the risk of vision loss from diabetic eye disease can be reduced with early detection and timely treatment.
- Encourage American Indians and Alaska Natives with diabetes to have annual comprehensive eye examinations with dilated pupils by trained eye care professionals.
- Encourage American Indians and Alaska Natives with diabetic eye disease to adhere to the recommended treatments.
- Provide culturally appropriate information on diabetic eye disease to accomplish more easily the objectives mentioned above.
- Provide information on diabetic eye disease in adaptable materials to accomplish more easily the objectives mentioned above.

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<sup>1</sup> The word 'Sioux' represents the common name most known and used; however, the appropriate name is Lakota, Dakota, or Nakota, depending on the tribal band.

## ***Target Audiences***

### ***Primary Target Audience***

*The primary target audience is American Indians and Alaska Natives with diabetes.*

### ***Secondary Target Audiences***

*Important secondary audiences are those who can influence or support the health practices of individuals at risk. These audiences include:*

- Eye and other health care-related professionals including diabetes health care teams (e.g., primary care physicians, nurses, health educators, community health workers)*
- Family members of people with diabetes, with a particular emphasis on women*
- Other intermediaries including local community members*
- Traditional healers, medicine people*

## **III. Target Audience Profile**

### **Demographic Characteristics of American Indian and Alaska Native Populations**

The term “American Indian and Alaska Native” refers to descendants of any of the original peoples of North America, Central America, or South America who maintain tribal affiliation or community attachment (Ogunwole, 2002). On the 2000 Census, the classification “American Indian and Alaska Native” includes Hispanic people who identified themselves as being of American Indian or Alaska Native descent, either alone or in combination with another race (Ogunwole, 2002).

### **The American Indian and Alaska Native Population: Census 2000**

The 2000 Census calculated the entire Nation’s population to be 281.4 million (Ogunwole, 2002). Of the total population, 4.1 million (1.5 percent) identified themselves as being of American Indian or Alaska Native descent (Ogunwole, 2002). Of the 4.1 million American Indians and Alaska Natives, 2.5 million (0.9 percent of the total U.S. population) identified themselves as being solely American Indian or Alaska

Native, and 1.6 million identified themselves as being American Indian or Alaska Native and one or more additional races (Ogunwole, 2002).

The 1990 Census reported a solely American Indian and Alaska Native population of 2 million, compared to the 2000 Census count of approximately 2.5 million—an increase of 25 percent (Ogunwole, 2002). In comparison, the entire U.S. population grew only 13 percent between 1990 and 2000 (Ogunwole, 2002).

## **American Indian and Alaska Native Population by Geographic Location**

According to the 2000 Census, 43 percent (1.8 million) of American Indians and Alaska Natives live in the West, 31 percent (1.3 million) live in the South, 17 percent (0.7 million) live in the Midwest, and 9 percent (0.4 million) live in the Northeast (Ogunwole, 2002). The 10 States with the largest American Indian and Alaska Native populations in 2000 were California, Oklahoma, Arizona, Texas, New Mexico, New York, Washington, North Carolina, Michigan, and Alaska; Florida had more than 100,000 American Indians and Alaska Natives (Ogunwole, 2002). These 11 States make up 62 percent of the Nation's American Indian and Alaska Native population (Ogunwole, 2002). California and Oklahoma, combined, account for 25 percent of the total American Indian and Alaska Native population in the United States (Ogunwole, 2002). Alaska Natives account for nearly 50 percent of the population in the boroughs of northern and western Alaska (Ogunwole, 2002).

According to the 2000 Census, American Indian and Alaska Native tribes with more than 100,000 members include Cherokee, Navajo, Latin American Indian, Choctaw, Sioux, and Chippewa tribes (Ogunwole, 2002).<sup>2</sup> These six tribes make up 40 percent of all the American Indian and Alaska Native people who identified tribe membership for the 2000 Census (Ogunwole, 2002). Eskimo was the largest Alaska Native tribal grouping, followed in order by Tlingit-Haida, Alaska Athabaskan, and Aleut (Ogunwole, 2002). These four Alaska Native tribes accounted for 3.6 percent of the total American Indian and Alaska Native population in the 2000 Census (Ogunwole, 2002).

Approximately 2 million (55.2 percent) American Indians and Alaska Natives lived in urban areas with populations of 50,000 or more in 1990 (U.S. Census Bureau, 1990). In 2000, the percentage of American Indians and Alaska Natives living in urban areas increased from 55.2 percent to 66 percent (Iceland et al., 2002).

The 2000 Census reported 944,317 American Indians and Alaska Natives living on federally recognized American Indian reservations or off-reservation trust lands (U.S.

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<sup>2</sup> Chippewa represents the more common name used; however, the more appropriate name is Ojibwe or Anishinabe.

Census Bureau, 2000). Of this population, 34.5 percent were under 18 years old, 9.3 percent were age 18 to 24, 26.6 percent were age 25 to 44, 19.8 percent were age 45 to 64, and 9.9 percent were over age 65 (U.S. Census Bureau, 2000). The median age of American Indians and Alaska Natives living on reservation land was 30.3 years (U.S. Census Bureau, 2000).

## **American Indian and Alaska Native Elder Demographics**

The 2000 Census reported approximately 259,000 American Indians and Alaska Natives age 55 and older, the defining age of “elder” (Baldrige, 2001). Many believe that this count—and other estimates for the American Indian and Alaska Native population—is not accurate because of undercounting and misclassification of race (U.S. Census Bureau, 2000). The American Indian and Alaska Native elder population speaks more than 150 different languages. Eighty percent of these elders live west of the Mississippi, and approximately half live in rural areas (Baldrige, 1996). More American Indian and Alaska Native elders live in poverty than any other older population in the Nation: 27 percent of American Indians and Alaska Natives age 65 to 74 live below the poverty level, compared to 10 percent of other races in this age group (Baldrige, 2001). Age-specific mortality rates for American Indians and Alaska Natives over age 60 are higher than the rates for older people in other U.S. populations (Rhoades, 1996).

## **Prevalence of Diabetes and Diabetic Eye Disease in American Indians and Alaska Natives**

Diabetes has been a major health concern for American Indians for more than 40 years (Acton et al., 2002). Since the early 1960s, diabetes has affected American Indians and Alaska Natives more than any other population in the Nation (Acton et al., 2002). Among American Indians and Alaska Natives, the prevalence of diabetes can run as high as 50 percent in some populations (IHS, 2001). Data collected from the Indian Health Service show that the number of American Indians and Alaska Natives diagnosed with diabetes rose from 43,262 in 1990 to 64,474 in 1997, a 29 percent increase in prevalence (Burrows et al., 2000).

Among American Indian populations, diabetic retinopathy is present in varying degrees. It is relatively common among Pima, Winnebago, and Omaha Indians, as well as the American Indians of Arizona, Utah, and Nevada with diabetes (Newell et al., 1989). Studies of American Indians with diabetes among the Choctaws of Oklahoma, the Coushatta of Alabama, as well as Navajo and Hopi tribes, showed a lower incidence of diagnosed diabetic retinopathy than in the previously listed populations (Newell et al., 1989; Sugarman et al., 1993). Obtaining accurate statistics on the prevalence and incidence of diabetes and diabetic retinopathy in American Indians and Alaska Natives is difficult because of the scarcity and incomplete nature of the data (Newell et al.,

1989). The American Diabetes Association estimates that the prevalence of diabetes may be as much as one-third or one-half higher than that reported for some populations (IHS, 2000).

The Pima Indians of Arizona have the highest rates of diabetes in the world. Approximately 50 percent of adult Pima Indians have diagnosed diabetes (Acton et al., 2002). Diabetic retinopathy occurs in about 18 percent of Pima Indians with diabetes (National Women's Health Information Center, 2001). In a study published by Nelson et al. (1989), 2.6 percent of Pima Indians with diabetes participating in the Strong Heart Study had developed proliferative retinopathy—a severe, vision-threatening form of diabetic eye disease in which new, abnormal blood vessels grow on the surface of the retina.

Indian participants of the Strong Heart Study—including members of the Cheyenne River Sioux and Oglala Sioux tribes with diagnosed diabetes—were tested for retinopathy. The prevalence of diabetic retinopathy was found to be 45.3 percent for both tribes (Berinstein et al., 1997).

Data on American Indians of Washington, Oregon, and Idaho were gathered from IHS centers in each State. Of 1,147 American Indians with diabetes surveyed, 1.7 percent (2.0 percent of females, 1.2 percent of males) had diabetic retinopathy needing one or more laser treatments (Freeman and Hosey, 1993). Inaccuracies in the data may be due to the fact that not all American Indians in Washington, Oregon, and Idaho use IHS to treat their diabetes. In a 1989 IHS survey of the Choctaw Indians in Mississippi, more than one-third of adults age 45 to 64 had diabetes (IHS, 2000). This survey did not collect data on diabetic retinopathy.

The rate of diabetes among Navajo Indians age 45 and older is 40 percent (IHS, 2000). The rate of diabetes among Hopi Indians was not available. Overall, Hopi Indians with diabetes had a retinopathy rate of 41 percent, compared to 29 percent of Navajos with diabetes (Rate et al., 1983). Among Hopi and Navajo Indians with diabetes for at least 10 years, retinopathy was present in 57 percent (61 percent of Hopi, 50 percent for Navajo) (Rate et al., 1983).

The incidence of diabetic retinopathy among 1,012 American Indians in Oklahoma surveyed in 1980 was 24.4 percent (West et al., 1980). A follow up study in 1992 found that, of the same group of Oklahoma Indians, 72.3 percent had developed diabetic retinopathy (Lee et al., 1992a). Another follow up study of Oklahoma Indians revealed that, of the 18.6 percent of participants who had background retinopathy at baseline, 45 percent developed proliferative diabetic retinopathy (Lee et al., 1992b).

A study on the prevalence and risk of diabetic retinopathy among Indians in southwest Oklahoma revealed a prevalence rate of 49.3 percent (Newell et al., 1989). The prevalence of diabetes was 10 percent for Athabascan Indians and 4.7 percent for

Yup'ik Eskimos (Murphy et al., 1992). This study did not collect data on the prevalence or rate of diabetic retinopathy.

A study of six reservations in Montana and Wyoming found the prevalence of diabetes to be 119 per 1,000 persons for the Blackfeet, Crow, Fort Belknap, Fort Peck, Northern Cheyenne, and Wind River (Acton et al., 1993). The prevalence of laser-treated diabetic eye disease was 35.9 per 1,000 (Acton et al., 1993).

The prevalence of diagnosed diabetes in the Northern Minnesota Chippewa Tribe was 148 per 1,000 persons (Rith-Najarian et al., 1993). Proliferative retinopathy occurred at a rate of 12 per 1,000 in the population with diabetes (Rith-Najarian et al., 1993). From 1990 to 1998, the total number of American Indians and Alaska Natives (age 34 and younger) with diabetes increased by 71 percent. Prevalence increased in this population by 46 percent—much higher than the 14-percent increase in the general U.S. population under age 45 (Acton et al., 2002). This may indicate that young American Indians and Alaska Natives will experience more of the morbidities—such as diabetic eye disease, diabetic nephropathy, and blindness—associated with diabetes later in life.

In many American Indian and Alaska Native populations, more than 50 percent of elders (age 55 and older) have diabetes (Roubideaux, 2002). Compared to other U.S. populations, American Indians and Alaska Natives are 2.3 times more likely to die from diabetes (Baldrige, 2001). The most striking statistics are for the Pima elders, more than 80 percent of whom have diabetes (Baldrige, 2001). No data were found on the prevalence of diabetic retinopathy among American Indians and Alaska Native elders. According to the 1996 Mortality and Morbidity Weekly Report study, which used data from 141 IHS units, the prevalence of diabetes was 9.3 percent for Woodland tribes, 12.7 percent for Plains tribes, 10.5 percent for Southwestern tribes and 4.5 percent for Pacific Coastal tribes (MMWR, 1998). Statistics on diabetic retinopathy per region were not available.

Diabetes and diabetic retinopathy affect American Indians and Alaska Natives to a greater degree than any other ethnic population in the United States. The rates of diabetes within the American Indian and Alaska Native populations vary by region, age, and gender. As the prevalence of type 2 diabetes increases among children and young adults, retinopathy may begin appearing at an earlier age, increasing the risk of blindness. The extent of diabetic retinopathy is difficult to determine due to limited data on American Indians and Alaska Natives.

### **Risk Factors for Developing Diabetes and Diabetic Eye Disease**

The Strong Heart Study examined risk factors for developing diabetes that are specific to American Indians. This study found that parental diabetes, obesity, genetics, and predominantly American Indian ancestry were associated with an increased risk for

developing diabetes (Lee et al., 1995). A study of the Pima Indians, conducted by the National Institutes of Health, identified similar risk factors, including a high-calorie, high-fat diet (Knowler et al., 1993).

Compared to the general U.S. population, American Indians and Alaska Natives have higher rates of diabetic complications—6.8 times more end-stage renal disease, 3 times more amputations of the lower extremities, and twice the rate of cardiovascular disease (Muneta et al., 1993; Valway et al., 1993; and Howard et al., 1999). Diabetes has become the fourth leading cause of death in American Indian populations (Indian Health Service, 1996). Complications from diabetes account for approximately \$6 billion of the annual \$12 billion spent for diabetes health care in the United States (Huse et al., 1989).

Risk factors for developing diabetes include insulin resistance, genetics, gestational diabetes, and obesity. Complications from diabetes include end-stage renal disease, lower extremity amputation, diabetic eye disease, and cardiovascular disease. These complications often result in a shortening of life. Due to westernization, genetics, and a lack of preventative health care available to many American Indians and Alaska Natives, these populations experience high levels of diabetes and its related complications.

Extensive studies on the incidence of and risk factors for diabetic retinopathy, a form of diabetic eye disease, have been conducted with Pima and Oklahoma Indians. Risk factors for diabetic retinopathy include hyperglycemia, hypertension, proteinuria, neuropathy, cholesterol, and duration of diabetes (Gohdes, 1995). The incidence of cataracts, a condition of diabetic eye disease, is higher in Pima Indians than in the general population—with patients with diabetes comprising more than 50 percent of those with cataracts. Cataract surgery rates are positively associated with the duration of diabetes (Gohdes, 1995).

Diabetic eye disease may be avoided or its progression slowed with regular eye exams and management of blood glucose and blood pressure (Indian Health Service, 2003; Berinstein et al., 1997). In a study of Navajo Indians with diabetes and proliferative diabetic retinopathy, 40.4 percent failed to obtain the recommended follow up treatment (Sugarman et al., 1993).

### **Socioeconomic Factors**

American Indians and Alaska Natives lag behind not only Whites but also other ethnic groups on many socioeconomic indicators, including educational achievement, employment status, and income level (Rhoades, 1996).

## ***Educational Attainment***

In 1990, 65.3 percent of American Indians and Alaska Natives age 25 or older residing in the current reservation States had graduated from high school, compared with 75.2 percent of all races in the United States. Among this same age group, 8.9 percent of American Indians and Alaska Natives had a bachelor's degree, compared to 20.3 percent of all races in the Nation (Parker et al., 2002; IHS, 1997).

In 2000, 70.9 percent of American Indians and Alaska Natives age 25 or older were high school graduates or higher, compared with 80.4 percent of all races in the United States. For bachelor's degree or higher, the percentages were 11.5 percent and 24.4 percent, respectively (U.S. Census, 2000).

One study used the Wide Range Achievement Test to measure reading skills among American Indians and Alaska Natives in Washington, Oregon, and Idaho. Researchers found that 66 percent of the study sample read at the 5th-grade level or higher and only 21 percent read at the 10th grade level or higher. Final evaluation, using the cloze procedure to test reading comprehension, showed that 62 percent of the target audience could read and understand diabetes education booklets in an instructional setting (Hosey et al., 1990).<sup>3</sup>

## ***Employment Status***

Many American Indian and Alaska Native families live and work for a time in metropolitan areas but have regular, sometimes routine patterns of living for other periods on the reservation or community of origin. Factors prompting this somewhat transient lifestyle include the scarcity of jobs on the reservation or in rural, isolated communities as well as the need to obtain services, particularly health care services, not available on the reservation or in the community. Other reasons for a somewhat transient lifestyle include the need to gather subsistence foods during the summer from the home of origin to be adequately prepared for the winter (Parker et al., 2002).

In 1990, 16.2 percent of American Indian and Alaska Native males age 16 or older residing in the current reservation States were unemployed, compared with 6.4 percent of all races in the United States. For females age 16 or older in this population, the percentage was 13.4, compared to 6.2 percent of all races in the Nation (Parker et al., 2002; IHS, 1997). In 2000, 13.1 percent of American Indian and Alaska Native males age 16 or older (civilians only) were unemployed, compared with 5.7 percent of all races

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<sup>3</sup> A cloze procedure is a test of reading comprehension that tests a person's comprehension as words are systematically deleted from a text.

in the United States. For females in this population, the percentage was 11.7 percent, compared to 5.8 percent of all races in the Nation (U.S. Census, 2000).

### ***Income Status***

According to the 1990 Census, the median household income in 1989 for American Indians and Alaska Natives residing in current reservation States was \$19,897, compared with \$30,056 for all races in the United States. During this period, 31.6 percent of American Indians and Alaska Natives lived below the poverty level, compared with 13.1 percent of all races in the Nation (Parker et al., 2002; IHS, 1997). According to the 2000 Census, the median household income in 1999 for American Indians and Alaska Natives was \$30,599, compared with \$41,994 for all races in the United States. In 1999, 25.7 percent of American Indians and Alaska Natives lived below the poverty level, compared with 12.4 percent of all races in the United States (U.S. Census, 2000). More American Indian and Alaska Native elders live in poverty than any other older population in the Nation: 27 percent of American Indians and Alaska Natives age 65 to 74 live below poverty level, compared to 10 percent of all other races age 65 to 74 (Baldrige, 2001).

Despite gains made among American Indians and Alaska Natives in educational attainment, employment status, and income level between 1990 and 2000, these populations still have not reached socioeconomic levels enjoyed by other populations in the United States. American Indians and Alaska Natives continue to experience adverse socioeconomic conditions: less than 70 percent of those age 25 and older graduated from high school with a degree or higher; less than 12 percent have a bachelor's degree or higher; at least 13 percent of males (and about 12 percent of females) age 16 and older are unemployed; the median household income is below \$31,000; and a striking 25 percent or more live below the poverty level.

### **Access To and Use of Health Care Services**

The issues American Indians and Alaska Natives have regarding access to health care are similar to those of most rural populations with high unemployment and poverty in the United States (Dixon, 2001a). Currently, the American Indian health care system comprises a three-part program: the IHS, tribal health services, and urban Indian clinics (Dixon, 2001a).

American Indians and Alaska Natives who are members of federally recognized tribes can receive health care services from IHS or they can access services provided by tribally run compact and contract health care programs (Dixon, 2001b).<sup>4</sup> American

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<sup>4</sup> American Indians and Alaska Natives are a diverse group represented by some 558 federally recognized tribes including 237 in Alaska.

Indians and Alaska Natives utilize resources from both these programs to meet their health care needs.

The Indian Health Service was established to make health care more accessible to American Indians and Alaska Natives. Private insurance, Medicare, and Medicaid have helped fill the service gap (Dixon, 2001a). However, the growing number of contract and compact health care programs managed by American Indians and Alaska Natives are becoming increasingly popular and present a possible solution to the shortcomings of IHS and private health care.

Use of health care services is often determined by availability rather than need and by the funding system selected by the tribe (Dixon, 2001b). For example, if a tribe decides that its IHS funding will be spent on enrolling members in a private managed-care program, tribe members will have access only to services provided by the chosen health maintenance organization.

### ***Indian Health Service***

The Indian Health Service was established in 1954 through the IHS Transfer Act, which transferred responsibilities for Indian health care from the U.S. Department of the Interior to the U.S. Public Health Service. Originally staffed by the U.S. Commissioned Corp, IHS is moving toward hiring and training American Indians and Alaska Natives (Dixon, 2001a). IHS provides services to American Indians and Alaska Natives who are members or descendants of federally recognized tribes (Dixon, 2001a). The extent of health care and range of services depends on Government funding (Dixon, 2001a). IHS and Alaska's Community Health Aide Program train local and indigenous people to provide health care, including emergency care, to rural populations (Dixon, 2001a). Trained health care workers are supervised by regional physicians who are accessible by telephone for consultation (Dixon, 2001a). As a result, IHS has become an excellent source of primary care, prevention, and community outreach for rural American Indians and Alaska Natives (Dixon, 2001a).

A survey of American Indians and Alaska Natives who have access to IHS programs and private-sector facilities found that they used both types of services (Dixon, 2001a). The survey included 409 tribal employees in two different tribes (Dixon et al., 1997). For routine health care and minor illnesses, 80 percent used IHS services (Dixon et al., 1997). Nearly 60 percent used private services for surgery or other serious health conditions (Dixon et al., 1997). Nearly 50 percent used private health care services for problems they considered potentially embarrassing or for services they wanted kept confidential (Dixon et al., 1997). American Indian and Alaska Native consumers of health care were more likely to access private services if they perceived a shortcoming in the IHS services, if they wanted a second opinion, if they did not want to wait to see a doctor, or if there was a need for confidentiality—such as for mental health services,

AIDS or STD testing, or substance abuse treatment (Dixon et al., 1997). Many of those surveyed stated that using IHS health care services was a choice based on habit and social reasons (Dixon et al., 1997).

### ***Contract and Compact Health Care***

Prior to the Indian Self-Determination and Education Assistance Act of 1975 (Public Law 93-638), the Federal Government controlled and managed all aspects of Government-funded health care for American Indians and Alaska Natives (Dixon et al., 2001). Contract and compact health care programs were established in an effort to provide American Indian and Alaska Native communities with more control of their health care services. The compact and contract programs are run solely by tribe members and are viewed as a creative and personalized solution to the health care needs of American Indians and Alaska Natives (Dixon et al., 2001).

Through Public Law 93-638, a tribe may contract with IHS to manage its own health care system. Once the tribe has established itself as a successful contractor—usually within 1 to 3 years—it becomes eligible for a compact (Dixon, 2001b). The compact is more like a treaty or block grant than a contract, therefore allowing for more flexibility in management (Dixon, 2001b). These “638 contracts” may be used for planning, conducting, and administering programs provided by the Federal Government for the benefit of American Indians (Dixon, 2001a). More than 279 tribes<sup>5</sup> have entered into a compact or contract with the Federal Government for their portion of the health care money that would have been retained at the IHS level. These mechanisms allow tribes to assume control over services previously provided by the Federal Government (through IHS) and give tribes great flexibility in the use of Government funds (IHS, 1997).

The contract and compact programs provide health care services tailored to the needs of individual tribes. These programs attempt to make the most of the Government funding the tribe receives in order to provide health care access to as many people in the program’s area as possible. Funding also serves as a limiting factor for the outreach that contract and compact programs can provide.

The growing trend in American Indian and Alaska Native health care has been toward contracting and compacting health care programs (Roubideaux, 2002). As of 2002, tribally managed health care programs provided more new health programs, built more facilities, and collected more third-party reimbursements than programs managed by IHS (Roubideaux, 2002). A 1997 survey predicted that in 5 years only 6 percent of tribes would be getting their outpatient medical care from federally funded services, compared to 30 percent in 1900 (Dixon et al., 1998). The hope of contract and compact

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<sup>5</sup> Figure provided by Office of Tribal Self-Governance, US DHHS Indian Health Service, September 2002.

health care is to attain greater autonomy so that health care systems can more effectively serve the diverse needs of American Indians and Alaska Natives.

### ***Urban Indian Clinics***

In 1974, Title 5 of the Indian Health Care Improvement Act allotted funding to urban Indian clinics (Dixon, 2001a). The IHS Urban Indian Health Program supports contracts and grants to 34 urban health programs. Like IHS, urban Indian clinics do not always provide a full array of health care services (Dixon, 2001a). Many urban American Indians and Alaska Natives do not have access to any other services in urban areas and must travel to rural health care providers (i.e., return to the reservation) for the care they need (Dixon, 2001a). Funding is the major hurdle for urban Indian clinics and urban Indian access to health care. Only 1 percent of IHS resources are allotted to urban Indian programs even though approximately 64 percent of American Indians and Alaska Natives live in urban areas (Forquera, 2001).

Even though American Indians and Alaska Natives are qualified to receive health care free of charge from IHS, only 10 percent of this population living in urban areas does so (Burhansstipanov et al., 2000). The two main reasons so few American Indians and Alaska Natives in urban areas receive IHS health care services are perceived ineligibility for services and inaccessibility to an IHS facility (Burhansstipanov et al., 2000). Another reason for low consumption of IHS services is the limited services provided as a result of minimal funding (Forquera, 2001).

### ***Access to Health Care***

Cost is a significant deterrent and private health centers are not found in many of the rural areas inhabited by American Indians and Alaska Natives. It is generally not cost effective for private health care providers—including hospitals and physicians—to set up practice in these areas (Dixon, 2002). For the private health care centers that are located in rural areas, accessibility to the population is based on cost, services provided, distance, and access to transportation (Dixon, 2002). Cost is a major factor affecting access to health care by American Indians and Alaska Natives. Approximately 32 percent of American Indian and Alaska Native families live below the poverty level (IHS, 1997), and many are underemployed or unemployed with no health insurance. Another limiting factor to health care access is the high turnover rate of health care providers in rural areas (Dixon, 2001a). For reasons described above, it is challenging to get providers to relocate to the rural areas where many IHS programs are located. Frequent changes in physician staff result in discontinuous care, and an unfilled position can lead to a long wait for needed services (Dixon, 2001a).

The 1987 Survey of American Indians and Alaska Natives found that Medicaid, despite its purpose of providing health care to the underinsured or uninsured, only provided coverage to 11.4 percent of the American Indians and Alaska Natives living below

poverty level (Kauffman et al., 1997). Many American Indians and Alaska Natives, especially elders, are not eligible for Medicaid because they live subsistent lifestyles and have not worked long enough to be eligible to for Social Security benefits (Kauffman et al., 1997). Several of those who are eligible for Medicaid cannot afford Part B supplemental coverage or premiums (Dixon, 2001a).

Education is also a determining factor in access to health care services for American Indians and Alaska Natives. The 1990 Census reported that only 65 percent of the American Indian and Alaska Native population over age 25 had completed high school (Dixon, 2001a). Lack of education can make navigating access to health care difficult and may prevent awareness of the benefits of health promotion, disease prevention, and early treatment (Dixon, 2001a). Because English is a second language for many American Indians and Alaska Natives, deciphering the nuances of health care services becomes even more difficult.

Factors that can lead to decreased access to health care services for ethnic minorities are cultural differences, language problems, folk illness beliefs, parental beliefs, and provider practices (Flores et al., 1999). Ethnic minorities in rural areas may be at an even greater disadvantage because of limited access to services based on their distance from health care centers (Flores et al., 1999). Unlike insurance or other health care coverage programs such as Medicaid and Medicare, IHS actually provides health care services and is not an insurance nor is it an entitlement though many Indians believe this to be so. Many American Indians and Alaska Natives living in rural areas must travel a great distance to facilities with the necessary equipment and specialists to administer diagnostics and treatments, and this is not always feasible.

Community health nursing and community health representative programs have improved access to health care for American Indians and Alaska Natives (Dixon, 2001a). Among other services, these programs offer in-home care for patients who cannot travel to get the services they need (Dixon, 2001a). Limitations arise when funding is lacking and the community health representative and nursing programs must prioritize services. In most cases, these programs are used as a last resort—when individuals cannot receive needed services from the IHS, or with Medicaid or Medicare.

### ***Use of Health Care***

The overall pattern for consumption of health care services among American Indians and Alaska Natives is to use IHS for primary care and to use compact and contract or private programs for specialty care. This pattern demonstrates that these populations consume health care to maximize health benefits while reducing costs. Being able to alternate resources allows for more health care choices while maintaining IHS as the main source for primary health care (Dixon, 2001a).

Researchers have found that consumers do not rank the availability of traditional healers or knowledge of tribal language as major determinants in choice of health care service (Dixon et al., 1997). In a list of 19 factors that determine health care choices, these factors were listed last (Dixon et al., 1997). However, patients prefer a physician or health care provider with experience with American Indians and Alaska Natives: this was ranked “very important” for 52 percent of tribal employees and 82 percent of Medicaid recipients (Dixon et al., 1997).

Many American Indians and Alaska Natives who are eligible for Medicaid or Medicare do not take advantage of these services because they feel entitled to health care by the Federal Government and therefore should not have to enroll in health care programs created for the general population (Forquera, 2001).

### **Culture and Acculturation**

Despite tremendous diversity across tribal cultures, American Indians and Alaska Natives share certain characteristics. These include a history of loss of ancestral lands; restriction of traditional means of obtaining food, shelter, and clothing; imposition of foreign forms of governance; mandated education in non-Indian schools; and destruction of language and religion (Hatton, 1994; Norton & Manson, 1996; DuBray & Sanders, 1999). American Indians and Alaska Natives also share a common bond that includes their spiritual attachment to the land; sharing with others; lack of materialism; belief that a supernatural power exists in all objects, animate and inanimate; desire to remain Indian; and determination to retain culture and language (Jackson & Broussard, 1987; DuBray & Sanders, 1999). The powers of nature, the personal quest of the soul, the solidarity of the tribe, and the acts of cooperation in daily life are all interrelated spiritual phenomena sustained by dance and ritual (DuBray & Sanders, 1999).

“Intertribalism” refers to the spread of common elements of Indian culture that helps strengthen a community of Indians removed from diverse tribally specific reservations (Cheshire, 2001). The separation of American Indians from reservations and the death of elders—the keepers and guiders of traditions—have led to cultural loss (Hatton, 1994; Cheshire, 2001). The family unit, however, has remained the chief conveyor of American Indian culture for several hundred years (DuBray & Sanders, 1999).

To identify values associated with the transmission of American Indian culture, Cheshire (2001) explored the ways in which urban American Indian mothers interact with their children. Study participants mentioned listening and talking, particularly listening to elders, as practices that aid in the transfer of cultural information. DuBray and Sanders (1999) also identified long pauses in conversation as common among Indian people because they have learned to be comfortable with silence. “Telling” (e.g., telling a child how to make a dream catcher) is another activity used to pass down culture: mothers who heard stories from their parents and grandparents are now telling these stories to their own children (Cheshire, 2001). “Watching,” “observing,” or “showing” (e.g., quill

work, craftwork, beading, dance) are other ways participants learn about their culture. The practices of “exposure,” “involvement,” and “participation” (e.g., dancing, drumming, singing, and discussing Indian issues at powwows) were the most frequently discussed methods for transmitting traditions, morals, beliefs, and values (Cheshire, 2001). More recently, American Indians and Alaska Natives have begun to embrace other methods of learning, such as reading, showing that Indian families can adapt to continue cultural transmission and survival (Cheshire, 2001).

A 1994 study of older urban American Indians revealed that most had attended U.S. Bureau of Indian Affairs boarding schools, the purpose of which was to assimilate students into the dominant non-Indian culture by deliberately ignoring customs and symbols of Indian life. For example, boarding school regulations prohibited American Indians from speaking their own Native language (Hatton, 1994).

A 1988 field study tested whether differences in cultural values corresponded with differences in health status among Cheyenne River Sioux tribe members. Results of this study suggested the healthiest women were the most traditional, or the least acculturated to non-Indian society (based on factors such as the degree of Indian blood, frequency of Lakota language spoken at home, and adherence to traditional Lakota beliefs such as altruism and devaluation of wealth). The healthiest men appeared to be those who were least traditional and most acculturated to non-Indian society (based on values such as hard work, personal control, industriousness, and individual action). This finding can be interpreted to mean that acculturation produces less stress for Lakota men than for Lakota women, or that Lakota men face more pressure to become acculturated to non-Indian society (Han et al., 1994). Of interest, the authors cautioned against over interpreting these data, questioning whether it is possible for survey-based studies to adequately define culture in a comprehensive and unbiased manner (Han et al., 1994).

A 1995 study found that Athabascan Indians had twice the rate of type 2 diabetes as Yup'ik Eskimos. Athabascan Indians, especially young Natives, reported significantly more frequent intake of “non-indigenous” proteins, carbohydrates, and fats and lower intake of “indigenous” carbohydrates and fat. This study also confirmed that the intake frequency for seal oil and salmon/fish is positively associated with the lower rate of type 2 diabetes seen in Yup'ik Eskimos. The pattern of retaining “indigenous” protein while adding imported protein, carbohydrate, and fat is similar to the acculturation of the Dogrib Athabascan and other Arctic Natives. These changes are associated with a cash-based economy, increasing urbanization, a shift toward mechanization of daily activities, and implementation of nutrition intervention programs (Murphy & Schraer, 1995).

Researchers in a 2000 study measured the degree of study participants' acculturation by asking, “To what extent do you follow the Native way of life?” and “To what extent do you follow the non-Indian/American way of life?” The researchers found that patients

who used traditional practices were more likely to follow the Native way of life. The majority of participants desired greater access to traditional health care and would use traditional practice options, if available, on a regular basis (Buchwald et al., 2000).

Many American Indians embrace a philosophy of life that emphasizes “being” rather than “doing” (DuBray & Sanders, 1999). In particular, unacculturated tribal groups value a present-time orientation, which involves enjoying the “now” and experiencing whatever is happening in the present, rather than being preoccupied with either the past or the future (DuBray & Sanders, 1999).

### ***Importance of Diet in American Indian and Alaska Native Cultures***

In many American Indian and Alaska Native cultures, food has health, religious, and social value (Jackson & Broussard, 1987; Carter et al., 1997). Where corn is considered sacred, for example, cornmeal is sprinkled on the floor around the bed of a hospitalized patient in a variety of curative ceremonies (Jackson & Broussard, 1987). Items believed to possess special healing powers may be placed on a patient’s bedstand or hung on the bed (Jackson & Broussard, 1987). Food is also a main attraction at feast day celebrations, powwows, and religious ceremonies. Hospitality, which includes serving food, is a serious obligation. It is socially and culturally unacceptable for a guest to refuse food offered at these occasions (Jackson & Broussard, 1987).

Herbalists prescribe special diets that eliminate certain foods for curing purposes. Herbal medicines or foods with spiritual properties are ingested in traditional Navajo Indian healing ceremonies (Jackson & Broussard, 1987). The Seminole Indians of Florida consider meat a food that gives individuals strength. Patients are often confused when counseled to substitute calorie-dense foods with vegetables. Never a major part of the traditional Seminole diet, vegetables are not considered foods that “give strength” (Jackson & Broussard, 1987).

Adherence to the prescribed diet for diabetes treatment is low among American Indians with diabetes. One study of Cherokee Indians with diabetes found 14 percent to be in compliance with the diet; nearly one-fifth of the sample had difficulty using the exchange system for meal planning, and 12 percent did not follow the diet because they wanted to use local foods and cooking methods (Jackson & Broussard, 1987). In another study, Florida Seminole Indians did not follow prescribed diets for diabetes treatment. Discussions with Seminoles using traditional medicine revealed they could not follow diets as prescribed by biomedicine practitioners because many fruits and vegetables are forbidden while using traditional medicine (Jackson & Broussard, 1987). More recently, traditional foods such as buffalo meat and local berries have been reintroduced in many tribal communities with the idea that indigenous foods are beneficial to a healthier lifestyle and combating disease than many of the foods adopted from non-Indian society. (Lindquist Mala, 2003)

In studying contemporary food intake patterns among Hopi Indians, researchers noted that the ritual and meanings surrounding the harvesting and preparation of food were highly associated with cultural integrity. The older Hopi Indians expressed concern that young people were no longer learning to produce and prepare “old foods.” The older Hopi Indians described the “old foods” as “giving good health,” and stated that local biomedical practitioners said to avoid traditional foods during illness because they are “fattening” or “caused diabetes” (Jackson & Broussard, 1987).

### ***Use of Traditional Medicine***

Traditional health practices are often spiritual in nature, focusing on underlying causes rather than on the relief of acute symptoms (Hatton, 1994; Buchwald et al., 2000). The causes of illness are sometimes attributed to an imbalance in one’s body, mind, or spirit (Avery, 1991; DuBray & Sanders, 1999). For example, the idea of locating the cause of disease in physiological processes simply does not fit traditional Navajo thinking; instead, health is closely associated with religion and is often explained from a holistic point of view (Hatton, 1994). The simultaneous use of different health care options, combining principles of traditional and Western medicine, characterizes much of the help-seeking behavior among American Indians and Alaska Natives (Avery, 1991; Hatton, 1994; Marbella et al., 1998; Buchwald et al., 2000).

For years, American Indians and Alaska Natives have responded to the personal, family, and community issues surrounding illness by relying on traditional medicine practitioners (e.g., medicine men, medicine women, herbalists, shamans, spiritual healers, Native American Church “roadmen,” diagnosticians including hand-tremblers, crystal-gazers, star-gazers, and “listeners”) and traditional health practices (e.g., purification ceremonies such as sweat lodges; healing ceremonies such as the Sun Dance; teas; herbs; balms; ointments; salves; purgatives; smudging; special foods; therapeutic “sings”; chants; protective prayers; dancing; sand-painting; pipe, drum, and naming ceremonies) (Jackson & Broussard, 1987; Avery, 1991; Marbella et al., 1998; Kim & Kwok, 1998; DuBray & Sanders, 1999; Buchwald et al., 2000; Carrese & Rhodes, 2000). Some American Indians who have attended missionary schools have integrated the Christian religion into their traditional ceremonies (DuBray & Sanders, 1999; Carrese & Rhodes, 2000). For many American Indians, medicine and religion are virtually identical (Avery, 1991).

Although not all American Indians and Alaska Natives practice traditional medicine, a considerable population does (Avery, 1991). A 1973 survey of 277 American Indian families living in the San Francisco Bay area showed 28 percent of respondents using traditional Indian medicine (Jackson & Broussard, 1987; Hatton, 1994). A study of 150 urban American Indian patients conducted in 1995 revealed 38 percent had seen a Native healer, and 86 percent of those who had not would consider doing so in the future (Marbella et al., 1998). A 1997 study of 300 Navajo patients found that 62

percent had used Native healers, or medicine men, at least once in their lifetime and 39 percent regularly sought their help for common medical conditions including diabetes (Kim & Kwok, 1998). In a study conducted in 2000, 70 percent of urban American Indian and Alaska Native patients in primary care reported using traditional health practices. The study's findings question the often-held assumption that American Indians and Alaska Natives living off reservation in urban areas are more assimilated and therefore less likely to participate in culturally rooted traditions of this nature. This investigation underscores health professionals' responsibility to respectfully ask American Indian and Alaska Native patients about use of all treatment approaches (Buchwald et al., 2000).

When the Papago Indian traditional healer is unable to diagnose a patient's illness, the illness is considered a "White man's disease," to be treated by biomedical practitioners (Jackson & Broussard, 1987).<sup>6</sup> For example, the Devil's Lake Sioux Nation describes diabetes as a condition that may not be treatable by traditional means because it is a new condition without specific traditional remedies (Jackson and Broussard, 1987).<sup>7</sup> In comparing medicinal herbs used by Iroquois Indians in 1915 and 1971, researchers found fewer herbal remedies for treating diabetes than for diseases having a longer tradition among the Iroquois; herbal medicines are said to alleviate certain symptoms for diabetes but cannot eliminate the disease (Jackson & Broussard, 1987). In 1982, 3 percent of Cherokee Indian women reported taking native herbal medicine to treat their diabetes (Jackson & Broussard, 1987).

In traditional Navajo culture, language does not merely describe reality; language shapes reality (Carrese & Rhodes, 1995; Carrese & Rhodes, 2000). In a focused ethnography conducted in 1994, researchers concluded that discussing negative information (e.g., news of a poor diagnosis, risks of an intervention during informed consent, advance care planning such as living wills) conflicts with the Navajo concept of *hózhó* (which combines the concepts of beauty, blessedness, goodness, order, harmony, and everything that is positive or ideal) and is viewed as potentially harmful (Carrese & Rhodes, 1995; 2000). For example, in the view of the traditional Navajo patient, discussing the potential complications of diabetes may result in the occurrence of such complications (Carrese & Rhodes, 1995; 2000).

### ***Cultural Beliefs***

The traditional practices and cultural values of both American Indians and Alaska Natives present significant considerations for any health communication or research effort. Of critical importance is the primacy of the tribe and its collective nature.

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<sup>6</sup> Papago represents the more common name used; however, the more appropriate name is Tohono O'odham.

<sup>7</sup> The Devil Lake's Sioux Tribe officially changed their name to Spirit Lake Nation in the 1990; that is the legal and federally recognized name of this Dakota tribe.

Education programs must be conducted in a way that respects the authority, autonomy, and identity of the tribal community; otherwise, opportunities for confusion, mistrust, and noncompliance will abound. Furthermore, tribal primacy is reinforced by the traditions, beliefs, and sensibilities imparted by kin, even in urban settings where tribal influence appears to be weaker. Many fundamental aspects of health are shaped by traditional beliefs. For example, diet involves far more than nutrition or taste preferences for most American Indians and Alaska Natives because traditional beliefs invest many foods with spiritual and social significance.

Medicinal views of foods also prevail, and many American Indians and Alaska Natives find difficulty negotiating traditional prescriptions for food consumption and medical prescriptions to balance their diet. Indeed, many continue to rely on traditional medicine while accepting Western medical treatment for ailments considered “White man’s diseases.” Even the very use of language can have a profound effect. Many American Indians and Alaska Natives find medical disclaimers, or discussion of potentially bad treatment outcomes, portentous or intimidating, and they seek to avoid them. Likewise, communication in treatment contexts must consider the tendency of American Indians and Alaska Natives to listen rather than question as a mode of learning.

#### **IV. Theoretical Tenets and Messages**

This section of the communication plan covers a discussion of the theoretical tenets, proposed message concepts, and messages. Included under messages are discussions of content, tone, challenges, and barriers to acceptance.

##### **Theoretical Tenets**

A number of theories and models have contributed to the field of health communication and have a direct bearing on eye health education program development. They include the social cognitive theory, community organization theory, and the stages of change model, among others. Social marketing provides a framework in which to identify the social science theories most appropriate for examining a particular health behavior (e.g., regular eye exams) at multiple levels.

##### **Social Cognitive Theory**

The social cognitive theory explains human behavior in terms of the dynamic interaction of an individual, behavior, and the environment in which a behavior is performed. Among the crucial personal factors are the individual’s capabilities to symbolize the meanings of behaviors, foresee the outcomes of given behavior patterns, learn by observing others, self-determine or self-regulate behavior, and reflect and analyze

behaviors. Cognitive representations of future events, for example, are thought to have a strong causal impact on present actions.

Behavioral acquisition can occur by watching the actions and outcomes of others' behavior (observational learning or modeling). A person's confidence in being able to perform a particular behavior (self-efficacy) is also an important factor in moving an individual closer to behavior, such as seeking regular eye exams (Bandura, 1986; Lefebvre & Floran, 2000; Rimer, 2003).

A 2000 study of 114 American Indian and Alaska Native adults examined the influence of self-efficacy on alcohol use. "General self-efficacy" was defined as a global feeling of one's perceived ability to bring about meaningful change within one's world. In this study, lower general self-efficacy was associated with higher alcohol use, indicating alcohol use may be in response to feelings of powerlessness within one's life and may be sustained by perceived feelings of control over use. This study suggests that the concept of self-efficacy appears to relate to empowerment issues and, as such, would have important applications for use with minority individuals (Taylor, 2000).

## **Community Organization Theory**

Community organization theory has its roots in theories of social networks and support. It emphasizes active participation and developing communities that can better evaluate and solve health and social problems. Community organization is the process by which community groups are helped to identify common problems or goals, mobilize resources, and develop and implement strategies for reaching their goals. Community organization is composed of several alternative change models including community (or locality) development, social planning, and social action. Community development uses a broad cross-section of people in the community to identify and solve its problems. It stresses consensus development, capacity building, and a strong task orientation. Outside practitioners help to coordinate and enable the community to successfully address its outcomes. Social planning uses tasks and goals and addresses substantive problem solving, with expert practitioners providing technical assistance to benefit community consumers. Social action aims to increase the problem-solving ability of the community and to achieve concrete changes to redress social injustice that is identified by a disadvantaged or group.

The process of empowerment is intended to stimulate problem solving and activate community members. Community competence is equivalent to self-efficacy plus behavioral capability—the confidence and skills to solve problems effectively. Media advocacy is the strategic use of mass media as a resource for advancing a social or public policy initiative (Rothman and Tropman, 1987).

The Kahnawake Schools Diabetes Prevention Project with Aboriginal people in Canada provides an interesting case for exploring issues related to program implementation and

evaluation in the context of promoting social justice through citizen participation. This project was successful in establishing an intervention based on a partnership between community groups and researchers (Potvin et al., 2003).

The Indian Family Wellness project has employed a model for collaboration between researchers and American Indian and Alaska Native communities called “tribal participatory research.” This approach emphasizes full participation of tribes and tribal members in all phases of the research process and incorporates cultural and historical factors vital to strengthening American Indian and Alaska Native families. Investigators involved with this project concluded that family-centered interventions with the greatest potential for sustainability and fidelity are those based on indigenous tribal cultural values and practices (Fisher and Ball, 2002).

A 2000 study of 1,396 3rd- to 5th-grade American Indian students tested skills and community-based approaches to prevent substance abuse. Youths in schools assigned to the intervention arms learned cognitive and behavioral skills for substance abuse prevention. One intervention arm additionally engaged local community residents in efforts to prevent substance abuse. Community intervention components appeared to exert no added beneficial influence on youths’ substance use, beyond the impact of skills intervention components alone. Researchers speculate that the inclusion of community involvement components may have diluted the combined intervention. Moreover, the skills-only intervention may have provided youths with a concentrated approach, resulting in demonstrable influence over American Indian youths’ substance abuse patterns for up to 3.5 years after initial intervention delivery (Schinke et al., 2000).

### **Stages of Change Model**

Comprehension of the process of behavior change is important to the development of an effective intervention to promote regular eye exam-seeking behavior. The stages of change model conceptualizes the continuum of change as being composed of five stages: (1) Pre-contemplation, (2) Contemplation, (3) Preparation, (4) Action, and (5) Maintenance. Pre-contemplators often fail to recognize the need for change or its feasibility. In contrast, the contemplation stage may be characterized by ambivalence—contemplators are starting to think about initiating change but are not actively doing so. The preparation stage includes individuals who intend to change their behavior in the next month and who have tried to do so within the past year. Individuals in the action stage report they have changed the target behavior within the previous 6 months. The maintenance stage reflects change that has been maintained for more than 6 months (Prochaska, 1997; Rimer, 2003). NEHEP’s American Indian and Alaska Native Diabetic Eye Disease Program outreach efforts will match individuals’ stages along this continuum. Educational materials can be identified and tied in to the stages of readiness by the audience.

In a 1999 study of 514 American Indians with diabetes, stage-of-change questions were used to measure exercise readiness. Among study participants, 82 percent reported they were in the preparation, action, or maintenance stage of change for exercise behavior. While physical activity and exercise adherence were related to stage of change constructs, they were not associated with knowledge. This study suggests motivating individuals with diabetes to progress from the pre-contemplation and contemplation stages to the action and maintenance stages of readiness for exercise, rather than simply informing people that exercise is good for them. This investigation also recommends addressing other modifiable factors known to influence physical activity and exercise adherence, such as self-efficacy (Stolarczyk et al., 1999).

## **Social Marketing**

Social marketing is an innovative approach to communication that uses the planning elements of commercial marketing—product, price, promotion, and place—within the various behavioral theories as described above, to reach broad audiences in order to direct behavior change.

The seven steps of the social marketing approach, as defined by Kotler (1987), are problem definition, goal setting, audience segmentation, analysis of audience approach, influencing channel analysis, strategies and tactics, and implementation and evaluation. As outlined by Lefebvre and Flora, the core components of the social marketing approach include:

- Consumer orientation in which the various consumer groups (e.g., community residents, opinion shapers, policymakers) are actively sought out and involved to understand their specific needs and concerns with respect to health issues.
- Audience segmentation and analysis in which the various consumer groups are further refined and defined into more homogenous subgroups and further characterized with respect to geographic, demographic, behavioral, and psychological attributes.
- Channel analysis in which communication channels (such as electronic and print mass media and social and interpersonal networks) are explored and evaluated with respect to the specific utilization and exposure patterns of the defined audience segments.
- Development of an exchange process between program providers and the various audiences. This ensures that the interactions serve mutually beneficial purposes.

- Formative research, conducted to guarantee that program elements are responsive to the audience's needs, delivered through appropriate channels to maximize their reach and efficiency, and can be acted upon by the audience.
- Responsive program messages/products/services, designed to meet the particular needs and characteristics of the audience group, to minimize costs to the consumer and convey anticipated benefits for responding to the offering, to be accessible to the primary audiences for which they are intended, and to ensure maximum attention and participation of these groups.
- Process tracking systems, which are utilized by the program managers to provide assurances that the program is being implemented as planned, the priority audiences are being reached, opponents concerns are addressed, and the information can be used to further refine or expand the program for other audiences.
- Strong program management systems that orchestrate the above elements so that the program remains attentive and responsive to the audience's needs while achieving the health objectives set by the program planners.

While the underpinnings of social marketing take into account the aforementioned theories, two interrelated principles are at the very core of the process. First, changing people's behavior requires developing an offer (i.e., a product, service, or idea) with perceived benefits that clearly exceed the perceived costs. The process is not one of simply selling harder or better, but one that begins with a formulation of what is being sold for the purpose of making it inherently more desirable. Second, the creation of an attractive offer requires considerable insight into the perspectives of the people whose behavior the organization is attempting to change. This offer involves identifying audiences (defined as groups of people who relate similarly to an offer) and conducting formative research with those audiences. Identifying audiences and understanding their needs enables the social marketing planner to develop offers that are inherently attractive (Andreason, 1995).

### **NEHEP's American Indian and Alaska Native Diabetic Eye Disease Program Goals**

The primary goal of the NEHEP's American Indian and Alaska Native Diabetic Eye Disease Program is to increase the awareness of the primary target audience of the need for early detection and timely treatment of diabetic eye disease to prevent vision loss. A second goal of the Program is to increase understanding and familiarity of what is early detection and treatment and its importance, thereby increasing the percentage of those in the primary target audience who receive annual dilated eye exams. This could also positively influence the rate of primary target group members who obtain appropriate treatment. The third goal is to increase awareness and understanding of

diabetes self-management that decreases the risk of development and progression of diabetic eye disease.

## **Messages**

The NEHEP draws on what it is known about the ways to reach these communities based on research and acknowledges that within any target audience people vary in where they lie on a behavioral change continuum.

## **Concepts**

As described above, there are five observed stages of behavior change.

### ***Pre-contemplation***

- Present basic facts on diabetic eye disease.
- Stress the importance of early detection.
- Tell them where to find more information.
- Present a call to action: For more information, contact \_\_\_\_\_.

### ***Contemplation***

- Provide the opportunity to assess individuals' personal risk.
- Put a face and a voice to diabetic eye disease by using credible and believable spokespersons for specific target audiences.
- Tell them what can happen if diabetic eye disease goes undetected and untreated.
- Tell them how they can help protect themselves from severe consequences with early detection by having a dilated eye exam at least once a year.
- Call to action: If you have diabetes, you should have a dilated eye exam.

### ***Preparation***

- Reiterate to those in need the importance of having a dilated eye exam at least once a year and why.
- Tell them where they can go to get these exams.
- Tell them what they can expect in terms of the exam and how much time it might take.
- Call to action: You can do it.

### ***Action***

- Stress benefits of acting on what they know and are able to do: better eye sight, more involved family and community life, more activities in which they can participate, a fuller life overall.
- Reiterate where they go to get the exams.

- Encourage them to tell others about what they have learned.
- Call to action: Make an appointment and go see an eye care professional for an eye exam.



should focus on having a positive and appealing tone for the target audiences.

**Tone**

*Another important consideration is the feeling conveyed by the message. Focus group and interview participants suggested the following possibilities for the tone of messages:*

- |   |                    |
|---|--------------------|
| <i>Hopeful</i>                          | <i>Encouraging</i> |
| <i>Straightforward and to the point</i> | <i>Strong</i>      |
| <i>Positive yet realistic</i>           | <i>Truthful</i>    |
| <i>Simple</i>                           | <i>Sincere</i>     |
| <i>Family focused</i>                   | <i>Humorous</i>    |

**Barriers to Message Acceptance**

The following barriers to message acceptance and action will be considered during message development:

- Limited awareness and/or knowledge of diabetic eye disease
- Misconceptions about eye disease and treatments. Many American Indians and Alaska Natives do not realize that many of the complications of diabetes are preventable and may make a fatalistic assumption that if they have diabetes they will eventually develop complications such as loss of vision.

- Fear of blindness
- Lack of knowledge and/or access to eye care services
- Lack of transportation
- Lack of access to eye care services
- Time and cost of eye examinations
- Concern only for other diabetic complications that present symptoms

***Challenges to Message Development:***

***Social and Environmental Considerations in American Indian and Alaska Native Communities***

- *Diversity among communities*
- *Priority of other basic needs before eye health*
- *Lack of resources. Because of limited resources, a crisis-oriented approach may be more frequent than a preventive one.*
- *Language. Some American Indian and Alaska Native languages do not have words to describe conditions such as diabetic eye disease (diabetic retinopathy, cataract, glaucoma).*
- *Values. Traditional values of noninterference may prevent communication about a disease and related preventive actions.*
- *Suspicious of outsiders and perhaps messages developed by outsiders*
- *Geographic barriers*

**Message Content**

Focus group and interview participants and Work Group members suggested the following regarding informational content of messages on diabetic eye disease that might resonate across Indian country:

- Symptoms of diabetes and its complications
- Tips for self-management including monitoring blood glucose levels, exercise, and weight management
- Elements of diabetes control and management as ways to prevent diabetes complications (e.g., "Take care of your diabetes. It will help your vision.")
- Logic in treating diabetes complications in a regular manner (e.g., reason behind the importance of annual "well" eye exams and that this means more than being tested for eyeglasses).
- Importance of annual eye exams in cyclical terms (e.g., seasons of the earth) to help communicate that patients are not done after having one eye examination but need to start another year's cycle leading to another exam.
- Consequences of improper diabetes management (e.g., vision loss and blindness). Those who put off having an eye examination and neglect their care may develop complications that affect them and their families and communities.
- Reminders loved ones to take care of their health, starting with their eyes.
- Identification and demystification of treatment that can prevent blindness: emphasize the importance of early treatment and explain that even those who have undergone treatment still need to have annual follow up examinations.
- Messages that challenge myths and misinformation and can help alleviate fear
- Messages that call attention to the role of prevention (e.g., *prevent blindness by proper management of your diabetes and by getting an annual eye exam.*).
- Messages that are relevant to American Indians and Alaska Natives' lives (e.g., why should people be motivated to take the recommended action? And do they believe that it is possible to prevent the potential consequences?)
- Messages that communicate the respective responsibilities for individuals and professionals.
  - Messages for individuals affected by diabetes should be positive and define the role of patients in working collaboratively and proactively with health care providers to manage the disease and its complications.
  - Messages for health care providers should give more detailed information on the importance of dilated eye exams and the need for one-on-one

communication with patients to allay fears and sensitivities that might create resistance to eye exams.

- Messages that educate people about why they should have hope
- The heart and the importance of relationship—a major motivation for change in American Indian and Alaska Native communities; messages should include this human element.
- The eye as the window of the heart through which you can see what is going on inside of people (e.g., “Protect your eyes so that you can see who you are”)
- Framing messages in terms of a choice (i.e., giving the information needed to make a wise decision), which can empower elders.

***Messages Should Include a Strong Emphasis on Prevention and Address These Information Points:***

- *Diabetic eye disease can cause blindness.*
- *All people with diabetes are at risk for developing diabetic eye disease.*
- *Early detection and treatment can usually control further damage and prevent blindness.*
- *Dilated eye exams at least once a year are necessary.*
- *These examinations are performed by eye care professionals.*
- *Self-management of diabetes can reduce the risk of diabetic eye disease.*

The message appeals used to create awareness must be relevant to the target audience and be considered credible by them. Ideas suggested by the target audiences can be incorporated into message development. Themes should reflect the values of target audiences, such as people taking action not only for themselves but also for their children and grandchildren (e.g., remind elders that they are role models for younger people). A related theme is that children are also teachers for their elders—all generations have a responsibility to teach each other well. Message pretesting is essential.

## **V. Strategies, Channels, and Materials**

This section of the communication plan covers a discussion of strategies, channels, and materials. Community involvement and spokespersons are discussed under strategies. Mass media and community channels are described. Formats, cultural sensitivity, and pretesting are covered under materials.

The educational and promotional materials should present the risk factors of diabetic eye disease, including the facts that there are no symptoms during the initial stages and that it can result in vision loss and even blindness. Messages should be presented in a believable, personal, and non-threatening way and validated by credible American Indian and Alaska Native sources and by scientific information. The positive side of the messages should be that an annual dilated eye exam can prevent loss of vision and blindness from diabetic eye disease and that effective treatment is available. This message will be presented in an encouraging way to make American Indians and Alaska Natives feel that they really are self-reliant in that they have control over the disease and their lives. The materials should be written in adaptable formats and aimed at American Indians and Alaska Natives of varying literacy skills. The communication strategy will be implemented in a way that is consistent with the social and cultural characteristics of the target audience(s).

The most effective ways of presenting the information (e.g., suitable appeals and spokespersons) will be selected. As mentioned previously, among the fundamental personal factors of social cognitive theory are the individual's capabilities to learn by observing others, self-determine behavior, and reflect and analyze behaviors. Behavioral acquisition can occur by watching the actions and outcomes of others' behavior. Spokespersons could be selected from among respected community members to deliver NEHEP messages. Of particular value would be those community member representatives who have managed to prevent diabetes complications.

### **Strategies**

The NEHEP will collaborate with groups, organizations, programs, and initiatives already investing resources into reaching American Indians and Alaska Natives with diabetes-related information to complement their efforts. A particular focus of this collaboration might involve partnering with community health worker programs in American Indian and Alaska Native communities. It is recommended to continue to forge an invested relationship with and actively collaborate with the Tribal Leaders Diabetes Committee (TLDC) of the Indian Health Service National Diabetes Program. This Committee involves elected tribal officials from each of the 12 IHS service areas who bring the tribal perspective to any discussion. Also indispensable to the success of this program will be the active participation of community members in the design and implementation of outreach activities and materials. The NEHEP will endeavor to

respect tribal protocol and communities. As referred to earlier, community organization theory emphasizes problem solving by active community members as a means of creating confidence and promoting skills to solve problems effectively.

Recommended strategies include:

- Use testimonials from people young and old in the community who have diabetes.
- Use storytelling; the stories of ancestors can provide inspiration and strength to younger generations.
- Create new health message-oriented stories to be shared in the community.
- Work with elders to develop and create programs; elders can help identify the key messages and messengers that will motivate members of their community to take action.
- Work with youth to develop and create programs; youth can be messengers that help motivate members of their community to take action.
- Present information to American Indian and Alaska Native elders in a visual, simple, step-by-step way utilizing culturally relevant symbols and icons.
- Use community forums involving tribal leaders, elders, youth, and providers as a template of basic questions to get feedback about key issues that will reflect local values, beliefs, and preferences.
- Provide compelling information based on what community members need and would like to tribal leaders when soliciting their help.
- Conduct outreach using mobile eye examination equipment to create rapport with communities.
- Create flexible models that can be adapted for use in the many diverse tribal communities.
- Establish the relevance of eye health in the context of diabetes, and complement existing programs.
- Enlist support from carefully screened American Indian and Alaska Native celebrities such as artists, actors, athletes, among others

- Participate in major intertribal events such as the Gathering of Nations, Crow Fair, rodeos, among others.
- Involve traditional healers in outreach activities.

## **Materials and Formats**

Health education materials will be developed to disseminate diabetic eye disease messages to the target audiences. These materials will undergo an extensive design and evaluation process, where cultural appropriateness, sensitivity, and representation will be considered. All messages and materials will be pretested with members of the target audience. A guiding principle is that all materials are culturally relevant and respect the cultural traditions of the particular target group. American Indian materials are not appropriate for Alaska Natives. Similarly, materials developed for American Indians in the Southwest will not be acceptable to tribes in northern areas such as Montana. Images should be representative of diverse tribes (e.g., Southwestern, Alaska Native) to ensure that the various target audiences see themselves in the materials. Also recommended is that a variety of mediums be used to communicate messages and information to a variety of populations that have a range of resources. Materials that can be custom-tailored diabetic eye disease messages to individual communities are encouraged. When possible, information should be presented in a conversational, group discussion, or storytelling format.

***A Sampling of Potential Products That May Be Produced for the Purposes of Increasing Awareness about the Importance of Regular Eye Exams to American Indians and Alaska Natives:***

- *Brochures that provide information on risk factors, causes, and treatment measures*
- *Speaker's guide available (print and CD-ROM) with adaptable talking points for workshops or small group meetings*
- *Television and radio PSAs*
- *Print PSAs placed in newspapers, newsletters, calendars*
- *Press releases about local initiatives*
- *Health tips or diabetes checklists for regional newsletters*
- *Short videos to be played in health center waiting areas and schools*
- *Posters for health and tribal facilities*
- *Flipcharts for health professionals to use with patients*
- *Billboards in primary audiences' communities*
- *Flyers for direct mailings or distribution at social gatherings.*
- *Train-the-trainer guides for personnel such as diabetes educators, health educators, and community health representatives in eye care and diabetic eye disease*
- *Promotional materials such as sunglasses, t-shirts, magnets, and others*
- *Student guide to healthy vision (middle school and up)*

## **Brochures**

A brochure could be produced to disseminate the NEHEP messages in the American Indian and Alaska Native community. If radio, television, and/or print public service

announcements (PSAs) are produced and disseminated, the brochure could then help to expand and reinforce the NEHEP messages. The information should be adapted to the American Indian and Alaska Native population and the graphic art should be representative of American Indian and Alaska Native individuals and their culture.

If a brochure is produced and distributed in an educational setting, it could increase the knowledge of eye disease among American Indian and Alaska Natives by providing more detailed information that they can read at their own pace and take home to use for future reference. It would also give this audience the opportunity to share the information with family members or friends who could be at risk for diabetic eye disease. A thorough review of available materials on diabetic eye disease designed for American Indians and Alaska Natives should occur. The NEHEP would like to complement and build on existing materials.

### **Speaker's Guide**

An assortment of mediums should be used to communicate messages and information to a diversity of populations that have a range of resources. A speaker's guide on diabetic eye disease could be developed and used to conduct community presentations in a variety of settings. Talking points in the guide could easily be adapted to match the characteristics of a specific community. The guide could be in a printed format, include transparencies for overhead projectors, or be in an electronic format such as a PowerPoint presentation. According to Work Group members, American Indian and Alaska Native elders prefer visual presentations rather than brochures. Because these elders learn visually, they prefer explanations with graphics. Elders want information that is relevant to their lives and their situation, and a speaker's guide is an adaptable tool.

If a brochure or a speaker's guide is developed, it should be distributed through the following channels:

- Public and nonprofit health care facilities that serve American Indians and Alaska Natives
- Clinic and health center educators and community health workers who service American Indian and Alaska Native communities
- National and local American Indian and Alaska Native organizations
- Exhibits presented at American Indian and Alaska Native festivals, powwows, and special events
- Diabetes programs

- Reservation health clinics
- Nearby hospitals
- Tribal community colleges
- Schools
- Churches
- Social gatherings (e.g., powwows, bingo , community center activities)
- Community sporting events (e.g., basketball)
- Village meetings
- Health fairs
- Arts and craft fairs

## **Proposed Channels**

### **Broadcast Media**

Limited data on media usage among American Indians and Alaska Natives are available. Focus groups conducted by the Koahnic Broadcast Corporation in Anchorage and Albuquerque indicated that most news and information came from television or print media, and radio was generally not considered a news source (CPB, 1995). However, many participants felt differently after hearing newscasts and feature programming specifically targeted to American Indians and Alaska Natives. Research by Nielsen Media Research and CommerceNet shows that American Indians and Alaska Natives are the fastest-growing group of Internet users among minority audiences (Nielsen Media Research, 1998). Increased usage in this population has been attributed to greater access to computers in the home, businesses, and schools as well as a growing need to connect with customs and heritage.

Radio and television PSAs could be used to create awareness about the risk of diabetic eye disease among American Indians and Alaska Natives and the importance of eye examinations for early detection and as a way to prevent loss of vision. Taped television and radio PSAs could feature trusted spokespersons who are able to deliver the NEHEP messages effectively. Live announcer radio PSAs could also be developed and

provided to the radio stations to reinforce the messages of the taped ones. If taped radio and television PSAs are produced, they should be disseminated through Native American public radio and television networks (e.g., Native America Calling—close to 60 U.S. radio stations). Local cable channels are another resource for disseminating diabetic eye disease information community-wide. For example, a diabetic eye disease awareness message could be promoted on local cable talk shows.

### **Print Public Service Announcements**

Print PSAs could also be used to disseminate the NEHEP messages, particularly if they are placed in community newspapers, newsletters, bulletins, and magazines. If television and radio PSAs are produced, the print PSAs could serve to reinforce the messages presented in the broadcast media.

### **Other Channels**

Other recommendations for dissemination channels in American Indian and Alaska Native communities are tribal websites, listservs and e-mail groups. Listservs specific to a community or a reservation or organizational e-mail groups are great tools for disseminating information quickly. The Internet is an important communication channel for American Indians and Alaska Natives. Radio stations also stream their programs on the Internet. However, youth are more likely to access the Internet than are elders. Another potential channel is telemedicine. Telemedicine offers an important opportunity to deliver health care to remote sites in Alaska and the lower 48 States.

Community events also provide opportunities for disseminating messages and materials. Announcers at powwows could be recruited to call out health messages promoting awareness of diabetic eye disease and the importance of eye exams at least once a year. Similar community-wide events could be identified for the broad dissemination of eye health messages for people with diabetes.

### **Role of NEHEP Partnership**

The strategy for promoting messages and materials about diabetic eye disease in American Indian and Alaska Native communities will be to identify and work with local and national organizations, including the NEHEP Partnership organizations. The first priority will be collaboration with key intermediaries who are already interested and/or involved in similar activities. Such collaboration will help strengthen existing efforts while identifying the NEHEP as an additional resource.

A parallel strategy will be to recruit additional organizations into the NEHEP Partnership from organizations with a special reach to or credibility with the target audiences.

***The Criteria for Assigning Priority to Collaboration Will Include the Following:***

- *Access to the target audiences*
- *Credibility with the target audiences*
- *Interest in collaboration*
- *Potential effect of the proposed activity*

***A Range of Collaborative Activities Between the NEHEP and Key American Indian and Alaska Native Organizations Could Include the Following:***

- *Help in developing, reviewing, and field testing materials*
- *Promoting and distributing materials*
- *Conducting presentations to patients and health care professionals*
- *Promoting messages through publications and newsletters*
- *Planning and implementing educational programs for risk groups*

## **Intermediaries**

Identified intermediaries can also supplement and extend the efforts of the NEHEP. The intermediaries will be organizations, associations, or groups that have direct contact with American Indians and Alaska Natives with diabetes and will provide assistance through the outreach and distribution of the materials. Potential intermediaries include associations or groups of American Indian and Alaska Native health care professionals, and national and local grassroots organizations that serve American Indians and Alaska Natives.

For example, the following entities could be involved in outreach:

- Tribal Colleges and Universities
- Community Health Representatives (CHR)
- National Indian Health Board
- Regional American Indian and Alaska Native health boards
- National Indian Council on Aging
- State and Regional Indian Aging Councils
- American Indian Health Centers (AIHC)
- National Indian Women's Health Resource Center
- National Council of Urban Indian Health
- Association of American Indian Physicians
- National Rural Health Association
- National Association of Community Health Centers
- Schools of Public Health
- United National Tribal Indian Youth (UNITY)
- National Congress of American Indians
- Native American Journalists Association
- National Alaska Native American Indian Nurses Association
- State Commissions on Indian Affairs
- Smithsonian Museum of the American Indian
- Native American and Alaska Native trade associations
- Native American and Alaska Native media organizations

## **VI. Evaluation**

This section of the communication plan discusses evaluation strategies. To assess whether the NEHEP reaches its specified goals and objectives, an evaluation plan will be incorporated into certain program components. Formative and process evaluation methods are proposed. Formative research measures materials development and product dissemination. Responses to formative research questions help shape the message content, channels for delivery, and effective appeals. Formative research includes pretesting of messages and materials.

Process measures help to document the extent to which a program is delivered and materials are developed as planned. Process measures focus on program implementation and outreach activities. Process evaluation measures often take the form of a monitoring and/or tracking system such as feedback on the dissemination and use of materials. The NEHEP should also consider the steps involved in developing programs that have long-term viability in American Indian and Alaska Native communities. Success can be measured by assessing whether the Program provides a method that can work and complement existing entities in American Indian and Alaska Native communities.

Process measures as well as outcome measures will be important in evaluating the success of the outreach initiative. Appropriate evaluation measures will be determined to assess whether the objectives set out above are being met.

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## VIII. Appendices

### A. Additional Resources

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## **B. National Eye Health Education Program Partnership**

- Administration on Aging, Department of Health and Human Services
- Alcon Laboratories, Inc.
- AMD Alliance International
- American Academy of Ophthalmology
- American Academy of Optometry
- American Academy of Physician Assistants
- American Association of Diabetes Educators
- American Association of Retired Persons
- American College of Occupational and Environmental Medicine
- American Diabetes Association
- American Foundation for the Blind
- American Medical Association
- American Optometric Association
- American Pharmaceutical Association
- American Society of Health-System Pharmacists
- American Society of Ophthalmic Registered Nurses
- Association for Education and Rehabilitation of the Blind and Visually Impaired
- Association of Schools and Colleges of Optometry
- Association of State and Territorial Directors of Health Promotion and Public Health Education
- Association of University Professors of Ophthalmology
- Centers for Disease Control and Prevention, U.S. Department of Health and Human Services
- Chi Eta Phi Sorority, Inc.
- Council of Citizens with Low Vision International
- Delta Gamma Foundation
- Department of Veterans Affairs, Veterans Health Administration
- EyeCare America
- The Glaucoma Foundation
- Glaucoma Research Foundation
- Helen Keller Worldwide
- Illinois Society for the Prevention of Blindness
- InFOCUS
- Indian Health Service, Department of Health and Human Services
- Joint Commission on Allied Health Personnel in Ophthalmology
- Juvenile Diabetes Foundation International
- Lighthouse International
- The Links, Inc.
- Lions Clubs International
- Lions Clubs International Foundation
- Low Vision Council

- Macular Degeneration Partnership
- Maryland Society for Sight
- The National Alliance for Hispanic Health
- National Association for Parents of Children with Visual Impairments, Inc.
- National Association for Visually Handicapped
- National Association of Area Agencies on Aging
- National Association of Hispanic Elderly
- National Association of Hispanic Nurses
- National Association of Vision Professionals
- National Black Nurses Association
- The National Caucus and Center on Black Aged, Inc.
- National Community Pharmacists Association
- National Council of La Raza
- National Council on Patient Information and Education
- National Council on the Aging, Inc.
- National Diabetes Education Program, National Institutes of Health/Centers for Disease Control and Prevention
- National Hispanic Medical Association
- National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health
- National Institute on Aging, National Institutes of Health
- National Medical Association
- National Optometric Association
- Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services
- Office of Minority Health, U.S. Department of Health and Human Services
- Prevent Blindness America
- Prevention of Blindness Society of the Metropolitan Area
- Rehabilitation Services Administration, U.S. Department of Education
- Research to Prevent Blindness
- Vision Council of America