

**ASSESSMENT OF VISION RELATED PROGRAMS  
AND SERVICES FOR AMERICAN INDIANS  
AND ALASKA NATIVES**

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## I. INTRODUCTION

In February 2001, the National Eye Institute (NEI), Office of Communication, Health Education, and Public Liaison awarded ORC Macro a contract to assess the current status of vision-related programs and services for American Indians and Alaska Natives—two groups that have been identified as being at high risk for chronic illnesses that affect eye health. Work on this project began in June 2001 and was completed by the end of that fiscal year.

Three program goals were identified—

1. To gather information about the vision-related programs and services that agencies, associations, and organizations (tribal and nontribal) provide to American Indians and Alaska Natives.
2. To conduct a literature search to—
  - identify and retrieve any published ophthalmologic studies that have been conducted that target American Indians and Alaska Native populations.
  - identify and retrieve any studies that describe the commonalities among the various American Indian and Alaska Native tribes.
3. To identify gaps in eye health information, services, programs, and materials targeted to American Indians and Alaska Natives.

In order to meet those goals, ORC Macro developed a study design that comprised the following six tasks—

*Task 1:* Identify American Indian and Alaska Native associations/organizations that may provide vision-related programs and/or services to their members.

*Task 2:* Meet with NEI staff to review the work plan and discuss associations and organizations identified in Task 1.

*Task 3:* Conduct a literature search.

*Task 4:* Design a discussion protocol that can be e-mailed to contacts or used when conducting telephone discussions.

*Task 5:* Perform data collection and analysis.

*Task 6:* Prepare a final written report for NEI.

A description of the study methodology is presented in Section II of this report. A brief literature review is presented in Section III. Information that each agency or organization provided about

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its health- and vision-related services to American Indians and Alaska Natives is presented in Section IV: Findings. The final section, Section V: Summary and Recommendations, points out the report's highlights and offers recommendations for NEI's consideration.

## **II. METHODOLOGY**

### **A. IDENTIFICATION OF POINTS OF CONTACT**

The NEI provided ORC Macro with a list of potential American Indian and Alaska Native agencies/organizations to contact. The list, however, was several years old, and ORC Macro staff contacted the agencies in order to update the contact information. Project staff also employed Internet search engines to find agencies that provided health- and vision-related services to American Indians and Alaska Natives. Ultimately, 59 Points of Contact (POCs) representing 23 organizations/agencies were identified. A list of the agencies/organizations, number of potential POCs identified, and number of responses received is shown in Table II-1.

### **B. PROTOCOL DEVELOPMENT**

ORC Macro prepared a discussion protocol suitable to e-mail to POCs that was approved by NEI. The protocol was modified slightly so that it could be used in telephone discussions. Both protocols included introductory paragraphs explaining that ORC Macro was working on behalf of the NEI to seek information about various agencies' provision of vision-related services to American Indians and Alaska Natives and about strategies that agencies employed to share health-related information with those populations.

The protocol contained discussion items on the following topics:

- Eye health programs and/or services that a particular association/organization/agency provided to American Indians and/or Alaska Natives.
- Effective approaches used to communicate health information to American Indians and Alaska Natives.
- Mechanisms in place used to disseminate health-related information, including eye health information, to American Indians and Alaska Natives.
- Barriers encountered when implementing vision-related programs and services for American Indians and Alaska Natives.

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**Table II-1: Identification of Points of Contact and Number of Responses**

Type of Agency/Organization	Number of POCs	Number of Responses Received
<b>Federal Agencies</b>		
Administration on Aging	1	1
Indian Health Service	30	15
National Institute of Diabetes & Digestive & Kidney Diseases	1	1
Office of Minority Health	6	3
<b>Subtotal</b>	<b>38</b>	<b>20</b>
<b>National Associations</b>		
Association of American Indian Physicians	1	0
Center for Native American and Alaskan Native Health	1	1
National Indian Council on Aging	1	1**
National Indian Health Board	1	0
National Rural Health Association	4	0
<b>Subtotal</b>	<b>8</b>	<b>2</b>
<b>State/Regional Affiliated Agencies' Programs/Services</b>		
Alaska Area Native Health Service	1	0
Alaska Native Tribal Health Consortium, Division of Planning, Evaluation, and Health Statistics	1	1
Arizona Health Care Cost Containment System	1	1**
California Area American Indian and Alaskan Native Diabetes Surveillance Project	1	1**
California Managed Risk Medical Insurance Board	1	1**
California Rural Indian Health Board	1	1
California Telehealth/Telemedicine Program	1	0
Indian Health Board of Minneapolis	1	0
Maniilaq Health Center Eye Clinic (AK)	1	1
Northwest Portland Area Indian Health Board	1	0
Seattle Indian Health Board	1	1
Sisseton Diabetes Prevention Program	1	1
University of Colorado Health Science Center	1	0
<b>Subtotal</b>	<b>13</b>	<b>8</b>
<b>GRAND TOTAL</b>	<b>59</b>	<b>30</b>
<p>**A representative of the organization responded via e-mail that the organization reviewed the discussion items and felt it could not respond to the items.</p> <p>We also identified the American Indian Health Care Association. After much searching, it appears that this association no longer exists.</p>		

- Primary gaps in knowledge among American Indians and Alaska Natives concerning eye health.
- Advice for the National Eye Institute as it considers new eye health program initiatives for American Indians and Alaska Natives.
- Strategies and/or approaches the NEI should consider in order to maximize its ability to communicate eye health information to American Indians and Alaska Natives.

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- Ways the NEI could better assist organizations that provide eye health services/programs to American Indians and Alaska Natives.
- Health education materials, targeted specifically for American Indians and/or Alaska Natives, that agencies would be willing to share with the NEI.

The protocol that was e-mailed to POCs is shown in Appendix A and the telephone protocol is shown in Appendix B.

### **C. DATA COLLECTION PROCEDURES**

For the contacts gleaned from Internet research, ORC Macro staff sent an introductory e-mail on July 2, 2001, that explained the purpose of the NEI project and inquired whether they would be interested in receiving some discussion points by e-mail or by telephone. Those who responded in the affirmative were e-mailed the formal discussion points. ORC Macro staff created a contact names table to track telephone numbers and e-mails sent and received. The first wave of e-mails was sent on July 9–10, 2001. E-mails that were returned were noted and the POC was contacted by telephone to confirm the e-mail address.

Since the protocol asked for POCs to identify other contact people who may have been interested in responding, the contact names table was continually updated and amended. We began the project with 42 contact names and ended with 59. ORC Macro staff identified an optometrist and a diabetes consultant for each of the 12 regional IHS offices and sent a protocol to each. At several area offices, the optometrist forwarded our e-mail and discussion items to other optometrists and diabetes coordinators who worked at other facilities in his/her IHS area.

For those who did not respond to the first e-mail, a reminder e-mail was sent on July 25, 2001, asking for a reply by July 31, 2001. For those who did not respond, a third e-mail was sent on August 10, 2001, requesting a reply by August 15. For those who were not added to the database until later, a final reminder e-mail was sent August 27 asking for a reply by August 30, 2001.

### **D. RESPONSE RATE**

We received a total of 30 responses. Four POCs indicated that they could not respond to the discussion items because their organization did not provide health care services to American Indians or Alaska Natives. Thus 26 individuals representing 10 organizations responded to some or all of the discussion items. Of those 26 responses, four were gathered by telephone interview, and 22 by e-mail. The initial POC response rate for this project was 50.8 percent.<sup>1</sup> The adjusted point of contact response rate was 54.5 percent.<sup>2</sup> If the organization becomes the unit of analysis, the response rate drops to 45.5 percent.<sup>3</sup>

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<sup>1</sup> Initial response rate was calculated based on 59 potential respondents and 30 responses.

<sup>2</sup> Adjusted rate calculated based on 55 respondents and 30 responses.

<sup>3</sup> Rate calculated based on 22 organizations and responses from 10 of these organizations.

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## III. REVIEW OF THE LITERATURE

ORC Macro staff initiated a literature search by using databases such as CHID online (Combined Health Information Database, Department of Health and Human Services), MEDLINE (National Library of Medicine), CRISP (Computer Retrieval of Information on Scientific Projects, National Institutes of Health), and Internet search engines such as Hotbot/Lycos and Yahoo! Staff also obtained abstracts and reviewed them for relevance. Project staff retrieved many of the articles at the National Library of Medicine. Each article's bibliography was reviewed to identify additional relevant articles that were also retrieved.

Presented below is a summary of some of the articles, monographs, and papers we reviewed. The literature review begins a discussion of the cultural issues related to American Indian and Alaska Native health care that have been published. This is followed with a brief summary of ophthalmological studies that have been conducted that target American Indians and Alaska Native populations. Included is a brief review of some of the diabetes literature regarding American Indians and Alaska Natives.

### A. CULTURAL ISSUES

In a study conducted to identify factors that influence Navajo patients to keep their appointments, Mealey and Kane (1997) found that 59 percent of follow-up appointments were kept. The percentage of kept appointment varied by condition. All (100%) of the eye check appointments were kept. The study revealed that non-appointment keepers were older and less educated than those who kept their appointments. Importantly, the authors pointed out that the individual who interviewed Navajos was a native born, bilingual Navajo. The authors also had Navajos review the study instruments for cultural sensitivity and appropriateness.

In a recent study Carrese and Rhodes (2000) sought to learn from Navajo informants a culturally competent approach for discussing negative information. In-depth interviews were conducted between 1993 and 1995 with Navajo informants, including patients, traditional healers, and biomedical health care providers. The authors acknowledged that cultural differences between doctors and their patients are common and may have implications for the clinical encounter. Unattended to, cultural differences between doctors and their patients may result in conflict, decreased patient satisfaction, misdiagnosis or suboptimal outcomes. Conversely, evidence exists that a culturally competent approach to health care will achieve better outcomes.

In an earlier study Carrese and Rhodes (1995) found that many Navajo hold to the tradition of not discussing negative information. The Navajo believe that thought and language have the power to control reality and discussing potential symptoms and complications of a disease will bring about those complications. The Navajo culture has a central concept of "combining the concepts of beauty, blessedness, goodness, order, harmony, and everything that is positive or ideal," (1995:829).

As a result of their studies, Carrese and Rhodes recommend a 4-step process when treating Navajo patients—

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1. Assessment—physicians should assess whether patients are willing to participate in a discussion that involves negative information.
2. Preparation—
  - Establish a trusting relationship.
  - Facilitate the involvement of family members.
  - Warn patients about the nature of the discussion and communicate to them that no harm is intended.
  - Facilitate the involvement of traditional healers if patient desires. Protective prayers or ceremonies are other measures to consider in preparing patients for a discussion.
3. Communication—
  - Communicate information in a caring, kind, respectful manner.
  - Do not rush the interaction.
  - Have a positive focus.
  - Refer to 3<sup>rd</sup> parties rather than to the patient directly.
  - Review the patient’s story relative to the issues at hand.
4. Follow-through—continue to care for patients and communicate hope.

Carrese and Rhodes conclude by saying that attempting to bridge cultural differences can be difficult. Cross-cultural differences can be profound and may defy good-faith efforts toward understanding and resolution. Health care workers should not assume that all patients from a particular group or culture are of the same mind, (2000:95).

Dubray and Sanders (1999) examined the interactions between American Indian ethnicity and health care. Their study addressed the needs of traditional and bicultural American Indians. Traditional American Indians were identified as those whose traditional language and customs are strongly maintained. These individuals/families often live in non-urban settings, and their needs are almost exclusively met from within their ethnic community. Bicultural American Indians are those individuals and families who have acquired traits of the dominant group, but also retain many of the ethnic characteristics, values, and beliefs of their tribal group.

The authors found that, among traditional and bicultural tribal peoples, language is commonly spoken briefly and in low tones, indirectly, and with little questioning or probing for information. Tribal peoples are also accustomed to long pauses in conversation, and will not participate in an argument, but will withdraw from the conversation.

Many Indian peoples who use biomedical health care also use traditional medicine or consult traditional healers. They may also participate in healing ceremonies such as the “sweat lodge.” Health care providers need to be aware of this, because traditional medicines may contraindicate



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prescribed medicines. In order to effectively treat American Indians, health care providers may want to consider partnering with a traditional healer.

The family is very important to Indian peoples. Family members may be consulted before any major decisions are made, and the physician must take this into account by involving family members in planning a treatment intervention. It is also important for the physician to understand how to correctly interpret non-verbal communication, which may indicate how the patient is receiving the information the physician is providing. This reaction may affect the impact of the treatment the physician is attempting to deliver. The authors conclude by saying the most effective approach to health care delivery among tribal peoples is a holistic, family systems approach.

A study done by Hatton (1994) explored health perceptions among older urban American Indians. The study focused on how these individuals perceived their health and how they managed their health problems. In a review of the literature conducted by the author, Hatton found that much of the literature addressing health beliefs and practices among American Indians pertained to the Navajo. Sobralske (1985), Davis (1980), and Adair and Deuschle (1970) found health among Navajos is often explained from a holistic point of view. Sobralske found that while some contemporary Navajos use biomedical health care, their traditional belief system remains intact.

Among other tribal groups, the literature indicates variation in adherence to traditional values and beliefs. Aamodt (1978) discovered traditional religious and supernatural beliefs about health among the Papago tribe. Hobus (1990) documented strong traditional practices in a case study of a Lakota family managing the health problems of elders. Bushnell (1981) however reported a decline in traditional health approaches in an investigation of childbearing American Indian women. These women did not replace lost traditions with biomedical health beliefs and practices (Hatton: 1994:393).

Over a 2-year period, Hatton (1994) conducted interviews with 19 older American Indians who reside in two urban communities. The author found that these older adults developed their ideas of health by observing signs of illness, incorporating the ideas of others, and evaluating their ability to get around. Generally these individuals conceptualized their health from a biomedical perspective. These older American Indians routinely sought health care from providers in IHS facilities. However, they said that they used traditional American Indian treatments for health problems during childhood and young adulthood. Hatton concludes by suggesting that similar studies should be conducted with elders residing on rural reservations to identify differences between rural and urban elder American Indians' health perceptions.

The National Indian Council on Aging (NICOA) disseminated a paper written by PRO-West, a private, nonprofit health care quality improvement organization. This paper, published in 1999, includes recommendations from the "Vulnerable Populations Project: Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations—American Indian and Eskimo populations in the states of Washington, Idaho, and Alaska Study: Recommendations." As stated on page 2 of the report, the following comments represent

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NICOA's recommendations for the strategic development and implementation of outreach to American Indian/Alaska Native (AI/AN) Medicare Beneficiaries residing in Alaska, Oregon, and Washington. It is NICOA's opinion that the recommendations in the report are generally applicable on a local, regional, and national scale.

PRO-West found that Indian elders are distrustful of mainstream providers that are culturally insensitive. They expect outsiders to adhere to behavioral and business protocol, whether formal or informal. They advise anyone who wishes to conduct business within a tribal community to enlist the assistance of a tribal employee.

Indian elders said they would like to receive information in the following ways:

- From family members or other trusted members of their communities
- On a one-to-one basis, in person
- In simple, understandable language, without acronyms
- With ample visual content that is appropriate and relevant to their lives.

Many American Indian and Alaska Native patients view health care as an entitlement that was given in exchange for their lands. However, because of the government's inadequate funding of the IHS, many patients have become accustomed to substandard service and have learned not to depend on biomedicine for long-term care. They depend more on families and community members who have their trust and respect. This independence is a probably barrier to outreach efforts.

NICOA recommends employing the following principles at every level of an outreach campaign:

- Involve Indian leadership at every level, from strategic planning to onsite delivery.
- Establish a collaborative partnership with selected agencies, Indian organizations, and providers.
- Use existing networks for outreach and service delivery.
- Focus solely on American Indian/Alaska Native client preferences.
- Develop/use culturally specific educational materials.

They also suggest that health care providers should hire full-time employees who are dedicated to the outreach effort, and implement a train-the-trainers program for those educating Indian elders about Medicare benefits and how they work in concert with other insurance.

Local outreach efforts should include the following:

- Obtain the assistance of respected local residents who are aware of, and willing to share, the community's traditional folkways.

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- Observe tribal protocols. These almost always include obtaining advance permission from tribal authorities before initiating business.
- Arrange, if at all possible, for a local resident to deliver the message.
- Provide the results of your work to both the tribal leaders and communities/recipients of your educational outreach.

Han et al. (1994) conducted a field study to identify cultural factors—values, beliefs, and related characteristics associated with health-risk behavior among adult members of the Cheyenne River Sioux Tribe in South Dakota. A Cultural Values Survey (CVS) and Health Risk Appraisal (HRA) were used to link health status with cultural beliefs. Women who scored high on questions regarding traditional Lakota lifestyle and culture, beliefs in altruism and self-control, and devaluation of wealth and occupation were generally healthier than those who scored lower on those questions. However, the healthiest men were those who appeared to be less traditional and more acculturated to Anglo society. This finding can be interpreted to mean that acculturation produces less stress for Lakota men than for Lakota women, or that there is more pressure on Lakota men to become acculturated to Anglo society. It is generally recognized that in the acculturation process, Lakota women are allowed to retain more elements of traditional Lakota culture than Lakota men do. The authors suggest that future studies be conducted to learn more about the relationship between cultural factors and health-related behavior.

In studying the Houma Indian Nation, Coughlin (1998:33) found many barriers to health care treatment: geographical isolation, rural residence (Louisiana), lack of transportation, poverty, unemployment, lack of education, language barriers, lack of access to health care, and cultural and attitudinal factors. The Houma tribe is not a federally recognized tribe and, as such, is not eligible for health care provided by the IHS. They exhibit many high-risk behaviors such as smoking, using chewing tobacco, and frying food in lard. Yet many Houma women believe they are healthier than white women are because they live in harmony with nature and take less medication.

Gohdes (1993) described a conference that took place in 1989 that explored diabetes in American Indians and Alaska Natives. The proceedings suggested the following when undertaking surveys among Indian communities:

- Establish relationships with tribal councils and health committees.
- Include presentations to the tribal council when planning the reporting process.
- Ensure that feedback to the communities takes the form of personal oral and written communications to the tribal councils and health committees.

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### B. OPHTHALMOLOGIC STUDIES

Pensyl et al. (1997) studied astigmatism among the Sioux in South Dakota. The authors found that in a clinical sample, 87 percent needed refractive correction and 24 percent had eye disease. These rates are higher compared to the general U.S. population of 50 percent with vision disorders and only 5 percent with ocular disorders.

This study corroborated earlier studies by Heard et al., Mohindra and Nagarj, and Goss (1989) that found that there is a high degree of astigmatism among American Indians. Some possible reasons may be genetics, nutrition, effect of the upper tarsal plate pulling across a cornea of low rigidity, or mode of transmission (autosomal dominant). Young adults tend to have with-the-rule astigmatism, while older adults display against-the-rule astigmatism. One hypothesis is that eyelid tension causes astigmatism by steepening the corneal vertical meridian and flattening the horizontal meridian. But as eyelid tension reduces with age, so does with-the-rule astigmatism.

Arnold et al. (1994) studied premature infants in Anchorage to determine the prevalence of retinopathy of prematurity (ROP) among Alaska Natives. Of 127 infants, 34 of which were Alaska Natives, the threshold rate for natives (32 %) was significantly higher than for non-natives (11%). The tendency for Alaska Natives to develop threshold ROP may be genetic or environmental. One hypothesis is that coastal Alaska Natives who seemed to have the highest risk of threshold ROP receive most of their protein from fish, which is rich in omega-3 substituted free-fatty acid. Land animals and plants are a source of omega-6. Dietary lipids may make a significant contribution in the correct development of the retina.

In another study (Lee et al., 1992), factors highly associated with the risk of developing diabetic retinopathy were found to be age, age at diagnosis, duration of diabetes, and systolic and diastolic blood pressure.

Adler-Grinberg (1986) describes eye care services provided to the Standing Rock and Cheyenne River reservations in North and South Dakota by the University of Houston College of Optometry. The sample included patients who voluntarily went to the optometry clinic from March through September 1980 or participated in a school vision program during July 1980. Participation was voluntary. The availability of services was advertised in reservation newspapers and spread by word-of-mouth by patients and by community health representatives (CHRs). Data from 1,886 clinical records were analyzed.

Almost 50 percent of the patients had compound myopic astigmatism, 14 percent had refractive error that had never been corrected, and 36 percent knew that they needed eyeglasses but no longer had any. It was not uncommon to find that patients wore glasses belonging to family members or friends.

Older patients did not use the eye care services as much as the younger tribal members possibly because of transportation issues and a general belief that decreased vision was a natural symptom of old age.

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In an effort to improve eye care for American Indians and Alaska natives with diabetes, the IHS posted on their Web site a Best Practice Model (IHS, 2001). Their model espouses the following suggestions:

- People with diabetes must have optimal management of their metabolism including blood sugar level and blood pressure to minimize progression of ocular complications. High-risk non-eye complications of diabetes such as high blood pressure and kidney disease must be managed according to American Diabetes Association recommendations.
- Laser treatment must be provided according to Diabetic Retinopathy Study (DRS) and Early Treatment of Diabetic Retinopathy Study (ETDRS) guidelines.
- Patients who have received laser and other diabetic eye treatments must be followed with regular examinations to detect recurrences needing additional treatment.

How to motivate patients to have annual eye exams:

- Provide patient travel costs.
- Ensure that patients understand the benefits of having annual eye exams.
- Provide prescription eyeglasses and/or other incentives to people with diabetes who are current with all their diabetic standards of care including eye evaluations.

How to ensure adequate availability and accessibility of eye evaluations for people with diabetes:

- Fully staff and provide adequate clinical space and equipment to deliver needed eye exams.
- Maximize the ease of making eye evaluation appointments by giving priority “fast-track” appointments to persons with diabetes.
- Provide telemedicine retinal imaging and evaluations in non-eye primary healthcare settings such as pharmacies, family medicine clinics, and community settings to reach patients who do not come to eye clinics.

Costs for providing in-facility clinical diabetes eye exams:

- Hiring full-time providers averages \$75,000 to \$85,000 yearly for an optometrist, \$125,000 to \$150,000 yearly for an ophthalmologist. The IHS RRM document recommends one primary eye care provider per 5,700 in the population.
- Hiring full-time ophthalmic technicians and assistants averages \$21,000 to \$30,000 annually. The RRM document recommends 1 support staff position per 2,187 in the served population.

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- Initial purchase of new eye clinic exam room equipment averages \$85,000 per room.

### **C. EYE HEALTH AND DIABETES**

Bowyer (1997) documents the experiences of a collaborative primary care team approach to the prevention and treatment of ocular complications of diabetes in patients receiving care at the Bemidji Area Indian Health Service's White Earth Indian Health Center in Minnesota. The study team's review summarized the process of implementing the Minnesota Department of Health's Diabetes Control Program and documented the experiences of the White Earth Indian Health Center in establishing priorities, selecting guidelines, and implementing and monitoring a pilot project for the prevention of ocular complications of diabetes on the basis of a quality improvement model (1997:241). As a result of implementing this program, Bowyer found that the rate of diabetic eye examinations increased to 86 percent of all individuals diagnosed with diabetes. Area-wide chart audits from FY 1989 indicated only 35 percent of people with diabetes had an eye examination documented on their health records.

In a study designed to discover why the Navajo did not complete treatment for diabetic retinopathy, Sugarman et al. (1993) surveyed Navajo on the reservation in New Mexico, Arizona, and Utah. They obtained approval from the Shiprock Service United Health Board, and the Navajo Area IHS Research and Publications Committee. Sugarman et al. found that patients' education level or modern facilities in the home did not affect completion of treatment. Females were less likely to obtain treatment than males, as were married patients than single, widowed, or divorced patients.

Many patients also believed that eye problems were caused by a previous trauma (stick scratching an eye), or by being out of harmony with nature and could be improved by traditional ceremonies. However, the biggest issue was transportation. The authors suggest that any interventions to increase use of ophthalmologic care must address transportation. Moreover, they found that when requesting permission of tribal councils to conduct research, many councils wanted reassurance of the benefits from the research—something that cannot be given before the clinical trials are conducted. The authors also suggest emphasizing that people who participate in clinical trials usually receive better health care. To address this issue, educational materials need to clearly articulate this point.

One researcher (Womack, 1995) surveyed American Indians about their beliefs on diabetes. Ironically, the study found that the more serious patients believe diabetes to be, the less likely they will be to comply with the advice of health care professionals. The author found that of the patients who were 40 years old and younger at the time of initial diagnosis, the more likely they felt that blood glucose control would help prevent long-term complications of diabetes.

Another in-depth study (Pine, 1988) compared low socioeconomic American Indians and Black Americans with higher socioeconomic status American Indians, Black Americans, and White Americans. The results show that regardless of ethnicity, lower socioeconomic status groups

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were more overweight than higher socioeconomic status groups. And the major factor related to a family history of diabetes was obesity.

Ryan (1981) posits that without family support, any major lifestyle changes undertaken to offset diabetes would be difficult. The changes may contradict the cultural norms, recommended diets may not fit with traditional food choices, foods may be expensive, or the family member with diabetes may have to prepare two separate meals—one for him/herself and one for the rest of the family (Joos, 1984).

Pine (1988:101) lists several factors that may influence the effectiveness of treatment interventions for American Indians:

- Ways in which a person's family and community are supportive and provide structure
- Traditional learning practices
- Social and cultural variables related to eating habits and practices
- Similarity or lack thereof of traditional foods that would comply with needed diet changes
- Perceptions of body image and actual prevalence of obesity
- Traditional/relevant physical activities that may or may not be useful in controlling weight and diabetes
- Traditional healing practices.

Gohdes et al. (1993) listed the leading causes of death (according to the IHS) among American Indians and Alaska Natives:

1. Heart disease
2. Accidents
3. Malignant neoplasms
4. Cerebrovascular diseases
5. Chronic liver disease and cirrhosis
6. Diabetes mellitus
7. Pneumonia and influenza
8. Homicide
9. Suicide
10. Chronic obstructive pulmonary diseases.

Although diabetes was listed as number 6, it undoubtedly contributes to heart disease, cerebrovascular disease, and pneumonia/influenza.

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One study (MMWR, 1996) reported on 141 service units of the IHS on the prevalence of diabetes among—

- Woodland tribes—Alabama, Connecticut, Florida, Kansas, Louisiana, Maine, Michigan, Minnesota, Mississippi, New York, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, Texas, and Wisconsin
- Plains tribes—Iowa, Montana, Nebraska, North Dakota, South Dakota, and Wyoming
- Southwestern tribes—Arizona, Colorado, Nevada, New Mexico, and Utah
- Pacific Coastal tribes—Alaska, California, Idaho, Oregon, and Washington.

The prevalence of diabetes varied by tribal group—12.7 percent among the Plains tribes, 10.5 percent among the Southwestern tribes, 9.3 percent among the Woodland tribes, and 4.5 percent among the Pacific Coastal tribes.

### **IV. FINDINGS**

#### **A. INTRODUCTION**

Twenty-three agencies, associations, and organizations that appeared to serve American Indians and Alaska Natives were identified. After repeated attempts, it was determined that the American Indian Health Care Association no longer is in existence. With the remaining 22 agencies, respondents from 4 agencies—

- Arizona Health Care Cost Containment System
- California Area American Indian and Alaska Native Diabetes Surveillance Project
- California Managed Risk Medical Insurance Board
- National Indian Council on Aging

replied and said their respective organization could not respond to the items. The POC from the Arizona Health Care Cost Containment System said that they are a Medicaid agency and do not have specific programs for American Indians. The POC from the California Area American Indian and Alaska Native Diabetes Surveillance Project wrote that they were a tribal organization that provided no healthcare services. The respondent from the California Managed Risk Medical Insurance Board said they are an insurance company with no special outreach to American Indians. Finally, the executive director of the National Indian Council on Aging (NICOA) said his organization does not provide health services, rather, they serve as an advocacy organization.

Of the remaining 18 organizations, 30 individuals representing 10 organizations responded to some or all of the discussion items. As shown in Table II-1, the majority of those respondents worked for the Indian Health Services (n=15).



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### **B. EYE HEALTH PROGRAMS AND SERVICES**

POCs were asked how they would characterize their organizations/associations eye health programs/services. Respondents could select one or more of the following types—

- Prevention/screening
- Education
- Treatment
- Advocacy

Of the 26 respondents, 30 percent (n=9) did not respond to this item. A review of the remaining 21 responses reveals that more than half characterized their program as education (62%, n=13) and/or prevention/screening (57%, n=12). Forty-eight percent (n=10) characterized their organization as a treatment program and 33 percent (n=7) as an advocacy program.<sup>4</sup>

Presented below are more detailed findings about the types of eye health programs and services that agencies/organizations/associations provide American Indians and Alaska Natives. Since the majority of the respondents represent one Federal agency—the Indian Health Service—those findings are presented first, followed by information about other Federal agency programs, and finally programs and services offered by other organizations/associations.

#### **1. INDIAN HEALTH SERVICE (IHS)**

The IHS is responsible for providing Federal health services to federally recognized American Indians and Alaska Native tribes in the continental United States and Alaska. One of the goals of the IHS is to raise the health status of American Indians and Alaska Natives to the highest possible level (IHS, 2001). IHS provides health services to approximately 1.5 million American Indians and Alaska Natives who belong to more than 557 federally recognized tribes in 34 States, and speak more than 200 different languages. Approximately 70 percent of the federally recognized tribes receive health care services from the IHS and approximately 30 percent of the tribes provide their own health care.

Among the myriad of health-related programs offered by the IHS, two were of interest to us—

- **Optometry Program.** This program provides “curative, preventive, and rehabilitative services through hospitals, health centers, and clinics located in primarily rural locations on or near reservations. To the extent possible within the resources available, the IHS will make available an organized and on-going eye care program that includes the following: ocular health promotion activities, general and specialty examinations, treatments and procedures, required prescription ophthalmic devices and associated dispensing services, and ophthalmic surgery,” (IHS, 2001).

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<sup>4</sup> Note: Total exceeds 100 percent because respondents were asked to select all that applied.

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- National Diabetes Program. Each area office has designed a model diabetes program. The program collects epidemiological data, lists clinical accomplishments, community-sponsored programs, education programs, and resources and publications. Most are staffed with a physician, dietician, nurse practitioner(s), and health educator(s). According to the IHS Web site, 9 of the 12 area model programs specifically identify eye exams and/or eye health as one of their services.

The delivery of IHS health and medical services is managed through local service units organized under the administration of Area Offices. Each service unit serves a specific geographic and tribal sector. The units work closely with tribal governments. For example, in Alaska, the Alaska tribes administer 99 percent of IHS funds earmarked for the State. In California, the Area Office contracts with federally recognized tribal governments and urban Indian organizations to provide health services.

Dr. Richard Hatch, IHS Chief Clinical Consultant for Optometry, reported that as of September 30, 2000, 143 optometrists were serving in the Public Health Service and affiliated programs. These optometrists provide comprehensive eye care to American Indians and Alaska Natives served at IHS and tribally operated health care facilities.

Fifteen POCs (optometrists and diabetes program coordinators) from 9 of the 12 area offices responded via telephone or e-mail to our inquiry about their program. This includes the following Area Offices—

- |                    |                   |
|--------------------|-------------------|
| ▪ Aberdeen Area    | ▪ California Area |
| ▪ Alaska Area      | ▪ Nashville Area  |
| ▪ Albuquerque Area | ▪ Oklahoma Area   |
| ▪ Bemidji Area     | ▪ Portland Area   |
| ▪ Billings Area    |                   |

Contacts were asked to provide information about their eye health programs and services; population(s) served; variations, if any, in the services provided because of differences in tribes, location, gender or age; and other organizations/associations that provide services to American Indians and Alaska Natives.

A review of the responses that contacts provided revealed that—

- IHS provides eye care services to eligible American Indians and Alaska Natives through direct onsite services or through contract health care.
- In the Alaska Area, the Anchorage service unit is the only area in the State that has full-time ophthalmologists. These doctors provide itinerant services to other service units.

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- The Pine Ridge Hospital (Aberdeen Area) in South Dakota has 3 full-time optometrists. The diabetes program includes a full-service vision clinic that provides routine care.
- The eye care or optometry portion of health services is only a small part of the overall medical services provided to American Indians/Alaska Natives in the Albuquerque Area. Services typically provided at some locations include ocular and vision diagnosis, treatment and monitoring, eyeglass services (i.e., ordering, adjustment, repairs), and vision screening for children and the elderly.
- The Bemidji Area provides direct optometry care including refraction and retinal screening, contract optometry care, and contract ophthalmology care. Of the 39 programs in the Bemidji Area, 3 are IHS, 31 are tribal (IHS contract/compact), and 5 are urban (partially IHS funded).
- The eye clinic of the Northern Cheyenne Service Unit, Billings Area participates in several services to improve eye care in their community including—
  - Refraction and eye health examinations, as well as onsite treatment of uncomplicated eye health problems.
  - Referral to ophthalmological services (monthly visits by a consulting ophthalmologist or referral for acute or extended care.
  - Participation in the national area diabetes program, giving priority to people with diabetes to try to provide annual dilated eye exams and assessments, as well as education.
  - Vision screening by an optometrist at local schools.
  - Providing free eyewear annually to school-aged children, people with diabetes, and senior citizens to encourage regular eye examinations.
  - Consultation with physicians and other providers on eye-related problems.
  - Participation in health fairs and job fairs.
  - The California Area has a number of facilities with optometry services onsite. This area serves 106 federally recognized tribes, including a large urban population made up of people who relocate.
- The Nashville Area does not have in-house optometrists. Rather, they contract out services.

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- The Oklahoma City Area Office, IHS' largest area office, has several optometrists. At one of their hospital-based clinics, a diabetic retinal ophthalmologist has a monthly clinic and performs laser eye surgery. The area also has a half-day general ophthalmology clinic. The clinic provides complete eye exams and manages all primary eye diseases such as glaucoma, eye infections, and the like.
- The diabetes area coordinator indicated that the Portland Area has not implemented a cohesive eye health program on an Area-wide level. Each site manages eye care on an individual basis. Some have onsite optometry facilities and provide comprehensive care, while other sites contract out for optometry and ophthalmic services. "Some tribes have no clinical services at all." She further wrote that some eye care is monitored through their diabetes clinical audit, which tracks the frequency of dilated funduscopy for people with diabetes. She estimated that 20 facilities in the Portland Area use this program.
- Respondents from the California, Nashville, and Oklahoma Area Offices mentioned a telemedicine program that is being used to screen for diabetic retinopathy. Another respondent from the Billings Area office also mentioned a telemedicine project in Phoenix.
  - The California Area contact wrote that his area is starting a telemedicine/ophthalmology program. They will use a retinal camera that is attached to a computer to electronically transmit retinal pictures to an ophthalmologist to read. To date, 10 programs have been funded and they anticipate funding an additional 8 sites. He estimates that it will cost \$65,000 for equipment per site.
  - The Nashville Area Diabetes Program has been looking at Tele-Ophthalmology for their isolated tribes. A university and a company are interested in providing this service to tribes.
  - The Oklahoma City Area contact wrote, "the most innovative [program] is the Diabetic Telemedicine Photographic Clinic. Using digital imaging and the Internet, gold standard retinal photographs are taken of the eyes of people with diabetes and read at Vanderbilt by expert technicians. Within 48 hours we have a report describing the findings and know whether eye doctors need to follow the patient for advanced diabetic retinopathy. The Chickasaw Nation provided a major role in developing this system beginning in 1995 and it has been fully operational to the general Indian public in a primary care setting at our facility [Carl Albert Indian Health Facility] for approximately 1.5 years through Inoveon, a private health system provider."

According to IHS contacts, each area office serves American Indians and Alaska Natives who typically reside in their area. An Aberdeen POC also wrote that his area office also serves the commissioned officers and their dependents who are stationed at the facilities.

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While respondents pointed out that there is no difference in services provided according to age or gender, the type of service provided differs across IHS areas because some facilities have optometrists on staff while others do not. One POC wrote that services differ because “funding between geographic and political areas is widely variant.” Another person wrote, “services differ because of access to services. The more remote the facility or the less available the transportation, the more limited the services are.” The POC responding for the California Area Office said the eye health programs and services “mainly differ according to the population size, since this affects the base budget. Some gaming tribes provide services to their members, so there is a mix of services.”

IHS contacts identified four other organizations that provide programs/services to American Indians and Alaska Natives. These include—

- Lion’s Club
- Shriners
- Christian Medical Society
- Save the Children.

In the Billings Area, the Lion’s Club assists tribal programs in the purchase of eyeglasses. The Shriners also provide services to children with eye deformities/congenital conditions in the Billings Area. The Lion’s Club and Christian Medical Society work with the Zuni Eye Clinic, which serves the Zuni and Navajo Reservations. Save the Children assists in offering services in the Navajo area by providing funding for an optometry residency program at the Gallup Indian Medical Center in Gallup, NM, and by providing the funds needed for glasses for sponsored American Indian children in the Navajo area.

### **2. OTHER FEDERAL AGENCY EFFORTS**

**Administration on Aging.** The Administration on Aging’s (AoA) American Indian, Alaska Native, and Native Hawaiian Program is responsible for serving as an advocate on behalf of older American Indians, coordinating activities with other Federal departments and agencies, administering grants to American Indians, and collecting and disseminating information related to the problems of older American Indians. The populations they serve live on or near reservations, in historical Tribal lands in Oklahoma, and in Alaska Native villages. Since their program helps to fund Senior Centers, most of the AoA’s education training takes place at the Center. In some cases, the local program will have optometrists or health educators talk to the elders about eye health.

**National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK).** NIH and the CDC jointly sponsor the NIDDK National Diabetes Education Program (NDEP) that includes both public- and private-sector partners. It is an education program designed to raise awareness and improve the quality of care of people with diabetes. One of the NDEP’s initial challenges was to develop educational messages that reached diverse cultures. The Program established several work groups, including the American Indian Work Group, to assist the larger NDEP in disseminating important research finds and developing culturally appropriate diabetes education

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messages and products. The NDEP American Indian Campaign has developed special messages intended for American Indian and Alaska Native populations using a broad-based media campaign that includes television, radio, print materials, community partnerships, the Internet, and toll-free telephone access. Key messages include “Control your Diabetes. For Life.” and “Control your Diabetes for Future Generations.” The campaign materials have been distributed to Indian health grant programs, and the program has received awards for the TV spots. Continuing challenges include the increasing burden of diabetes in Indian populations; increasing demands for educational materials; the increasing need to reach out to children, families, and communities; continuing development of creative, informative resources, products, and messages to disseminate; and identifying resources to evaluate campaign outcomes.<sup>5</sup>

**The Office of Minority Health (OMH).** We attempted to contact 4 individuals who work as health educators for the OMH. Only one person responded and two other individuals who work within OMH responded. OMH’s mission is to improve the health of racial and ethnic populations through the development of health policies and programs that help to eliminate disparities in health. OMH’s resource center (OMHRC) provides referrals, publications, reference information, and access to its resource persons network. The health educator who did respond reported that she worked with Pueblo groups, but does not specifically provide health information/education on eye health.

### **3. OTHER ORGANIZATIONS/ASSOCIATIONS**

Contacts from two Indian Health Boards responded to our inquiry. The California Rural Indian Health Board, which serves American Indians in Humboldt and Del Norte counties in California, reported having ophthalmologists at their main facilities once a month. No ophthalmologic services are provided at their three satellite clinics. Optometrists are able to screen patients onsite 2 times per week. They are starting a tele-optometry program in one of their satellite clinics.

Prior to September 1, 2001, the Seattle Indian Health Board referred all eye care out. Now they are providing onsite eye exams and health education about the need for annual eye exams.

The Sisseton Diabetes Prevention Program in South Dakota is a tribal diabetes prevention program that has funding to provide dilated eye exams for as many people with diabetes per year as their funding can handle. This program serves American Indians with a priority given to members of the Sisseton Wahpeton Sioux Tribe.

The Maniilaq Association is a non-profit corporation and a tribal consortium representing 12 federally recognized tribes in the Northwest Arctic Borough of Alaska. They operate an eye care clinic in their health center located in Kotzebue, Alaska. The clinic is equipped with state-of-the-art equipment. Eye exams are performed at the clinic and most patients can be treated by the onsite optometrist or by ophthalmologists that come to the center from the Alaska Native

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<sup>5</sup> Sources for information on the NIDDK’s NEDP include written responses provided by NIDDK contacts and from minutes of the Diabetes Mellitus Interagency Coordinating Committee (DMICC) Meeting, May 11, 2000.

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Medical Center in Anchorage several times each year. Eye surgeries are performed in Anchorage.

Also in Alaska, the Alaska Native Tribal Health Consortium serves 6 different tribes—

- Aleut
- Athabascan
- Eskimo
- Haidas
- Tlingits
- Tsimpsons

Eye care is provided at 7 different service units across the State. The Anchorage service unit is the only area in the State that has full-time ophthalmologists who provide itinerant service to other service units. Contract optometry service is provided at some units.

### **C. EFFECTIVE APPROACHES USED TO COMMUNICATE HEALTH INFORMATION**

Universally, most respondents said the most effective approach they used to communicate health information to American Indians and Alaska Natives is one-on-one personal contact. Other suggestions included translation in Native language, emphasis on the cultural appropriateness of the information shared, concern for the literacy level of printed materials, and community involvement. Contacts' verbatim comments are presented below.

- I counsel them in the exam room both with general information and then information directly pertinent to their case.
- One-on-one [contact] is the most effective with frequent repetition over time. Having a family member present is important for the elderly. Community programs that emphasize health issues work well also.
- I feel that the most effective approach in communicating health information is in the doctor-patient setting during the examination.
- The most effective approach is having a variety of approaches including one-on-one patient education, patient educational resources such as written materials and videos, and translation services for those who speak their traditional language. Of importance is the cultural appropriateness of the information shared and low literacy applications.
- Working directly with tribes and through the regional IHS eye care providers.
- Attempting to communicate on a one-on-one basis is the most effective approach I have seen.
- Word-of-mouth from patients and community members. Printed materials, public service announcements (PSAs), and videos are also acceptable.

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- Using a public health approach to providing awareness. Also using public health nurses and educators.
- Videotapes and literature designed for lay individuals.
- One-on-one communication with patients. The diabetes program has used radio spots with some success.
- Developing contacts within the community and using teachers from the community.
- When it is done locally by health providers, public health nurses, or community health provider.
- Working with the community to develop and disseminate messages.
- Intense public relations within the community.
- Individual education both by providers and educators as well as group education.

### **D. MECHANISMS USED TO DISSEMINATE HEALTH-RELATED INFORMATION**

Contacts use a variety of methods to disseminate information to American Indians and Alaska Natives including radio spots, posters, articles in tribal newsletters, mass mailings, posting information on Web sites, health educators, and community health fairs. The Bemidji Area uses direct mailings, sponsors provider-education workshops, and postings on their IHS Web site. In the Albuquerque Area, contacts also use tribal newspapers, radio stations, and community health fairs to communicate information.

The California Area Office has a Web page that they use to post information. The contact also mentioned that tribal programs have Web pages, use health letters, and distribute information at clinics in written format. Some of the written information is designed specifically for American Indians, while some is general information that the Area office gets from other organizations.

The Nashville Area contact mentioned lectures to medical staff, faxes of current literature, and pictures of eye diseases. Other area offices rely on health educators to disseminate health-related information. The Sisseton Diabetes program uses local tribal radio stations, tribal newspapers, and posters at clinics to disseminate information.

The Maniilaq Eye Health Center is currently working on patient education brochures that are written for the Northwest Arctic and Inupiaq cultures. The Seattle Indian Health Board asks providers to share information with their patients. The Board also does an annual mass mailing



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when they offer free eye screenings. They have begun to track annual eye exams and will offer education as part of their recall system.

### **E. BARRIERS ORGANIZATIONS HAVE ENCOUNTERED WHEN IMPLEMENTING VISION-RELATED PROGRAMS AND SERVICES**

Many respondents said the sizes of the areas they serve and lack of transportation are two of the main barriers encountered. Others mentioned lack of funding and other cultural issues. POCs' verbatim comments include—

- The reservation is large and patients sometimes have to come 60 miles to us. There is no public transportation.
- [The lack of] transportation causes patients not to keep their appointments. In the winter, weather-related problems also cause difficulty. Thus, some patients have difficulty keeping appointments at my clinic and also have trouble keeping appointments with the specialists I refer them to.
- For us [Alaska], specifically the geography and size of the area involved is a major barrier. At 586,000 square miles, we encompass 1/5 the land mass of the United States. Since most of the state is not serviced by roads, many people have to fly to other areas for specialized health care, including eye care.
- Having folks make it to their appointments, getting a streamlined referral process in place, and when it is available, getting the providers to use it, are barriers.
- Lack of insurance, cost of copays for those with insurance or Medicare; failure to keep appointments, especially referrals; and competing demands. For example eye health may not be a priority for those who do not wear glasses and/or those whose vision is not impaired.
- Costs related to services are always a barrier. Not all necessary services may be available. Assisting the client in understanding all the nuances of appropriate follow-up care and/or services, such as laser treatment, can be challenging given cultural and language challenges. Transportation to keep appointments can also be a barrier.
- Mainly financial, lack of insurance coverage, inability to purchase insurance. Not so much geographic.
- Not enough funding.
- As with most programs, increased funding would help. Also cultural differences impact care. Some people are loathe to discuss diabetes and other eye diseases

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since they feel that talking about it helps bring on the problem, and there is some feeling that the IHS brought health problems to the reservation to further its own ends.

- Language is a barrier with some, as well as the acceptance of Western medicine over traditional ways.
- Limited data on the burden of eye disease other than diabetic retinopathy.

### **F. GAPS IN KNOWLEDGE REGARDING EYE HEALTH**

One of the goals of this project was to identify gaps in eye health information, services, programs, and materials targeted to American Indians and Alaska Natives. Several POCs reported that some of the clients they serve do not understand the ramifications of diabetes and how it can affect vision. One contact wrote, “since eye disease occurs slowly, it is very difficult to convince some tribal members to control their blood sugar and follow up with their eye care professional.” Another person wrote, “Many patients do not understand how diabetes can affect vision.” The contact from the California Rural Indian Health Board wrote that patients often “do not understand the importance of routine exams and the critical importance of and ability to prevent complications [of diabetes] with good blood sugar control.”

Also in California, the Area Office contact said the gap is the “connection between eye disease and diabetes. That is a huge problem that we are focusing on. We also want to focus more on eye care in general.”

Other POCs did not know of specific gaps of information. One person wrote, “I have no documented information on this topic.” Others simply did not respond to this discussion item. Another person said that the gaps in knowledge were “probably no different from those of the general population. Individuals do not know that diabetic eye disease is serious, but preventable.” Finally, another contact stated, “I’m not sure if there is any one area Natives have trouble with. Some are very interested in their health and attentive to any and all patient education you provide, while others don’t care much and fail to adopt healthy habits. The former group does well; the later develop most of the complications.”

### **G. ADVICE FROM THE POINTS OF CONTACT TO THE NATIONAL EYE INSTITUTE**

Contacts in each of the agencies/organizations were asked what advice they would offer the NEI as they consider new eye health program initiatives for American Indians and Alaska Natives. Suggestions ranged from a reminder that any programs/services developed must be culturally relevant, to soliciting input directly from American Indian and Alaska Native tribes, to providing financial incentives to encourage participation. As shown below, one POC suggested conducting focus groups with tribes located in different geographic areas of the country. Presented below are their verbatim suggestions—

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- [Since many] eye care providers are isolated; produce common materials that let them know what is out there.
- Perhaps some Native-specific information, using Native themes in the pamphlet design.
- [The initiative(s)] need to be culturally related.
- Understand the differences in structure in [the] Indian Nation. The Navajo tribe has a coordinated health system, as opposed to other tribes in California, hundreds of smaller ones that aren't as formalized. Understand the local providers.
- I know your agency is probably aware of the phenomenal rates of diabetes among the American Indian/Alaska Native populations, especially among many Southwestern tribes. Diabetes is an increasing problem in Alaska. A collaborative effort between diabetes organizations and yours [NEI] might result in increased funding for eye care for people with diabetes.
- [Provide] information to the communities and present it at an 8<sup>th</sup> grade level of understanding or less. Video presentations are well received.
- Get to know the people you serve before you attempt to design a program. Treat them as people, not cases. Enlist the help of community members and build trust. Coordinate efforts with Indian Health Service facilities in the area.
- ASK THE PATIENTS!! Conduct focus groups with American Indians and Alaska Natives from different parts of the country, from different tribes, from different age groups.
- Financial help would certainly be an incentive to participation.
- Focus on those problems most prevalent among this population, such as diabetic eye disease and cataracts.
- Get the American Indian/Alaska Native population involved from the very beginning. Ask them what they need.
- Based on data this agency collected (from the tribes they service on reservations, in historical Tribal lands in Oklahoma, and in Alaska Native villages) and personal communications with elders, it is clear that any new program should focus on services, i.e., providing glasses, providing funding for optometrist visits, etc. Education is needed, but actual services are an

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immediate need.

- When you provide initiatives, also provide funding and materials to teach with.
- Telemedicine Diabetic Photography Clinic in family practice or internal medicine clinics, free glasses annually for all diabetic patients, the use of portable laser clinics by contract ophthalmologist retinal specialists, and more IHS and Tribal optometrists and technicians to improve the doctor-to-patient ratio.
- I think teleophthalmology screening is very helpful and also getting providers to explain the critical link between blood sugar control and complications.
- There is a hodgepodge of “free” eye care available through professional associations, but barriers to accessing it are numerous.

Some of the contacts also suggested strategies/approaches that NEI should consider to maximize its ability to communicate eye health information to American Indians and Alaska Natives. The vast majority encouraged NEI to enlist the assistance and support of other agencies, organizations, and associations, including the IHS, CDC, the Association of American Indian Physicians, tribal health directors and diabetes coordinators, and the American Indian/Alaska Native community. Specific suggestions included—

- Working directly with health care providers.
- Contact tribal health boards such as the Alaska Native Tribal Health Board ([www.anhb.org](http://www.anhb.org)) or tribal epidemiology centers to help initiate programs.
- Whatever is developed needs to be done within the cultural context of American Indians and Alaska Natives and specifically for the local tribe/community. [An example was given:] the purpose and outcome of laser treatment is misunderstood by many elders. Asking for input from community members may shed light on appropriate approaches and types of information.
- Direct communication with IHS, the National Indian Health Boards, tribes, and the Association of American Indian Physicians. Further, collaborate with other public health agencies, state health departments, and the CDC.
- I think NEI needs to consider all age groups and develop materials for each. One of the problems I see in our field is the thought that if a subject is written with Native Americans in mind, that just putting a Native American on a

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poster or brochure does not work. Moreover, there are many tribes and they do not always use the same information. I would suggest that materials be developed for each of the DHHS regions in the country or by IHS area.

Points of contact were asked what type(s) of health information would be most useful. Options included printed material, video, poster, training curriculum, or another type of material. POCs could choose one or more of the options. Results revealed POCs equally liked each of the 5 options identified. Other suggestions included funding, one-on-one personal education, health fairs, and one contact noted that the American Indian population communicates orally, so this type of communication needs to be considered. Another contact thought training was okay if the providers receive in-person, state-of-the-art training. This person also suggested providing continuing education credits.

When asked whether their organization would be willing to assist the NEI by reviewing, pretesting, and disseminating new materials as they are developed, the vast majority said they would. Some added the caveat that they would assist the NEI as time and resources permitted, and one contact specifically mentioned that she would review materials as they related to diabetes.

### **H. ASSISTANCE THAT THE NATIONAL EYE INSTITUTE CAN PROVIDE TO ORGANIZATIONS**

The NEI was interested in learning how they could better assist agencies, organizations, and associations that provide eye health services and programs to American Indians and Alaska Natives. Toward this end, a discussion item was included on the protocol to elicit this information. Slightly more than half (n=15, 58%) of the contacts offered a comment. As shown in the box below, the majority of responses were requests for materials and funding. The verbatim comments contacts wrote are listed below.

- Having printed material and getting the information to providers.
- Keep your Web site up and running so that I can place more orders for patient education pamphlets. I like them and they do a good job.
- Often youngsters go without glasses because of lack of funds. If there were some program for meeting this need it would be helpful.
- Recognize that optometrists provide the majority of eye care to American Indians. Include them in your literature and avoid suggesting that ophthalmologists are the primary source of eye care.
- Continue to produce health information in various formats (video, posters, etc.) that can be shared with patients.

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- Providing posters and handouts that can be distributed at clinics would be helpful.
- Offer training programs for primary care providers in screening eye diseases, state-of-the-art care. [There are] no resources to do training.
- Become a friend of the agency [IHS] and lobby Congress for more funding for both research and treatment initiatives that are specific to American Indians and Alaska Natives in order to reduce racial disparities that continue despite the best efforts of dedicated IHS health care professionals.
- Economic help would go a long way in our Area [Nashville].
- Continue to provide materials to help educate those we serve.
- Certainly funding to disseminate the materials would be great.
- More funding for people in the trenches, front-line community workers.
- Work together to send similar messages, reinforce each other, pool resources [NIDDK].
- Include the health programs of the specific tribes on your mailing list. Each of the programs has a branch chief in the Area Office. There is also one at the National level. This way, we could all receive the information you are distributing. I have not received any type of mailing from your organization yet. I do have information that I pick up at health fairs.
- Provide culturally appropriate educational materials and money for eye care.

### I. INFORMATION SHARING

So that the NEI can learn from other agencies and organizations, contacts were asked whether they had health education materials targeted for American Indians and Alaska Natives that they would be willing to share. The IHS Navajo Area Office reported they primarily use NEI's materials as part of their awareness programs. While the Aberdeen Area has some posters, the contact wrote, "I'm not sure where they came from and where they are at the moment." The diabetes consultant in the Bemidji area referred us to IHS materials on diabetes and diabetic retinopathy. The California Area POC suggested contacting the California telemedicine/

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telehealth center. The Area Officer is interested in extending this program to other eye diseases. He suggested that we ask about additional services they may be able to provide.<sup>6</sup>

The NIDDK contact referred NEI to their Web site: <http://ndep.nih.gov>. The Alaska Native Tribal Health Consortium forwarded a copy of *The Pap Test: A Healthy Habit For Life* and *Breast Cancer Screening: A Healthy Habit for Life*. Both pamphlets are distributed by the Alaska Native Women's Wellness Project. They were particularly proud of the artwork in the pamphlet that was done by an Alaskan artist.

One of the POCs from the Office of Minority Health Resource Center (OMHRC) sent two documents they distribute:

- *American Indian/Alaska Native Sources of Health Materials*. The list includes culturally sensitive health materials for American Indians and Alaska Natives, including resources on nutrition, exercise, and AIDS educational materials.
- *Pocket Guide: Minority Health Resources*. This guide contains information about OMH, a list of Public Health Service (PHS) minority health liaisons and state minority health liaisons, federal health information centers and clearinghouse, national minority organizations, sources of health materials, and colleges and universities.

Additionally, one of the OMH contacts provided three additional references “that may be useful for developing outreach programs to American Indians and Alaska Natives.” This includes the following documents—

- *Assessing and Treating Culturally Diverse Clients: A Practical Guide*. Available from Sage Publications, 2455 Teller Road, Thousand Oaks, CA 91320. Telephone: 805.499.0721. Cost \$16.95 per copy.

This publication offers effective, practical guidelines in dealing with cultural and other issues. The Guide contains suggestions for working with African Americans, Hispanics, American Indian, and Asian clients. Some of the topics covered include—

- A description of cultural variables that may affect assessment and treatment across groups
  - Explanations of epidemiological mental health data across groups
  - A discussion on how to apply data from culturally specific biased measures
  - A description of many of the important factors to consider during treatment delivery.
- *Health Promotion in Diverse Cultural Communities*. (1991). Copies of this publication can be obtained from the Distribution Center, Health Promotion Research

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<sup>6</sup> It should be noted that we contacted the California Telehealth/Telemedicine Program, but did not receive a response to our e-mail inquires.

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Center, Stanford Center for Research in Disease Prevention, 730 Welch Road, Suite B, Palo Alto, CA 94303. Telephone: 650.723.0003. Cost \$14.00 plus \$4.95 shipping/handling.

This manual gives practical guidance to those seeking to develop culturally sensitive and appropriate programs in diverse communities. There are three sections:

- Gathering background information
- Establishing contacts and developing relationships
- Program planning and implementation.

A list of organizations serving diverse cultural communities is included in Appendix I. Appendix II contains suggested activities and references for training in cultural sensitivity and awareness and Appendix III contains types of community contacts.

- *Reaching Out: Expanding Outreach to Culturally Diverse Populations.* Copies of this publication are available from the Office of Minority Affairs, AARP, 601 E Street, NW, Washington, DC 20049. Telephone: 202.434.2460. Stock number: D16501.

This Guide was developed in response to requests from AARP staff and volunteers and other service providers for assistance in their outreach activities. It aims to—

- Provide information on diversity including definitions, concepts, and benefits
- Enhance service providers' knowledge and sensitivity to other people's values and practices
- Provide practical tips on how to conduct outreach activities to culturally diverse groups
- Provide information on recruitment and interviewing techniques.

The four documents that were mailed to ORC Macro are shown in Appendix C.

Other contacts including the Sisseton Diabetes Program, Seattle Indian Health Board, and IHS Area offices in Alaska and Billings said they did not have any materials. The Maniilaq Health Center is in the process of developing patient information brochures.

Contacts were asked whether there were any other organizations or people that project staff should contact. Several IHS contacts suggested that we contact others in the IHS. Three names were provided. As it turned out, these individuals were on our list of POCs to contact and we received responses from two of these people. The Alaska Native Tribal Health Consortium suggested contacting the national IHS Epidemiology Office and the Office of Minority Health (OMH). We identified 6 POCs from OMH and 3 of these people responded. We did not contact the IHS Epidemiology Office.



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### **J. OTHER INFORMATION**

The contact for the Administration on Aging (AoA) provided useful information outside of what was requested in the protocol. As previously mentioned in the report, AoA has programs for American Indian, Alaska Native, and Native Hawaiian elders. A requirement of their program is that each grantee tribe must conduct a needs assessment of the elders in their community. According to the contact, AoA currently has information from 2,450 respondents from 23 different tribes throughout the country. The contact provided data on some of the items included in their needs assessment survey and compared their findings to those from the National Health and Nutrition Examination Survey III (NHANES III) for age 55 and older.

- 13.8 percent responded “yes” to the question, “Do you have total blindness in one or both eyes?” compared to 3 percent who responded “yes” on the NHANES III, age 55 and older population survey.
- 86.2 percent responded “yes” when asked whether they use eyeglasses or contact lenses compared to 89 percent who said they use eyeglasses or contact lenses on the NHANES III, age 55 and older population survey.
- 34.1 percent responded “yes” to the question, “Do you have trouble seeing with one or both eyes, even when wearing glasses or contact lenses?” compared to 19 percent who responded “yes” to the same question on the NHANES III, age 55 and older population survey.
- 2.7 percent of the respondents said they had **never** visited an optometrist and 40.2 percent said they **had not** visited an optometrist within the past year. [Note: comparable data was not provided.]

### **V. SUMMARY AND RECOMMENDATIONS**

#### **A. SUMMARY**

Three goals were identified for this project—

1. To gather information about the vision-related programs and services that agencies, associations, and organizations provide to American Indians and Alaska Natives.
2. To conduct a literature search.
3. To identify gaps in eye health information, services, programs, and materials targeted to American Indians and Alaska Natives.

In June 2001, 23 agencies, associations, and organizations were identified as providing eye related programs and services to American Indians and Alaska Natives. Fifty-nine points of contact were identified. In July and August 2001, discussion items were sent to these points of

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contact. By mid-August we received responses from 30 contacts. Four of these contacts indicated that their organization did not provide services directly targeted to American Indians and Alaska Natives. The resulting 26 contacts, representing 10 different agencies, associations, and organizations responded to the protocol.

The majority of contacts that responded to the discussion items represented Federal agencies. Most of these contacts were from the IHS. The IHS is divided into 12 regional areas that serve the 48 contiguous states and Alaska. In each area, there are a variety of services offered, including optometry and diabetes programs. However, each area has varying levels of service, for example, the Nashville area does not have in-house optometrists, while most others have full or part-time optometrists and some areas have ophthalmologists on staff.

Some IHS Area Offices, such as California, Nashville, and Oklahoma have begun to use telemedicine/ophthalmology programs. This service allows retinal photographs to be taken onsite and transmitted electronically to expert technicians to read the pictures. California has 10 programs funded using this technology, and expects to fund an additional 8 sites.

Some IHS service units work in concert with private organizations, such as the Lion's Club and the Shriners to provide eye programs and services to American Indians and Alaska Natives. Other Federal agencies that provide outreach to American Indians and Alaska Natives are the Administration on Aging, the Office of Minority Health, and the National Institute of Diabetes and Digestive and Kidney Diseases. These agencies have specific programs targeted to American Indians and Alaska Natives. NIDDK's National Diabetes Education Program is particularly concerned with the increasing burden of diabetes in Indian populations. This has resulted in the need for educational materials, and more outreach to children, families, and communities.

Some other organizations/associations that provide eye health education and services to American Indians/Alaska Natives are the California Rural Indian Health Board, the Seattle Indian Health Board, the Sisseton Diabetes Prevention Program, the Maniilaq Association, and the Alaska Native Tribal Health Consortium. The California Rural Indian Health Board holds a monthly eye clinic at their main facilities and the Seattle Indian Health Board until recently referred out all eye care. The Sisseton program provides dilated eye exams for as many people with diabetes per year and their funding can handle and the Maniilaq operates a state-of-the-art clinic in Kotzebue, AK.

A review of the literature revealed that American Indian and Alaska Natives hold to a different culture and mindset than mainstream Americans do. Some tribal peoples will refrain from discussing adverse diagnoses in the belief that talking about them will bring those circumstances about. Due to past discrimination, many native peoples are wary of "outsiders" seeking to provide assistance. The use of traditional healers is also widespread, which may or may not interfere with biomedical treatment interventions. The concept of family is very important, and family members' advice is sought in most situations.

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### B. RECOMMENDATIONS

ORC Macro has gathered information about vision-related programs and services that organizations currently provide American Indians and Alaska Natives and have attempted to identify gaps in eye health information. In seeking to provide eye care services and eye health information to these populations, ORC Macro recommends that the NEI consider the following when developing new program initiatives for American Indians and Alaska Natives:

- Develop culturally appropriate educational materials in language that is understandable at an 6<sup>th</sup> grade level. Include appropriate visual content.
- Involve Indian leadership at every level in program development.
- Establish a working relationship with Indian organizations, agencies, and providers.
- Observe tribal protocols.
- Work with community health representatives (CHRs).
- Employ a multifaceted approach, including use of one-on-one patient education, print materials, videos, and translation services.
- Consider collaborating with the IHS and NIDDK as new initiatives are developed.
- Pretest all materials before they are disseminated.

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