

**NATIVE AMERICAN HEALTH CARE DISPARITIES
BRIEFING**

EXECUTIVE SUMMARY

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Native American Health Care Disparities Briefing

Executive Summary

Four years ago, the U.S. Commission on Civil Rights examined the efforts of the Department of Health and Human Services and concluded that, even after 35 years of periodic monitoring and reporting by the Commission, equal access to health care was not accorded the same federal protection as equal opportunity in housing, education, and employment.¹ The Commission reported that discrimination against minority populations manifests itself in a variety of ways, including:

- Differential delivery of health services.
- Inability to access health services because of lack of financial resources, culturally incompetent providers, language barriers, and the unavailability of services.
- Exclusion from health-related research.²

Revisiting the specific issue of disparities in Native American health care, the Commission held a briefing on October 17, 2003, in Albuquerque, New Mexico.³

In preparation for the briefing, the Commission examined compelling evidence that disparities in the health status of Native Americans persist. While some disparities result from intentional discrimination based on race or ethnicity, more frequently discrimination must be inferred from the continued existence of a chronically underfunded, understaffed, and inadequate health care delivery system. For Native Americans, the existence of glaring disparities across a wide range of health status, outcome, and service indicators, combined with the manner in which the disparities mirror patterns of historical discrimination, makes a convincing argument that the current situation is in fact discriminatory.

The purpose of the briefing was to examine the role of discrimination and bias in the existence of ongoing health disparities for Native Americans by consulting with tribal leaders, key government officials, leading experts, health care advocates, and concerned citizens. By necessity, the disparities were explored and the causes documented. In evaluating the various

¹ U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality* September 1999, p. vii (hereafter cited as USCCR, *The Health Care Challenge*).

² *Ibid.*, p. iii.

³ Throughout this report, the term “Native American” is used in lieu of “American Indian” or other terminology when not specifically citing or paraphrasing other work. It should be understood to include Alaska Natives unless otherwise noted. Native Hawaiians are not included in the Native American category because they are not recognized as having the same government-to-government relationship, and are thus not eligible for the federal programs available to other Native groups. The term “Indian Country” refers to geographic regions encompassing reservations and trust lands within which Indian laws and customs and federal laws relating to Indians govern. See Theodore H. Haas, chief counsel, United States Indian Service, *The Indian and the Law* (Lawrence, KS: Haskell Institute, June 1949), p. 15 <<http://thorpe.ou.edu/cohen/tribalgovtpam2ptl&2.htm>> (last accessed Nov. 21, 2003). It is also important to recognize that Native Americans are not simply another minority or ethnic group. They enjoy a unique political status that carries unique privileges discussed in more detail in this executive summary.

causes, the Commission focused its attention on the structure and operation of the Native American health care delivery programs, the availability and adequacy of funding, as well as legislative, structural, and managerial changes that affect the delivery of health services to Native Americans.

This executive summary presents the issues and concerns raised during the October briefing by panelists and the public. The first section will briefly review the basis for the federal government's obligation to provide health care to Native Americans, an obligation both substantive and indisputable. Next follows a depiction of the current health status and then an accounting of the government's efforts to meet its obligation to Native Americans. Despite encouraging efforts by the Indian Health Service and recent reductions in the prevalence and incidence of some illnesses and deaths, health status disparities remain troubling. In fact, the health status of Native Americans remains unquestionably far below that of the general population.

The largest portion of the executive summary will focus on the various causes for the existing disparities in the health status of Native Americans, including the many barriers that inhibit access and perhaps the most critical underlying fact, that promised health care services for Native Americans have never been fully funded.

Finally, this summary will explain current legislative efforts to address present disparities. In the end, this discussion will begin to address the critical question of whether the current framework for providing health care to Native Americans perpetuates an indirect, yet insidious, discriminatory effect on the Native Americans it is committed to serve.

Information acquired during the briefing will be supplemented with additional research in preparation of a full report on health care disparities, expected to be submitted to the Commissioners for approval later in 2004. The report will include findings and recommendations.

THE TRIBAL-FEDERAL GOVERNMENT RELATIONSHIP

Native Americans are dying of diabetes, alcoholism, tuberculosis, suicide, unintentional injuries, and other health conditions at shocking rates. Beyond the mortality rates, Native Americans also suffer significantly lower health status and disproportionate rates of diseases compared with all other Americans. During the briefing, Michael Bird, executive director of the National Native American AIDS Prevention Center, made evident how long these devastating realities have afflicted the Native American peoples as he quoted from an address to Congress by President Nixon in 1970:

The First Americans—the Indians—are the most deprived and most isolated minority group in our nation. On virtually every scale of measurement: employment, income, education, and health, the condition of the Indian people ranks at the bottom. This condition is the heritage of centuries of injustice. From the time of their first contact with European settlers, the American Indians have

been oppressed and brutalized, deprived of their ancestral lands, and denied the opportunity to control their own destiny.⁴

The conditions described by President Nixon, which still exist today, are the result of the federal government's failure to respect promises made to Native Americans over the past 300 years in exchange for 400 million acres of tribal land and the unfulfilled "trust" relationship that requires the government to protect tribal lands, assets, resources, treaty rights, and health care, among other obligations. The legal source of this trust obligation, however, is imprecise as the boundaries and duties of the trust relationship have evolved over the past two centuries. Pursuant to the power "[t]o regulate Commerce . . . with the Indian tribes"⁵ a series of treaties, judicial decisions, and statutes has shaped federal trust responsibility. Accordingly, the federal government has accepted many obligations, including education, construction, law enforcement, and medical services. This health care obligation requires the government to provide medical treatment to all Native Americans living in the United States.

Federal Government Oversight and Responsibility

Very early in the life of this country, the federal government promised health care services to Native Americans in exchange for land.⁶ The motive for providing health care was not solely altruistic. The government was also attempting to gather information on the numbers of Native Americans, to control the Native American population, and to protect white citizens from the spread of infectious diseases.⁷ The federal government initially assigned the responsibility for Native American health care to the Office of Indian Affairs in the War Department. Health care duties were subsequently transferred to the newly formed Department of the Interior, where the responsible office was eventually renamed the Bureau of Indian Affairs (BIA).⁸ Starting in the 1920s, concerns developed regarding the administration of government programs by BIA. Specifically, there were complaints that BIA was poorly equipped to combat

⁴ Michael Bird, statement before the U.S. Commission on Civil Rights, briefing, Albuquerque, NM, Oct. 17, 2003, transcript, pp. 82–83 (hereafter cited as Briefing Transcript).

⁵ U.S. CONST. art. I, § 8, cl. 3.

⁶ Over the past 300 years, Native American nations have traded hundreds of millions of acres to the federal government in exchange for benefits to guarantee the survival and integrity of their tribes, including health care. *See* Indian Health Care Improvement Act Reauthorization of 2003, S. 556, 108th Cong. § 2 (2003). *See also* Holly T. Kuschell-Haworth, *Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act*, 2 DEPAUL J. HEALTH CARE L. 843, 844 (1999) (hereafter cited as Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*), citing American Indian Policy Review Commission, *Report on Indian Health: Task Force Six*, 1976, p. 33.

⁷ National Library of Medicine, "Early United States Government Interest in Native American Health," <www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_03.html> (last accessed July 15, 2003).

Although U.S. Army surgeons treated Native American victims of smallpox near the opening of the 19th-century, government concern for Native American health at this time was manifest more in counting the numbers of people who died from this and other diseases, and estimating how many were left, than in providing institutional remedies.

Ibid.

⁸ Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*, citing American Indian Policy Review Commission, *Report on Indian Health: Task Force Six*, 1976, p. 29.

public health emergencies.⁹ Because of these concerns, a commission was formed to inspect reservations, schools, and hospital settings. This commission issued the Meriam Report, documenting substandard health conditions resulting from government inefficiency and inadequate funding.¹⁰ To develop an effective system of preventive medicine and public health, the commission recommended adequately funding Native American health care,¹¹ spurring a short-lived movement to improve health conditions for Native Americans.¹² In 1955, the division responsible for Native American health care was transferred to the Department of Health and Human Services (HHS). Today, the Indian Health Service (IHS), an agency within HHS, is the principal federal health care provider.

Legislation

Perhaps the most significant achievement for Native American health care has been the codification of the federal responsibility in the Snyder Act of 1921.¹³ Together, the Snyder Act and the Indian Health Care Improvement Act of 1976¹⁴ form the basic legislative authority for today's Indian Health Service. The Snyder Act charged BIA to "direct, supervise, and expend such moneys as Congress may from time to time appropriate, for the benefit, care, and assistance of the Indians . . . for relief of distress and conservation of health."¹⁵ Congress subsequently enacted the Indian Health Care Improvement Act (IHCIA), establishing the basic programmatic structure for delivery of health services to Native Americans and authorizing the construction and maintenance of health care and sanitation facilities on reservations. The wording and effect of IHCIA clearly acknowledge the legal and moral responsibility for "providing the highest possible health status to Indians . . . with all the resources necessary to effect that policy."¹⁶

Like the Snyder Act, the IHCIA provides appropriations authority for the delivery of health services to Native American people. In fact, the IHCIA provides comprehensive directives to the federal government for the delivery of health care services. Although the most recent

⁹ National Library of Medicine, "Reservation and Hospital Health Care Under the Office of Indian Affairs (c.1890–1925)," <www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_06.html> (last accessed July 15, 2003).

¹⁰ National Library of Medicine, "The Meriam Commission and Health Care Reform (1926–1945)," <www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_07.html> (last accessed July 15, 2003).

¹¹ Lewis Meriam et al., *The Problem of Indian Administration*, Chapter 1: General Summary of Findings and Recommendations, Report of a Survey made at the request of Honorable Hubert Work, Secretary of the Interior, Feb. 21, 1928, <www.alaskool.org/native_ed/research_reports/IndianAdmin/Chapter1.html#chap1> (last accessed July 15, 2003).

¹² National Library of Medicine, "Transfer to Department of Health, Education, and Welfare (1946–1969)," <www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_08.html> (last accessed July 15, 2003).

¹³ Ch. 115, 42 Stat. 208 (1921) (codified as amended at 25 U.S.C. § 13 (1994)).

¹⁴ Pub. L. No. 94-437, 90 Stat. 1400 (codified as amended in scattered sections of 25 U.S.C.).

¹⁵ The Snyder Act, 25 U.S.C. § 13 (1994).

¹⁶ The Indian Health Care Amendments of 1980, Pub. L. No. 96-537, 94 Stat. 3193 (codified as amended in scattered sections of 25 U.S.C. (1994)). In reauthorizing the IHCIA in 1990, Congress passed three major health bills amending the IHCIA and providing statutory authorization for a comprehensive and community-based mental health program, the authorization for self-governance demonstration projects, and the expansion of the urban Indian health programs.

IHCIA has expired and not been reauthorized, Congress has nevertheless continued to appropriate funds for IHCIA programs under the authority of the Snyder Act.¹⁷

CURRENT NATIVE AMERICAN HEALTH DISPARITIES

Despite the funds appropriated by Congress to deliver health care services for Native Americans, a wide range of public health status indicators demonstrate that Native Americans continue to suffer disproportionately from a variety of illnesses and diseases.¹⁸ Dr. Jon Perez, director of behavioral health for IHS, described these health disparities as “real and highly visible” to Native Americans.¹⁹ He explained that while the incidence and prevalence of many infectious diseases have been dramatically reduced through increased clinical care and public health efforts such as vaccination for infectious diseases and the construction of sanitation facilities, Native Americans continue to experience health disparities and higher death rates than the rest of the U.S. population.²⁰ IHS has been given primary responsibility for eliminating this disproportionate health status and has been largely successful in reducing mortality rates, while making significant improvements in other areas.²¹

Today, Native Americans continue to experience significant rates of diabetes, mental health disorders, cardiovascular disease, pneumonia, influenza, and injuries. Native Americans are 770 percent more likely to die from alcoholism, 650 percent more likely to die from tuberculosis, 420 percent more likely to die from diabetes, 280 percent more likely to die from accidents, and 52 percent more likely to die from pneumonia or influenza than other Americans, including white and minority populations.²² As a result of these increased mortality rates, the life expectancy for Native Americans is 71 years of age, nearly five years less than the rest of the U.S. population.²³ Dr. Perez pointed out some of these health disparities as well as some of the

¹⁷ The IHCIA has been introduced in the last three sessions of Congress, however, it has not reached the floor of Congress. At the time of this writing, two separate versions awaited action in House and Senate committees. The chances of reauthorization and the subsequent impact will be discussed in greater detail in a later section. *See* Myra Munson, Esq., partner, Sonosky, Chambers, Sachse, Miller & Munson, interview, Aug. 11, 2003.

¹⁸ *See generally* Office of Management and Budget, Statistical Policy Directive No. 15, “Race and Ethnic Standards for Federal Statistics and Administrative Reporting,” 1977; Office of Management and Budget, “Recommendations from the Interagency Committee for the Review of the Racial and Ethnic Standards to the Office of Management and Budget Concerning Changes to the Standards for the Classification of Federal Data on Race and Ethnicity,” July 9, 1997, <www.whitehouse.gov/omb/fedreg/print/directive_15.html> (last accessed July 15, 2003).

¹⁹ Perez Statement, Briefing Transcript, p. 14.

²⁰ *Ibid.*, p. 15.

²¹ Since 1973 mortality rates have been reduced for the following: tuberculosis (82 percent); maternal deaths (78 percent); infant deaths (66 percent); accidents (57 percent); injury and poisoning (53 percent); and pneumonia and influenza (50 percent). Indian Health Service, *Trends in Indian Health 1998–99*, <www.ihs.gov/publicinfo/publications/trends98/part2.pdf> (last accessed Aug. 21, 2003) (hereafter cited as IHS, *Trends in Indian Health 1998–99*). *See also* Perez Statement, Briefing Transcript, pp. 14, 15.

²² *A Bill to Reauthorize the Indian Health Care Improvement Act and H.R. 2440, Indian Health Care Improvement Act Amendments of 2003: Joint Hearing Before the Senate Committee on Indian Affairs and the House Resources Committee, Office of Native American and Insular Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service). *See also* H.R. 2440, Indian Health Care Improvement Act Amendments of 2003.

²³ U.S. Department of Health and Human Services, Assistant Secretary for Legislation, “Testimony of David Satcher, Assistant Secretary for Health and Surgeon General of the U.S. Public Health Service, U.S. Department of

mortality rates during the briefing. Additionally, he explained that fully seven of the top 10 causes of the high morbidity and mortality rates are “directly related to, or significantly affected by individual behavior and lifestyle choices.”²⁴

The following is a discussion of the specific health disparities suffered by Native Americans in contrast to whites and minority populations.²⁵ Information on the health status and outcomes of individual tribes is presented when it is illustrative of the existence of similar disparities throughout the Native American community. Incidence, prevalence, morbidity, or mortality rates of diseases and health conditions are used to examine and measure those public health issues disproportionately affecting Native Americans.²⁶

Diabetes

Diabetes is one of the most serious health challenges facing Native Americans, resulting in significant morbidity and mortality rates.²⁷ In fact, Native Americans have the highest

Health and Social [sic] Services, Before the House Commerce Committee, Subcommittee on Health and Environment,” May 11, 2000, <www.hhs.gov/asl/testify/t000511a.html> (last accessed July 15, 2003) (hereafter cited as HHS, “Satcher Testimony”).

²⁴ Perez Statement, Briefing Transcript, p. 19.

²⁵ The Department of Health and Human Services defines a health disparity as “a population-specific difference in the presence of disease, health outcomes, or access to care.” U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care, “Current Needs and Current Issues in Minority Health Research,” *UNC 7th Annual Summer Public Health Research Institute on Minority Health*, June 18, 2001, <www.cmh.pitt.edu/PPT/H20010614.ppt> (last accessed July 15, 2003) (hereafter cited as HHS, “Current Needs”). Federal, state, and local health agencies measure existing health disparities for specific populations by a variety of “health status indicators.” Indicators include incidence, prevalence, morbidity, and mortality rates for a number of illnesses that relate to a particular segment of the population, as well as maternal and infant mortality rates. Centers for Disease Control and Prevention, National Center for Health Statistics, *Healthy People 2000—Statistical Notes: Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990–98*, no. 23, January 2002, p. 1 (hereafter cited as CDC, *Trends in Racial and Ethnic-Specific Rates*).

²⁶ “Incidence is the number of cases of disease having their onset during a prescribed period of time. It is often expressed as a rate (for example, the incidence of measles per 1,000 children 5–15 years of age during a specified year). Incidence is a measure of morbidity or other events that occur within a specified period of time.” Centers for Disease Control and Prevention, National Center for Health Statistics, “Incidence,” *NCHS Definitions*, Aug. 21, 2002, <www.cdc.gov/nchs/dataawh/nchsdefs/incidence.htm> (last accessed Sept. 20, 2003).

“Prevalence is the number of cases of a disease, infected persons, or persons with some other attribute during a particular interval of time. It is often expressed as a rate (for example, the prevalence of diabetes per 1,000 persons during a year).” Centers for Disease Control and Prevention, National Center for Health Statistics, “Prevalence,” *NCHS Definitions*, Aug. 23, 2002, <www.cdc.gov/nchs/dataawh/nchsdefs/prevalence.htm> (last accessed Sept. 20, 2003).

The mortality rate is defined as the total or crude death rate from all causes, usually expressed as deaths per 1,000. A disease-specific mortality rate includes those deaths due to one disease and is usually reported per 100,000 persons. The population can be defined by sex, age, or other factors. University of Kansas Medical Center, “Mortality Rate,” <www.kumc.edu/instruction/medicine/pathology/ed/keywords/kw_mortalit.html> (last accessed Sept. 20, 2003).

The morbidity rate is defined as “[a]n incidence rate used to include all persons in the population under consideration who become clinically ill during the period of time stated. The population may be limited to a specific sex, age group or those with certain other characteristics.” University of Kansas Medical Center, “Morbidity Rate,” <www.kumc.edu/instruction/medicine/pathology/ed/keywords/kw_morbidit.html> (last accessed Sept. 20, 2003).

²⁷ National Institute of Diabetes & Digestive & Kidney Diseases of the National Institutes of Health, “Diabetes in American Indians and Alaskan Natives,” *NIDDK National Diabetes Information Clearinghouse*, <www.niddk.nih>

prevalence of Type 2 diabetes in the world, and rates are increasing at “almost epidemic proportions.”²⁸ The National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK) defines diabetes mellitus as a group of diseases characterized by high blood levels of glucose stemming from defective insulin secretion and/or action.²⁹ Most Native Americans with diabetes have Type 2 diabetes, also known as adult onset diabetes, which is caused by the body’s resistance to the action of insulin and impaired insulin secretion. Type 2 diabetes can be managed with healthy eating, physical activity, oral medication, and/or injected insulin.³⁰ In fact, Dr. Jon Perez stated that one of the most distressing aspects of Type 2 diabetes is that with lifestyle changes it is largely preventable.³¹

Despite the fact that the rates of diabetes in the Indian community are “staggering,” the rates do not paint a true picture of how devastating the disease can really be, according to Dr. Dee Ann DeRoin, board member of the Association of American Indian Affairs.³² This is because the leading cause of mortality in the Indian community is heart disease, and hidden in that statistic is the fact that the largest percentage of deaths from heart disease are caused by diabetes. Thus, diabetes is both devastating the community in terms of quality of life and “maiming and killing” Native Americans.³³

Another startling fact regarding the prevalence of Type 2 diabetes is that it has recently become a significant threat to Native American children.³⁴ Its incidence is rising faster among Native American children and young adults than any other ethnic population.³⁵ IHS has documented a 54 percent increase in the prevalence of diagnosed diabetes among Native American youth 15 to 19 years of age since 1996.³⁶ Historically, Type 2 diabetes has been restricted to adults, at least partially as a result of declining insulin sensitivity with age.³⁷ Its presence among children foreshadows the early arrival of more serious complications.³⁸

Another national health care authority expressed concern about the challenges that diabetes presents for Native Americans of all ages. In 2000, Dr. David Satcher, the Surgeon General of the United States, testified that “the diabetes rate for American Indians and Alaska Natives is more than twice that for whites. The Pima [American Indians] of Arizona have one of

gov/health/diabetes/pubs/amindian/amindian.htm> (last accessed July 15, 2003) (hereafter cited as NIDDK, “Diabetes in American Indians”). *See also* Jack Trope, president, and Dee Ann DeRoin, M.D., board member, Association of American Indian Affairs, telephone interview, July 15, 2003.

²⁸ Perez Statement, Briefing Transcript, p. 18.

²⁹ NIDDK, “Diabetes in American Indians.” *See also* Trope and DeRoin interview.

³⁰ NIDDK, “Diabetes in American Indians.” *See also* Trope and DeRoin interview.

³¹ Perez Statement, Briefing Transcript, p. 18.

³² Trope and DeRoin interview.

³³ *Ibid.*

³⁴ American Academy of Pediatrics, “Significant Health Disparities Threaten American Indian Children and Youth,” press release, Aug. 1, 2002, <www.aap.org/advocacy/washing/american_indian.htm> (last accessed Sept. 24, 2003) (hereafter cited as American Academy of Pediatrics, “Significant Health Disparities”).

³⁵ Perez Statement, Briefing Transcript, p. 18.

³⁶ American Academy of Pediatrics, “Significant Health Disparities.”

³⁷ Mayo Clinic, “Mayo Clinic Study Finds People Over 40 Need Frequent Exercise to Prevent or Treat Type 2 Diabetes,” news release, Aug. 15, 2003, <www.mayoclinic.org/news2003-rst/1911.html> (last accessed Aug. 22, 2003).

³⁸ Perez Statement, Briefing Transcript, p. 18.

the highest rates of diabetes in the world.”³⁹ Furthermore, NIDDK estimates that approximately 15 percent of Native Americans who receive health care from IHS have diabetes.⁴⁰ Native Americans are 2.6 times more likely to be diagnosed with diabetes than non-Hispanic whites of a similar age.⁴¹ As troubling as these numbers are, they may understate the number of Native Americans with diabetes. In a screening study conducted in three geographic areas, NIDDK found that 40 to 70 percent of Native American adults between the ages 45 and 74 have diabetes, many previously undiagnosed. Data from the Navajo Health and Nutrition Survey showed that 22.9 percent of Navajo adults 20 and older had diabetes. At least 14 percent had a history of diabetes, but another 7 percent were found to have undiagnosed diabetes during the survey.⁴²

Although measures can be taken to reduce the likelihood of disability and death from diabetes, the disease is still associated with serious health complications and premature death.⁴³ From 1994 through 1996, the IHS age-adjusted death rates for diabetes mellitus were 350 percent greater than the rates for the rest of the American population.⁴⁴ Dr. Perez emphasized the prevention of diabetes as a way of eliminating costly treatment options, in addition to reducing the disease burden from the suffering population.⁴⁵

Tuberculosis

Although the tuberculosis rate among Native Americans is declining, it continues to disproportionately affect this population in the number of cases and severity of disease.⁴⁶ The American Lung Association reported that in 1998, the incidence rate of tuberculosis among Native Americans was 12.6 cases per 100,000 persons, which is more than five times the rate for non-Hispanic whites (2.3).⁴⁷ Similarly, in 2001, it was reported that the annual incidence of tuberculosis for Native Americans was twice that of the overall U.S. population; mortality rates were six times higher.⁴⁸

Mental Health

Native Americans are at a higher risk for mental health disorders than other racial and ethnic groups in the United States,⁴⁹ and are consistently overrepresented among high-need

³⁹ HHS, “Satcher Testimony.”

⁴⁰ NIDDK, “Diabetes in American Indians.”

⁴¹ Ibid. See also Perez Statement, Briefing Transcript, p. 18.

⁴² Ibid.

⁴³ American Academy of Pediatrics, “Significant Health Disparities.”

⁴⁴ IHS, *Trends in Indian Health 1998–99*.

⁴⁵ Perez Statement, Briefing Transcript, p. 19.

⁴⁶ Jay C. Butler et al., “Emerging Infectious Diseases Among Indigenous Peoples,” *Emerging Infectious Diseases*, vol. 7, no. 3 supplement, June 2001, p. 554 (hereafter cited as Butler et al., “Emerging Infectious Diseases”).

⁴⁷ American Lung Association, “American Indians/Alaskan Natives and Lung Disease,” fact sheet, September 2000, <www.lungusa.org/diseases/nativelung_factsheet.html> (last accessed Sept. 20, 2003).

⁴⁸ Butler et al., “Emerging Infectious Diseases,” p. 554.

⁴⁹ See S. Nelson, G. McCoy, M. Stetter, and W.C. Vanderwagen, “An Overview of Mental Health Services for American Indians and Alaska Natives in the 1990s,” *Hospital and Community Psychiatry*, vol. 43, 1992, pp. 257–61. See also USCCR, *The Health Care Challenge*, p. 46.

populations for mental health services.⁵⁰ The Surgeon General reported that this overrepresentation might be attributed to the high rates of homelessness, incarceration, alcohol and drug abuse, and stress and trauma in Native American populations.⁵¹ The Surgeon General's report further indicated that the U.S. mental health system is not well equipped to meet these needs; specifically that IHS, due to both budget constraints and personnel problems, is mostly limited to basic psychiatric emergency care.⁵² According to Dr. Perez, IHS does not provide quality, ongoing psychiatric care.⁵³ Instead, IHS' approach is one of responding to immediate mental health crises and stabilizing patients until their next episodes.⁵⁴

The most significant mental health concerns today are substance abuse, depression, anxiety, violence, and suicide.⁵⁵ Of these, substance abuse, notably alcoholism, has been the most visible health disorder crisis,⁵⁶ while depression is emerging as a dominant concern.⁵⁷ These two illnesses are often a consequence of isolation on distant reservations, pervasive poverty, hopelessness, and intergenerational trauma, including the historic attempts by the federal government to forcibly assimilate tribes.⁵⁸

Alcohol abuse is widespread in Native American communities. Native Americans use and abuse alcohol and other drugs at younger ages, and at higher rates, than all other ethnic groups.⁵⁹ Consequently, their age-adjusted alcohol-related mortality rate is 5.3 times greater than that of the general population.⁶⁰ The Department of Health and Human Services, Substance Abuse and Mental Health Services Administration's *National Household Survey on Drug Abuse* reported the following for 1997: (1) 19.8 percent of Native Americans ages 12 and older reported using illegal drugs that year, compared with 11.9 percent for the total U.S. population; and (2)

⁵⁰ High-need populations include the following: people who are homeless, people who are incarcerated, people exposed to trauma, and people with drug and alcohol problems. See U.S. Department of Health and Human Services, Office of the Surgeon General, "Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General," fact sheet, <<http://www.surgeongeneral.gov/library/mentalhealth/cre/fact4.asp>> (last accessed Dec. 19, 2003).

⁵¹ Ibid.

⁵² Judy Nichols, "Special Report—Part 2, Indian Health Care: Critical Condition," *Arizona Republic*, July 21, 2002 <www.azcentral.com/news/specials/indianhealth/0721hospital21.html> (last accessed Sept. 24, 2003).

⁵³ Jon Perez, director of behavioral health, Indian Health Service, interview in Rockville, MD, July 21, 2003.

⁵⁴ Ibid.

⁵⁵ See U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, "Cultural Competence Standards in Managed Care Mental Health Services: Four Underserved/Underrepresented Racial/Ethnic Groups," Introduction, <www.mentalhealth.org/publications/allpubs/SMA00-3457/intro.asp> (last accessed Sept. 15, 2003).

⁵⁶ See, e.g., Kay Culbertson, executive director, Denver Indian Health and Family Services, telephone interview, Sept. 3, 2003; Emery Johnson, interview in Silver Spring, MD, Aug. 18, 2003; Ralph Forquera, executive director, Seattle Health Board, telephone interview, Aug. 27, 2003; Perez interview.

⁵⁷ Perez interview.

⁵⁸ Ibid.

⁵⁹ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment, "Cultural Issues in Substance Abuse Treatment," 1999.

⁶⁰ Ibid.

Native Americans had the highest prevalence rates of marijuana and cocaine use, in addition to the need for drug abuse treatment.⁶¹

One of the more troubling indicators of the toll depression takes on Native Americans is reflected in the suicide rates. The suicide rate for Native Americans continues to escalate and is 190 percent of the rate of the general population. In fact, suicide is the second leading cause of death for Native Americans 15 to 24 years old and the third leading cause of death for Native American children 5 to 14 years old.⁶² Recent data from the American Academy of Pediatrics indicate that in 2002 the youth suicide rate for Native Americans was twice as great among 14- to 24-year-olds, and three times as great among 5- to 10-year-olds, as it was in the general population.⁶³

Despite a significant demand for mental health services, there are approximately 101 mental health professionals available per 100,000 Native Americans, compared with 173 mental health personnel per 100,000 whites.⁶⁴ With a greater need for mental health specialists, but fewer available for treatment, Native Americans frequently do not receive the necessary care for substance abuse, depression, anxiety, suicide ideations, and other mental health conditions.

Unintentional Injuries

Public health authorities consider death and disabilities from unintentional injuries as a safety issue affecting the health of entire populations.⁶⁵ During the October briefing, Dr. Jon Perez identified unintentional injuries as an issue of particular concern for Native Americans.⁶⁶ In fact, unintentional injuries are the leading cause of death for Native Americans under the age of 44 and the third leading cause of death overall.⁶⁷ The age-adjusted injury death rate for Native Americans is approximately 250 percent higher than that for the total U.S. population.⁶⁸ Moreover, Native Americans suffer injuries at rates 1.5 to five times the rate for other

⁶¹ U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, National Clearinghouse for Alcohol & Drug Information, "Drug Use Among Native Americans Is Higher than Other Racial/Ethnic Groups," *The NCADI Reporter*, Oct. 29, 1998, <www.health.org/newsroom/rep/95.aspx> (last accessed July 15, 2003). See also Centers for Disease Control and Prevention, *Trends in Racial and Ethnic-Specific Rates*, p. 11 (between 1990 and 1998, the lung cancer death rate for American Indians or Alaska Natives increased by 28 percent).

⁶² IHS, *Trends in Indian Health 1998–99*, p. 66.

⁶³ American Academy of Pediatrics, "Significant Health Disparities."

⁶⁴ U.S. Department of Health and Human Services, Office of the Surgeon General, Substance Abuse and Mental Health Services Administration, "Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General," fact sheet, <www.surgeongeneral.gov/library/mentalhealth/cre/fact4.asp> (last accessed Dec. 19, 2003).

⁶⁵ Association of Schools of Public Health, "The Population Approach to Public Health," Apr. 7, 2003, <www.asph.org/print.cfm?page=724> (last accessed Sept. 20, 2003).

⁶⁶ Perez Statement, Briefing Transcript, p. 17.

⁶⁷ Indian Health Service, "Injuries," *IHS Health and Heritage Brochure—Health Disparities*, <www.info.ihs.gov> (last accessed Sept. 26, 2003) (hereafter cited as IHS, "Injuries"). The causes of death include unintentional motor vehicle crashes, unintentional pedestrian events, firearm use, unintentional drowning, and unintentional fire. See Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report*, vol. 52, no. 30, Aug. 1, 2003, p. 698.

⁶⁸ U.S. Department of Health and Human Services, *Healthy People 2010: Understanding and Improving Health*, 2d ed., ch. 15, November 2000 (hereafter cited as HHS, *Healthy People 2010*).

Americans.⁶⁹ In real terms this translates to more than 1,300 deaths and more than 10,000 hospitalizations each year for more than 50,000 days of medical care.⁷⁰ Outpatient clinics treat an additional 330,000 for injuries.⁷¹ The financial cost of treating these injuries is correspondingly high. Each year IHS spends more than \$150 million to treat those suffering from unintentional injuries.⁷² Injuries result in 46 percent of all Years of Potential Life Lost (YPLL) for Native Americans.⁷³ This is five times greater than the YPLL due to the next highest cause, heart disease (8 percent).⁷⁴

Major Cardiovascular Diseases

In the past, heart disease and strokes were rare among Native Americans, but recently heart disease has become the number one cause of death; stroke is now the fifth leading cause of death.⁷⁵ This dramatic increase appears as the general population has experienced a 50 percent decrease in heart disease; thus, Native Americans now have cardiovascular disease rates twice that of the general population.⁷⁶ These soaring rates can be traced to the high rates of diabetes, high blood pressure, and the presence of other risk factors, including poor eating habits and sedentary lifestyles.⁷⁷

The Centers for Disease Control and Prevention conducted a national telephone survey to determine the extent that risk factors for heart disease and stroke (i.e., high blood pressure, current cigarette smoking, high cholesterol, obesity, and diabetes) were present in this population. According to the survey, 63.7 percent of Native American men and 61.4 percent of Native American women reported having one or more of these risk factors. The following specific risk factors were reported in significantly high percentages:

- 21 percent of men and 23 percent of women said they had been told by a health professional that they had high blood pressure.

⁶⁹ IHS, “Injuries.”

⁷⁰ HHS, *Healthy People 2010*.

⁷¹ Ibid.

⁷² IHS, “Injuries.”

⁷³ HHS, *Healthy People 2010*, ch. 15. Years of Potential Life Lost is a measure of premature mortality. It is calculated using the numbers of deaths in each age group and the difference between the midpoint of the age group and the average life expectancy. See Centers for Disease Control and Prevention, National Center for Health Statistics, *NCHS Definitions*, <<http://www.cdc.gov/nchs/datawh/nchsdefs/yearsopotentiallifelost.htm>> (last accessed Dec. 19, 2003).

⁷⁴ HHS, *Healthy People 2010*, ch. 15.

⁷⁵ Indian Health Service, “Heart Disease & Strokes,” *IHS Health and Heritage Brochure—Health Disparities*, <www.info.ihs.gov> (last accessed Sept. 26, 2003). This jump in heart disease and stroke is attributed to the gradual improvement of health care for Native Americans. In the past, Native Americans were dying of other diseases before they reached the age where heart disease becomes more prominent. See Dr. Charles W. Grim, “Eliminating Disparities Is More Than an Access Issue,” Remarks before the Association of American Indian Physicians, Aug. 4, 2003, <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Dec. 19, 2003) “The health of Indian Country has changed from one of disease and illness to one of primarily chronic conditions influenced strongly by behavioral and lifestyle issues.”

⁷⁶ Ibid.

⁷⁷ Trope and DeRoin interview.

- 32.8 percent of men and 28.8 percent of women reported that they were current smokers.
- Almost 16 percent of respondents had been told by a health care professional that they had high cholesterol and more than 7 percent were told that they had diabetes.
- Almost a fourth of the male respondents (23.6 percent) and nearly one-fifth of the females (19.1 percent) were obese (21.5 percent of all Native Americans).⁷⁸

The CDC also observed that having more than one risk factor for heart disease and stroke was more common among older Native American men and women, the unemployed, those with less education, and those reporting their health status as fair or poor.⁷⁹

Pneumonia and Influenza

From 1994 through 1996, the Indian Health Service estimated that the age-adjusted death rate from pneumonia and influenza for Native Americans was 71 percent greater than the rate for the entire U.S. population.⁸⁰ In 1998, Native American patients hospitalized for pneumonia accounted for the greatest number of hospital discharges for elderly Medicare beneficiaries (49.3 per 1,000 discharges) in the entire U.S. population.⁸¹

Cancer

Cancer among Native Americans is a growing concern.⁸² While some statistics indicate lower cancer mortality rates for Native Americans in some regions of the United States than for whites, African Americans, Asians, and other races, it has become the leading cause of death for Alaska Native women and is the second leading cause of death among Native American women.⁸³ Among health care professionals there is concern that lower mortality rates obscure

⁷⁸ Centers for Disease Control and Prevention, Office of Communication, "Facts About Heart Disease and Stroke Among Native Indians and Alaska Natives," *Media Relations*, June 2, 2000, <www.cdc.gov/od/oc/media/pressrel/r2k0602.htm> (last accessed July 15, 2003) (hereafter cited as CDC, "Facts About Heart Disease and Stroke"). See also Georgetown University Center for Child and Human Development, University Center for Excellence in Developmental Disabilities, National Center for Cultural Competence, "Rationale for Cultural Competence in Primary Health Care," *Policy Brief 1*, <www.georgetown.edu/research/gucdc/nccc/nccc6.html> (last accessed July 15, 2003) (hereafter cited as Georgetown University, "Rationale for Cultural Competence") (only 50 percent of Native Americans, 44 percent of Asian Americans, and 38 percent of Mexican Americans have had their cholesterol checked within the past two years).

⁷⁹ CDC, "Facts About Heart Disease and Stroke."

⁸⁰ IHS, *Trends in Indian Health 1998–99*. This rate of influenza is significant since influenza can be particularly severe among diabetic patients. Agency for Healthcare Research and Quality, "National Healthcare Disparities Report: 4. Management of Chronic Diseases Presents Unique Challenges," <www.ahrq.gov/qual/nhdr03/nhdrsum03.htm> (last accessed Dec. 31, 2003).

⁸¹ Paul W. Eggers, Ph.D., and Linda G. Greenberg, Ph.D., "Racial and Ethnic Differences in Hospitalization Rates Among Aged Medicare Beneficiaries, 1998," *Health Care Financing Review*, Summer 2000, <www.cms.hhs.gov/review/00summer/eggers.pdf> (last accessed July 15, 2003). In comparison, the number of hospital discharges per 1,000 for other racial/ethnic groups, due to pneumonia, included: whites, 22.1; blacks, 22.4; Hispanics, 25.3; and Asians, 17.1.

⁸² Native American Cancer Research Corporation, "Native Americans and Cancer," <<http://members.aol.com/natamcan/nativeca.htm>> (last accessed Dec. 31, 2003).

⁸³ Centers for Disease Control and Prevention, "Cancer Mortality Among American Indians and Alaska Natives—United States, 1994–1998," *Morbidity and Mortality Weekly Report*, Aug. 1, 2003, <www.cdc.gov/mmwr/preview/

important regional and cancer-specific differences in mortality, knowledge of which could assist local cancer prevention and treatment strategies.⁸⁴ Specifically, higher rates of cancer mortality appeared in Alaska and the Northern Plains region of the United States, with 217.9 deaths (per 100,000 population) and 238.6, respectively, from 1994 through 1998.⁸⁵ The overall cancer mortality rate for the rest of the United States for this period was 164.2 deaths per 100,000.⁸⁶ These Native American cancer mortality rates in Alaska and the Northern Plains region are attributed to colorectal, gallbladder, kidney, liver, lung, and stomach cancers.⁸⁷ Similarly, cervical cancer mortality rates were higher among Native Americans than among all racial and ethnic populations (3.7 versus 2.6, respectively), especially in the East and Northern Plains regions of the United States.⁸⁸

A startling fact about cancer in Indian Country is that Native Americans have the lowest cancer survival rates among any racial group in the United States.⁸⁹ Though some data are available, there is insufficient research on cancer among Native Americans.⁹⁰ Nevertheless, experts have suggested that Native American cancer patients experience the disease differently from non-Native populations.⁹¹ Reasons for the difference include genetic risk factors, late detection of cancer, poor compliance with recommended treatment, presence of concomitant disease, and lack of timely access to diagnostic or treatment methods.⁹² Lyle Jack, a representative of the Lakota Sioux, testified that misdiagnosis and late diagnosis were especially

mmwrhtml/mm5230a4.htm> (last accessed Sept. 23, 2003) (hereafter cited as CDC, “Cancer Mortality Among American Indians and Alaska Natives”); Native American Cancer Research Corporation, “Native Americans and Cancer,” <<http://members.aol.com/natamcan/nativeca.htm>> (last accessed Dec. 31, 2003). The cancer mortality rate for Native Americans was lower during 1989 through 1993, as compared with the rate for the overall U.S. population. Similarly, from 1996 through 2000, Native Americans also experienced one of the lowest mortality rates from invasive cancers (138 deaths per 100,000 persons), compared with other racial and ethnic groups: blacks (257.1), whites (199.1), Hispanics (137.9), and Asian/Pacific Islanders (124.5). CDC, “Cancer Mortality Among American Indians and Alaska Natives.”

⁸⁴ American Public Health Association, “Abstract #55992: Regional Patterns of Cancer Mortality in American Indians and Alaska Natives in the U.S., 1994–1998,” <http://apha.confex.com/apha/131am/techprogram/paper_55992.htm> (last accessed Sept. 23, 2003) (hereafter cited as American Public Health Association, “Regional Patterns of Cancer Mortality”) (David King Espey, M.D., an IHS cancer epidemiologist in Albuquerque, New Mexico, was scheduled to present his study on regional cancer mortality rates in American Indians and Alaska Natives before the annual meeting of the American Public Health Association in November 2003).

⁸⁵ American Public Health Association, “Regional Patterns of Cancer Mortality.” *See also* Associated Press State & Local Wire, “CDC: Indians in Upper Midwest Have Higher Rates of Cancer Deaths,” Aug. 1, 2003, BC Cycle (the Northern Plains region includes Indiana, Iowa, Michigan, Minnesota, Montana, Nebraska, North and South Dakota, and Wyoming).

⁸⁶ American Public Health Association, “Regional Patterns of Cancer Mortality.”

⁸⁷ *Ibid.*

⁸⁸ CDC, “Cancer Mortality Among American Indians and Alaska Natives.” *See also* *ibid.* (the East consists of Alabama, Connecticut, Florida, Kansas, Louisiana, Maine, Massachusetts, Mississippi, New York, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, and Texas).

⁸⁹ Native American Cancer Initiative, Inc., “Native American Cancer Research, Chapter 1: Introduction and Background,” <<http://members.aol.com/natamcan2/cha01.htm>> (last accessed Dec. 31, 2003).

⁹⁰ *Ibid.*

⁹¹ *Ibid.*

⁹² *Ibid.*

prevalent on his reservation.⁹³ Accordingly, additional research must be conducted to more fully explore the magnitude and causes of cancer disparities among Native Americans.

Infant Mortality and Maternal Health

Infant mortality and maternal health rates are also considered to be indicators of health status for a particular community.⁹⁴ Historically, Native Americans have suffered inordinately high infant mortality rates.⁹⁵ Despite recent improvement, disparity persists. Native American infants continue to die at a rate two to three times higher than the rate for white infants.⁹⁶ Moreover, Georgetown University's Center for Child and Human Development, National Center for Cultural Competence, reported that for Native Americans, the incidence of sudden infant death syndrome (SIDS) is more than three to four times the rate for white infants.⁹⁷

Not surprisingly, maternal health factors also indicate lower health status. Pregnant Native American women consistently hold the lowest percentage of women receiving early prenatal care when compared with women of other races and ethnicities. For example, the percentage of Native American women receiving early prenatal care was 66.7 percent in 1995, compared with 83.6 percent of white non-Hispanic women.⁹⁸

In sum, the health indicators discussed above document the reality that Native Americans have significantly higher mortality rates and markedly lower health status than the general population. To understand why these health disparities persist, despite the federal government's promise to provide quality health care, we examine the health care programs, services, and facilities available to Native Americans.

CAUSES OF HEALTH DISPARITIES

The causes of the disparities in the health status of Native Americans are many and varied. Among the causes identified by the director of IHS is racial discrimination.⁹⁹ Analyzing the effects of that discrimination proves difficult as the unique racial or ethnic status and political history of Native Americans introduce unique emotional variables. According to Michael Bird, "when you dispossess people of their land or labor, their culture, their language, their tradition, and their religion you set into force powerful forces that impact in a very negative and adverse way."¹⁰⁰ These comments on discrimination echoed the findings of the Commission's 1999 report on health care disparities,¹⁰¹ as well as those of several other government agencies. The

⁹³ Jack Statement, Briefing Transcript, p. 54.

⁹⁴ HHS, "Current Needs."

⁹⁵ CDC, *Trends in Racial and Ethnic-Specific Rates* (between 1990 and 1998 the infant mortality rate for infants of American Indian or Alaska Native women declined by 29 percent).

⁹⁶ Georgetown University, "Rationale for Cultural Competence"; CDC, *Trends in Racial and Ethnic-Specific Rates*.

⁹⁷ Georgetown University, "Rationale for Cultural Competence."

⁹⁸ Food Research and Action Center, "WIC in Native American Communities: Building a Healthier America," *Report Summary*, 2000, <www.frac.org/html/publications/wic01summary.pdf> (last accessed July 15, 2003).

⁹⁹ Grim Statement, Briefing Transcript, p. 60.

¹⁰⁰ Bird Statement, Briefing Transcript, p. 82.

¹⁰¹ USCCR, *The Health Care Challenge*, p. 73.

National Institutes of Health recognized that racial bias contributed significantly to differences in health care among people of color in its Strategic Plan for Health Disparities Research,¹⁰² while the Institute of Medicine established that “whites are more likely to receive more, and more thorough, diagnostic work and better treatment and care than people of color—even when controlling for income, education, and insurance.”¹⁰³ Few studies, however, have addressed how racial bias systematically affects the health of Native Americans. Though the categorization of discrimination in general terms is possible, the nature of that discrimination has changed to become subtle and more difficult to address.¹⁰⁴ Consequently, identifying all areas in which racial bias and discrimination influence or contribute to existing health disparities proves difficult.

Current research indicates that there are five primary contributors to disparities in health status and outcomes for Native Americans. It must be observed that these factors are not beyond the influence of racial bias and discrimination, either systemic or individual. The five factors include:

- Limited access to appropriate health facilities.
- Poor access to health insurance, including Medicaid, Medicare, and private insurance.
- Insufficient federal funding.
- Quality of care issues.
- Disproportionate poverty and poor education.¹⁰⁵

These five factors are not mutually exclusive; in fact, there is substantial overlap. As heard throughout the briefing, this is particularly true when funding considerations are implicated. For example, a person may arrive at a health facility only to find that lack of funding has prevented the facility from providing the necessary services or that there is an extended waiting period before services will be available. Lyle Jack, councilman of the Oglala Sioux, stated that although his tribe has what is considered to be one of the best rehabilitation centers, it does not have sufficient funding to staff the facility properly.¹⁰⁶ Regardless of the reason, health care access remains limited. Thus, we turn to a discussion of the five factors that sustain the disparities in health status.

¹⁰² National Institutes of Health, Office of the Director, Office of Behavioral and Social Sciences Research, “Strategic Plan for Health Disparities Research, FY 2002–2006,” Mar. 28, 2001, <www.obssr.od.nih.gov/Activities/HealthDisp.htm> (last accessed July 14, 2003). See generally Institute of Medicine of the National Academies, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2002) (hereafter cited as Institute of Medicine, *Unequal Treatment*).

¹⁰³ Vernellia Randall, *Racial Discrimination in Health Care in the United States as a Violation of the International Convention on the Elimination of All Forms of Racial Discrimination*, 14 J. LAW & PUB. POL’Y 45, 57–8 (2002). See also Institute of Medicine, *Unequal Treatment*, pp. 1–5.

¹⁰⁴ Institute of Medicine, *Unequal Treatment*, p. 630.

¹⁰⁵ The extent to which health disparities for a specific Native American are affected by each of these causes is largely dependent on geography and tribal affiliation. See also Grim Statement, Briefing Transcript, pp. 60–61.

¹⁰⁶ Jack Statement, Briefing Transcript, p. 24.

1. Limited Access to IHS Health Facilities

Access to health care is determined by four major factors of health care coverage: affordability, availability, accessibility, and acceptability.¹⁰⁷ Affordability is the ability to purchase insurance or care.¹⁰⁸ Availability of care is determined by availability of staff and facilities and measured by the ratio of providers to population.¹⁰⁹ Accessibility is indicated by the eligibility for and/or entitlement to receive care, and by the ease of service access and utilization.¹¹⁰ Acceptability is determined by whether the service provided and received is perceived to be acceptable to the health care recipients.¹¹¹

These four factors are of major concern for Native Americans. To a limited degree, IHS services have made health care affordable for eligible Native Americans. A later section of this summary will examine funding issues and the degree to which federal funding makes adequate health care affordable. Additionally, IHS initiatives and a greater number of tribes getting involved in the management and operation of health care services are making IHS services more culturally acceptable for Native Americans. These and other issues associated with quality and acceptability of care will also be discussed later. The remaining factors, availability and accessibility of health care, are influenced by IHS organization and its service delivery system. How IHS services are structured and provided significantly influence the degree to which Native Americans have access to health care. Each will be discussed below.

Unfortunately, for the more than 538,000 Native Americans living on reservations or other trust lands where the climate is inhospitable, the roads are often impassable,¹¹² and where transportation is scarce, health care facilities are far from accessible. Anslem Roanhorse, director of the Division of Health for the Navajo Nation, stated that on the Navajo reservation 78 percent of the public roads are unpaved and 60 percent of the homes lack telephone service.¹¹³ Even worse, for those who can get to the facilities, the equipment, medicine, and services are often not available for their needed treatment. Traveling to more distant facilities or delaying treatment are the only options.

For example, in Eagle Butte, South Dakota, the Cheyenne River Sioux tribe does not have an obstetrics unit in its hospital and is worried that the new proposed hospital will not have one. "Obstetrics services for the tribe's approximately 210 births a year are contracted out, 'and last year there were five births in the ambulance on the way to Pierre,' 90 miles away."¹¹⁴ For the Kalispel tribe in Usk, Washington, the problem extends beyond specialty services. The tribe has no on-site primary care facility, so tribal members must travel 75 miles to receive care at the

¹⁰⁷ Gwendolyn Roberts Majette, *Access to Health Care: What a Difference Shades of Color Make*, 12 ANN. HEALTH L. 121, 121 (2003); Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 246.

¹⁰⁸ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 246.

¹⁰⁹ *Ibid.*

¹¹⁰ *Ibid.*

¹¹¹ *Ibid.*

¹¹² "Native Americans in the Census," *Anchorage Daily News*, Nov. 1, 2002, <www.adn.com/alaska/v-printer/story/2059310p-2157469c.html> (last accessed July 15, 2003); Restructuring Initiative Workgroup, *Transitions 2002: A 5-Year Initiative to Restructure Indian Health*, Final Report to the Indian Health Service, October 2002 (hereafter cited as Restructuring Initiative Workgroup, *Transitions 2002*).

¹¹³ Roanhorse Statement, Briefing Transcript, p. 139.

¹¹⁴ Peter Harriman, "Indian Health Worries Shared," *Argus Leader*, Aug. 25, 2003, p. 1A.

Wellpinit Service Unit IHS clinic or use an IHS contract facility, if available.¹¹⁵ Geographical access problems are not limited to remote, rural facilities. For the 25,000 urban Indians living in Denver, Colorado, the closest IHS hospitals are in Albuquerque, New Mexico (450 miles away) and Rapid City, South Dakota (400 miles away).¹¹⁶

Beyond location and inadequate transportation, understanding the availability and accessibility factors requires an understanding of how the eligibility requirements, and structure and operation of IHS influence access. After discussing eligibility requirements, this section will explore the three delivery mechanisms for health services (IHS direct delivery, tribally operated facilities, and urban Indian health facilities), including their respective advantages and disadvantages.

IHS Health Care Services Eligibility Requirements

Native Americans must meet specific eligibility criteria before they can access IHS health care services.¹¹⁷ They do not need to establish economic need to receive services. However, the very eligibility requirement that is the basis for providing health care has become contentious. This eligibility concern mainly lies with the determination of who is “Indian” and which “Indians” should receive services.¹¹⁸ Some argue that the eligibility requirements are established to exclude and not to extend health care services to Native Americans.¹¹⁹ From an IHS perspective, however, establishing a firm eligibility requirement is necessary to meet the demand for services in light of limited resources.¹²⁰

¹¹⁵ American Indian Health Commission of Washington State, “2003 American Indian Health Care Delivery Plan,” July 2003, p. 103, <www.aihc-wa.org/Issues/AIHCDP.htm> (last accessed Aug. 28, 2003).

¹¹⁶ *The Reauthorization of the Indian Health Care Improvement Act: Hearing Before the Senate Indian Affairs Comm.*, 107th Cong. (2001) (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services).

¹¹⁷ IHS services are provided to (1) an individual of Indian or Alaska Native descent; (2) an Indian of Canadian or Mexican origin, recognized by an Indian tribe or group as a member of an Indian community served by the Indian Health program; (3) a non-Indian woman pregnant with an eligible Indian’s child for the duration of her pregnancy through post-partum (usually six weeks); or (4) a non-Indian member of an eligible Indian’s household when the medical officer in charge determines that services are necessary to control a public health hazard or an acute infectious disease which constitutes a public health hazard.

A person is of Indian or Alaska Native descent as evidenced by one or more of the following factors: (1) is regarded by the community in which he lives as an Indian or Alaska Native; (2) is a member, enrolled or otherwise, of an Indian or Alaska Native Tribe or Group under federal supervision; (3) resides on tax-exempt land or owns restricted property; (4) actively participates in tribal affairs; (5) any other reasonable factor indicative of Indian descent.

Indian Health Service, “Indian Health Manual,” pt. 2, ch. 1 <<http://www.ihs.gov/publicinfo/publications/ihsmanual/Part2/pt2chapt1/pt2chpt1.htm#212>> (last accessed July 15, 2003).

¹¹⁸ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 248.

¹¹⁹ *Ibid.* See also Ralph Forquera, *Urban Indian Health* (the Henry J. Kaiser Family Foundation, November 2001), p. 8 (hereafter cited as Forquera, *Urban Indian Health*); Delight Satter, M.P.H., research scientist, UCLA Center for Health Policy Research, and director, American Indian and Alaska Native Research Program, interview, July 1, 2003.

¹²⁰ See Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 248.

IHS Direct/Tribal/Urban Programs

IHS provides health care services to approximately 1.5 million of the 2.6 million Native Americans in the United States.¹²¹ Recipients include members of more than 560 federally recognized tribes in 35 states.¹²² IHS provides services primarily to the Native Americans living on or near reservations, in rural areas.

IHS is not a health insurance program; rather, it is a federally funded service providing health care services to eligible Native Americans. According to Dr. Charles Grim, director of the Indian Health Service, it is a program of “universal eligibility but limited availability.”¹²³ Funds for IHS health care are discretionary, not a personal entitlement.¹²⁴ Consequently, IHS provides health care services only to the extent appropriated funding allows. In addition to its health services role, IHS is the principal health advocate for Indian people.¹²⁵ Accordingly, it collaborates with federal entitlement programs, state or local health care programs, and private insurance providers to ensure that adequate care is funded and provided.

IHS is made up of 12 regional administrative units called area offices, as shown in Figure 1, and these area offices oversee the operation of IHS programs.

¹²¹ Indian Health Service, “Indian Health Service Introduction,” <www.ihs.gov/publicinfo/publicaffairs/welcome%5Finfo/ihsintro.asp> (last accessed Oct. 3, 2003) (hereafter cited as IHS, “Introduction”).

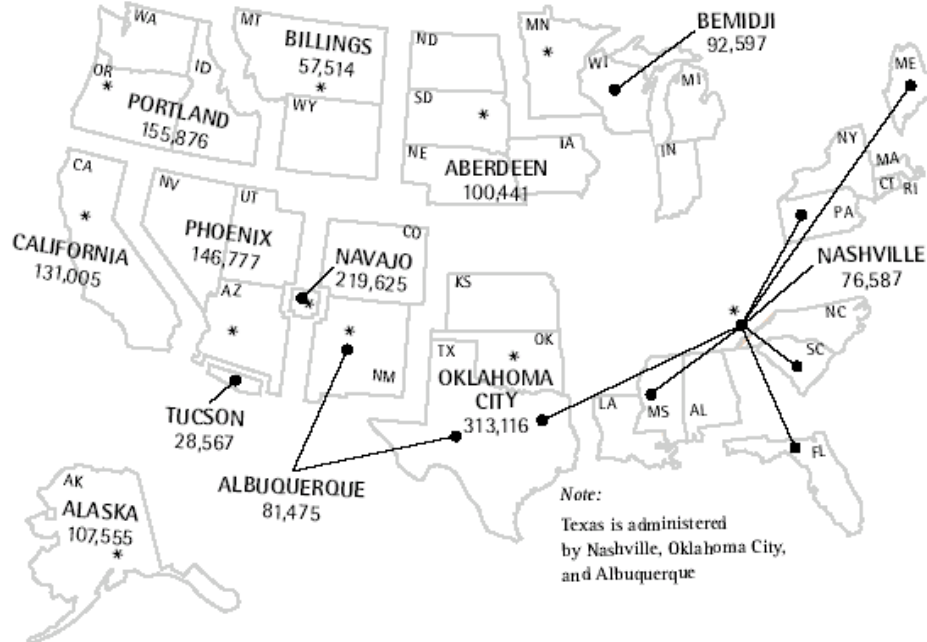
¹²² *Ibid.* See also Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs, Notice, 67 Fed. Reg. 46,328 (July 12, 2002).

¹²³ Grim Statement, Briefing Transcript, p. 104.

¹²⁴ As will be discussed in the sections on barriers to health insurance, there is a widely held perception among Native Americans that they are entitled to health care based on their unique relationship and history with the federal government. Related, in part, to this historical view is a vigorous debate as to whether Native American health care should become a formal government “entitlement program.” Those in favor see entitlement status as a means of enforcing sufficient funding to fully meet federal health care obligations. Those opposed see entitlement as a potential ceiling for individual services and a potential loss of bargaining position as the federal obligation becomes enforceable only by individuals rather than the tribes. See Munson interview; Ed Fox, executive director, Northwest Portland Area Indian Health Board, interview, Aug. 14, 2003.

¹²⁵ IHS, “Introduction.”

Figure 1: Indian Health Service—Service Population by Area



Source: Indian Health Service, *Trends in Indian Health 1998–99*, <<http://www.ihs.gov/publicinfo/publications/trends98/part2.pdf>> (last accessed Aug. 21, 2003).

As of October 1, 2001, the area offices consisted of 155 basic administrative units called service units.¹²⁶ Within these 12 areas are 545 health care delivery facilities, including 49 hospitals, 231 health centers, 133 health stations, five school health centers, and 176 Alaska village clinics operated by IHS or the tribes.¹²⁷ IHS-funded services are delivered in three ways: direct IHS services, tribal services, and Urban Indian Health Programs. For those Native Americans who qualify, IHS health services are delivered directly, through tribally contracted and operated health programs, or at IHS contract facilities.¹²⁸ Additionally, 34 Urban Indian Health Programs provide limited health and referral services to approximately 150,000 Native Americans living in cities throughout the country.¹²⁹ Each of the three delivery programs is discussed in turn, followed by a discussion of the Contract Health Services program.

¹²⁶ Indian Health Service, Office of Public Health, *Regional Differences in Indian Health 2000–2001*, p. 4 (hereafter cited as IHS, *Regional Differences*).

¹²⁷ *Ibid.*, p. 17.

¹²⁸ Indian Health Service, “Fact Sheet,” <www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisFacts.asp> (last accessed Sept. 4, 2003) (hereafter cited as IHS, “Fact Sheet”).

¹²⁹ *Ibid.* Jennie R. Joe, “The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives,” in Institute of Medicine of the National Academies, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2002), p. 534 (hereafter cited as Joe, “The Rationing of Healthcare”). Currently, only about 38 percent of Native Americans live on federal trust lands; the remainder reside in off-reservation or urban communities. *See also* *ibid.*, p. 529.

Direct Delivery System

The IHS direct care delivery system consists of hospitals, health centers, health stations, and residential treatment centers.¹³⁰ Federal employees in the Indian Health Service provide health care services in 63 IHS-operated service units, administering 36 hospitals and 59 health centers, 49 health stations, and two school health centers.¹³¹ Most IHS hospitals also have active outpatient departments that provide dental, mental health, and other services.¹³² IHS-operated facilities will expend \$674 million or 46 percent of the FY 2004 budget appropriated for non-contract services.

Health centers are physically separate from hospitals and offer a complete range of ambulatory services (including primary care physicians, nursing, pharmacy, laboratory, and radiology services) for a minimum of 40 hours per week.¹³³ By comparison, health stations are often smaller mobile units, which offer fewer outpatient services for fewer than 40 hours per week. Mid-level practitioners usually provide primary care, with physician care available on a regularly scheduled basis.¹³⁴

In general, IHS direct services are limited in scope compared with services in non-IHS facilities. IHS hospitals are smaller and have fewer beds than other U.S. community hospitals. In addition, IHS hospitals provide limited inpatient services and fewer high-technology services. Aside from the three large IHS hospitals (the Alaska Native Medical Center in Anchorage, Alaska; the Gallup Indian Medical Center in Gallup, New Mexico; and the Phoenix Indian Medical Center in Phoenix, Arizona), IHS hospitals have fewer than 50 beds and most are without surgical or obstetrics services.¹³⁵ Following the national trend, IHS services are shifting from inpatient care to an emphasis on ambulatory care services.¹³⁶

Despite IHS efforts to provide for the health care needs of Native Americans, limited funding has led to the rationing of services.¹³⁷ Rationing of health services limits patients' access to only medically necessary services.¹³⁸ Medically necessary services are defined by an attending physician who determines the health care treatment that is necessary to "preserve life, limb, and sensory organs or to prevent clear deterioration of health status."¹³⁹ Limited funding also forces

¹³⁰ IHS, "Fact Sheet."

¹³¹ IHS, *Regional Differences*, p. 4.

¹³² Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 233.

¹³³ IHS, *Regional Differences*, p. 13.

¹³⁴ Indian Health Service, "IHS Glossary of Terms," <www.ihs.gov/aboutihs/thisglossary.asp> (last accessed Dec. 30, 2003).

¹³⁵ Joe, "The Rationing of Healthcare," p. 534.

¹³⁶ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 234. See generally South Carolina Hospital Association, "Glossary," <http://www.bluecrossca.com/bus_units/lgrp/50plus_Glossary.htm> (last accessed Sept. 30, 2003). Ambulatory care services are defined as "[s]ervices rendered to persons not confined overnight, including emergency, clinical, laboratory, radiology and home health services. Often referred to as 'outpatient' services." Ibid.

¹³⁷ Craig Vanderwagen, M.D., acting chief medical officer, Indian Health Service, interview, July 21, 2003; see also Roanhorse Statement, Briefing Transcript, p. 169.

¹³⁸ Vanderwagen interview.

¹³⁹ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 253.

IHS officials to restrict patient access to specialty care services.¹⁴⁰ Dr. Craig Vanderwagen, acting chief medical officer for IHS, acknowledged that rationing health care is not the optimal method of treating patients:

We don't feel good about the number of patients who need care who are rejected because their problem is not life-threatening. . . . It's rationing. We hold them off until they're sick enough to meet our criteria. That's not a good way to practice medicine. It's not the way providers like to practice. And if I were an Indian tribal leader, I'd be frustrated.¹⁴¹

In addition, where services are not available through IHS direct or tribal providers, IHS purchases those services from non-IHS providers under the Contract Health Services program.¹⁴² IHS has increasingly relied on contract services, as it is difficult to provide complicated services to many widespread and remote areas with small populations.¹⁴³ As IHS uses more of its resources for contract services, fewer resources are available for IHS direct services. As a result, it becomes more difficult to develop and improve IHS services.¹⁴⁴

Despite these problems with IHS-provided health care, there are advantages to using a federally operated system. First, the direct delivery system does bring services to remote Indian reservations where market conditions would otherwise prevent the delivery of health services.¹⁴⁵ Even though service is limited, eligible Native Americans do receive health care. In many situations, tribes have neither the resources nor the expertise to provide or manage care. IHS brings both resources and expertise.¹⁴⁶ Second, several sources familiar with Native American health care issues agree that IHS has done a remarkably good job providing for the health needs of Native Americans, considering formidable obstacles and limited funding.¹⁴⁷ Third, while disparities still exist, the health status of Native Americans has improved over the past few decades.¹⁴⁸

¹⁴⁰ Vanderwagen interview.

¹⁴¹ Ibid.

¹⁴² IHS, "Fact Sheet." See the section in this summary on Contract Health Services for a detailed discussion on this program.

¹⁴³ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 235.

¹⁴⁴ Ibid.

¹⁴⁵ Lyle Jack, tribal councilman, Oglala Sioux, interview, Oct. 23, 2003.

¹⁴⁶ Ibid. The ability of the federal government to provide federal benefits (of greater value than the tribes can afford to pay) and therefore recruit more and higher quality individuals is one reason some tribes choose not to enter into compacting agreements. See Taylor McKenzie, former vice president, Navajo Nation, interview, Sept. 11, 2003. Additionally, as long as the government is providing care there is less fear that all money will be withdrawn. As the tribes take over, some tribes fear that the federal government will use that as motivation to back out of their obligation to pay. See Joe, "The Rationing of Healthcare," p. 544.

¹⁴⁷ Jennifer Giroux, M.D., Indian Health Board of Minneapolis, health care policy research and administrative fellow, Center for American Indian and Minority Health, University of Minnesota, interview, July 23, 2002; Jennie Joe, Ph.D., M.P.H., R.N., professor, Family and Community Medicine, University of Arizona School of Medicine, interview, June 24, 2003; J.T. Petherick, Esq., M.P.H., executive director, National Indian Health Board, interview, July 2, 2003; Delight E. Satter, M.P.H., research scientist, UCLA Center for Health Policy Research, director, American Indian and Alaska Native Research Program, interview, July 1, 2003.

¹⁴⁸ See Perez Statement, Briefing Transcript, p. 15. Since 1973 mortality rates have been reduced for the following: tuberculosis (82 percent); maternal deaths (78 percent); infant deaths (66 percent); accidents (57 percent); injury and poisoning (53 percent); and pneumonia and influenza (50 percent). Indian Health Service, *Trends in Indian Health*

Tribal Health Programs

In addition to IHS direct services, the Indian Self-Determination and Education Assistance Act (the Self-Determination Act) allows tribes to contract or compact to provide health care services to their tribal members.¹⁴⁹ Where tribes choose not to contract for health programs, IHS continues to provide health services to the tribes.¹⁵⁰ While some tribes have chosen to receive health care services directly from IHS, more tribes are taking on the management and delivery of health care services.¹⁵¹

Congress first enacted the Self-Determination Act in 1975 to further the goal of Native American self-determination by ensuring maximum Native American participation in the management of federal programs and services for Native Americans.¹⁵² The act authorizes tribes to take over the management and administration of programs through contractual arrangements with the agencies that previously administered them.¹⁵³ Under the act, tribes receive funding for the programs they contract to manage. IHS and the Bureau of Indian Affairs are two federal agencies that enter into “self-determination contracts” with tribes.

In 1992, the Self-Determination Act was reauthorized through amendments to the Indian Health Care Improvement Act.¹⁵⁴ The self-governance programs created pursuant to the Self-Determination Act were designed to provide tribal governments with more control and decision-making authority over the day-to-day operation of programs providing services to Native Americans. The Self-Determination Act also promotes the government-to-government relationships referenced in the Constitution.¹⁵⁵

Currently, there are 61 self-governance tribal compacts and 81 funding agreements representing 285 tribes and providing health services to more than 51 percent of the tribes.¹⁵⁶

1998–99, <www.ihs.gov/publicinfo/publications/trends98/part2.pdf> (last accessed Aug. 21, 2003) (hereafter cited as IHS, *Trends in Indian Health 1998–99*). See also Perez Statement, Briefing Transcript, pp. 14, 15.

¹⁴⁹ 25 U.S.C. §§ 450–458hh (1994 & Supp. VI 1998). Under this law, tribes can contract with the federal government to take over the management of all or part of their health care programs; subsequent amendments allowed tribes to compact with the federal government to obtain more power and independence in the management of their health programs.

¹⁵⁰ It is important to recognize that the decision to continue to rely on IHS for health services “is as legitimate a self-governance decision as that of a tribe that chooses to operate the program themselves.” Munson Statement, Briefing Transcript, p. 252.

¹⁵¹ Joe, “The Rationing of Healthcare,” p. 534.

¹⁵² Pub. L. No. 93-638, 88 Stat. 2203 (1992) (codified as amended in 25 U.S.C. §§ 450–457 (1994)).

¹⁵³ U.S. General Accounting Office, *Federal Tort Claims Act: Coverage and Claims for Tribal Self-Determination Contracts at the Indian Health Service*, July 31, 2001, GAO-01-1001T.

¹⁵⁴ Pub. L. No. 102-573, Title VII, § 814, 106 Stat. 4590 (1992) (codified as amended in 25 U.S.C. § 450f (1994)). See also Pub. L. No. 102-573, 106 Stat. 4526 (1992) (codified as amended in scattered sections of 25 U.S.C.).

¹⁵⁵ The tribal self-governance demonstration project mandated that the Secretary of the Department of the Interior (DOI) select 20 tribes, for the period of five years, to plan, conduct, consolidate, and administer programs, services, and functions previously administered by DOI. See Pub. L. No. 102-573, Title VII, § 814, 106 Stat. 4590 (1992) (codified as amended in 25 U.S.C. § 450f (1994)). The project required DOI to negotiate and to enter into an annual written funding agreement with the participating tribes. This funding agreement allowed the participating tribal governments to “redesign programs, activities, functions or services and to reallocate funds for such programs, activities, functions or services.” *Id.*

¹⁵⁶ Indian Health Service, Office of Tribal Self-Governance, “Purpose and Method of Operation,” <www.ihs.gov/NonMedicalPrograms/SelfGovernance/index.asp> (last accessed Sept. 22, 2003).

During FY 2003, \$796 million of the \$1.47 billion appropriated to IHS for non-contract services was transferred to the tribes under these programs.¹⁵⁷ In terms of available hospital care, tribally operated hospitals are generally small; 80 percent have 50 or fewer beds.¹⁵⁸ Native American tribes manage 13 hospitals, 172 outpatient health centers, 176 village clinics in Alaska, 84 health stations, and three school health programs.¹⁵⁹ Although these tribally operated facilities are intended to promote tribal self-governance, IHS considers these tribal programs as extensions of IHS.¹⁶⁰ IHS provides technical assistance, helps prospective tribal contractors develop applications, and assumes responsibility, oversight, and control of these tribally operated health care services.¹⁶¹

While contracts allow the tribes to take over and manage existing health programs without making substantial programmatic changes, compacts allow tribes more flexibility in re-prioritizing or changing the health programs to meet what they perceive to be the most urgent health care needs in their communities.¹⁶² Compacting, created in response to criticisms that IHS oversight of tribal programs was excessive, promotes and supports tribal initiative.¹⁶³ Compacting also gives more authority to the tribes and reduces IHS bureaucracy.¹⁶⁴

Generally, the shift toward tribal autonomy in health care matters has been a dramatic success.¹⁶⁵ Virtually every tribe that has taken control of health facilities has expanded the services provided.¹⁶⁶ Additionally, tribal authority has brought an increase in the number of Native American employees. Consequently, the knowledge gained regarding specific techniques and the general importance of health remains in the community, building a foundation or “corporate knowledge” that might otherwise have rotated to other communities with the transfer of Public Health Service employees.¹⁶⁷ Employees’ earnings, as well, usually remain in the community, providing economic stimulus.¹⁶⁸ More importantly, as tribes take over the management and operation of their health programs, the overall quality of care provided has improved by being more responsive to local needs.¹⁶⁹ Finally, tribal control creates two financial

¹⁵⁷ Ibid. See also U.S. Department of Health and Human Services, “FY 2004 Budget in Brief,” <www.hhs.gov/budget/04budget/fy2004bib.pdf> (last accessed July 14, 2003) (hereafter cited as HHS, “FY 2004 Budget in Brief”).

¹⁵⁸ U.S. General Accounting Office, Report to the Ranking Minority Member, Human Resources and Intergovernmental Relations Subcommittee, House Committee on Government Reform and Oversight, *Indian Health Service—Improvements Needed in Credentialing Temporary Physicians*, April 1995, p. 10 (hereafter cited as GAO, *IHS—Improvements*) (the three largest IHS hospitals are in Phoenix, Arizona; Gallup, New Mexico; and Anchorage, Alaska).

¹⁵⁹ IHS, *Regional Differences*, p. 17.

¹⁶⁰ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 237.

¹⁶¹ Ibid., p. 237.

¹⁶² Ibid.

¹⁶³ Ibid.

¹⁶⁴ Ibid.

¹⁶⁵ Paula Williams, Indian Health Service, interview, Sept. 8, 2003; Dorothy Dupree, Centers for Medicare & Medicaid Services, interview, June 30, 2003; Don Kashevaroff, Alaska Native Tribal Health Consortium, interview, Sept. 3, 2003.

¹⁶⁶ Munson interview.

¹⁶⁷ Ibid.

¹⁶⁸ Ibid.

¹⁶⁹ Joe, “The Rationing of Healthcare,” pp. 539–40.

gains for health care. First, the tribes become more efficient at third-party recovery because they recognize the direct increase in the amount of money available for the purchase of additional health services. Second, the tribes have become willing to seek out private and public grants, knowing that their share of IHS funding will not be reduced as a result.¹⁷⁰

While tribal autonomy has its advantages, potential drawbacks exist. The most significant of these potential drawbacks is the inability to take advantage of “economy of scale” or the fall in average costs resulting from an increase in the scale of production.¹⁷¹ Economies of scale in health care delivery reduce health care costs by improving efficiency. Improved efficiency enables larger health care facilities to provide services at a reduced cost in the same manner that large corporate retail stores provide reduced prices to consumers of retail goods. A second drawback stems from the discretion granted a sovereign authority. Tribes now control their own data. Consequently, not all tribes contribute all data to IHS. This affects available data on actual health status, administration, and funding. Dave Baldrige, formerly with the National Indian Council on Aging, was especially critical of the impact these data problems would have on the ability to address health concerns on a national level.¹⁷² In the context of behavioral health, he saw the potential for “500 tribes operating in 500 different directions.”¹⁷³ The absence of consistent, reliable data would make it impossible to compare and contrast. He referred to the shift, or “devolution,” of the established, integrated system of Indian health care in the direction of tribally operated programs as the “balkanization” of a previously effective health care system.¹⁷⁴

Overall, the increase in tribal operation of health care services has brought more autonomy for the tribes and in turn has established care that fits the needs of each individual tribe. However, tribal services generally lack the technology and the knowledge gained in a larger health care delivery system.¹⁷⁵ Additionally, while tribal services have found some success in third-party collection and in utilizing non-IHS funding to support their health care service needs, like IHS, tribal services are faced with limited resources in meeting the health care needs of their tribal members. Accordingly, tribal services face significant obstacles in providing full access to health care for Native Americans.

Urban Indian Health Programs

In addition to IHS direct services and tribal services, Urban Indian Health Programs provide health care services to urban Native Americans. According to 2000 census data, 61 percent of the Native American population lives in urban areas. The Indian Health Care Improvement Act (IHCIA) allows for federal funding to sponsor operation of Urban Indian Health Programs to provide limited services to this community.¹⁷⁶ In FY 2004, \$31.5 million has

¹⁷⁰ Munson interview.

¹⁷¹ Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 237. See also Collins English Dictionary, “Economy of Scale,” <<http://www.wordreference.com/english/definition.asp?en=economy+of+scale>> (last accessed Dec. 17, 2003).

¹⁷² Baldrige Statement, Briefing Transcript, p. 346.

¹⁷³ Dave Baldrige, interview, Nov. 4, 2003.

¹⁷⁴ Baldrige Statement, Briefing Transcript, p. 346.

¹⁷⁵ Baldrige interview.

¹⁷⁶ Joe, “The Rationing of Healthcare,” p. 535.

been requested for the Urban Indian Health Program, an increase of \$245,000 from FY 2003. This represents less than 1 percent of annual IHS appropriations for programs serving 24 percent of the Native American population. In addition to the severe underfunding of urban Indian programs, Norman Ration of the Nation Indian Youth Council described problems associated with the lack of representation for urban Indians. He noted that the inability to voice urban Indian concerns has resulted in funding mechanisms that allow funds designated for urban Indians to be spent elsewhere.¹⁷⁷ Consequently, with only 24 percent receiving limited service from these urban programs, 37 percent of all Native Americans (almost 1 million Native Americans) remain with no access to IHS facilities.¹⁷⁸

These urban-based Indian programs, which began as not-for-profit clinics and survived on donated equipment, supplies, and volunteer services, became slightly more reliable sources of care with the funding made available through IHCI. ¹⁷⁹ Currently, approximately 34 Urban Indian Health Programs in more than 41 locations are partially supported by IHS.¹⁸⁰ The balance of their funding is obtained through tribal support, as well as public and private grants.

Urban Indian Health Programs serve approximately 100,000 Native Americans who either do not meet IHS eligibility criteria or who reside outside IHS and tribal service areas.¹⁸¹ Another 49,000 Native Americans use urban programs in cities located in IHS direct or tribal service delivery areas.¹⁸² Far more (the 37 percent identified above) are forced to seek their own care, even if that means returning to tribal lands to obtain health care services.¹⁸³

The services provided vary among the 34 programs. Several provide comprehensive medical services as well as substance abuse and community preventive care programs. A greater percentage provide only limited service, with 26 percent providing only diagnostic and referral services.¹⁸⁴ Urban Indians who are on public assistance, unemployed, or employed in jobs without health benefits most often use these facilities.¹⁸⁵

Unlike IHS and tribal health services that are provided without charge to eligible Native Americans, Urban Indian Health Programs provide services on a sliding-fee basis.¹⁸⁶ In addition,

¹⁷⁷ Ration Statement, Briefing Transcript, p. 78.

¹⁷⁸ Urban Indian Health Institute, "National Aggregate Urban Indian Data," <www.uuhi.org/data.asp> (last accessed Aug. 23, 2003). See also Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis and Recommendations" (14th Annual), Mar. 19, 2003, pp. 7, 25 (hereafter cited as Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis").

¹⁷⁹ Joe, "The Rationing of Healthcare," p. 535.

¹⁸⁰ Indian Health Service, "Urban Indian Health Programs," <www.ihs.gov/NonMedicalPrograms/Urban/UIHP.asp> (last accessed Oct. 4, 2003); Forquera, *Urban Indian Health*, pp. 9–10.

¹⁸¹ Ibid.

¹⁸² Ibid. IHS, Office of Urban Programs, telephone interview, Sept. 30, 2003 (while these urban Native Americans may live within IHS or tribal service delivery areas, even if a facility is in close proximity, they may not meet the eligibility requirements to receive services).

¹⁸³ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 25.

¹⁸⁴ ITU Budget Workgroup, "FY 2003 Needs Based Budget Presentation," p. 44, <www.npaihb.org/index.html> (last accessed Aug. 19, 2003). See also Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis."

¹⁸⁵ Joe, "The Rationing of Healthcare," p. 535.

¹⁸⁶ Forquera, *Urban Indian Health*, p. 12.

many of the services are restricted to primary care.¹⁸⁷ Urban Indians must also pay when referred for such services as inpatient hospital care, specialty services, and diagnostics.¹⁸⁸

Panelists at the Commission briefing agreed that despite the fact that a large majority of Native Americans are living in urban settings, the Urban Indian Health Programs leave those without private insurance, Medicaid, or Medicare with virtually no access to health care.¹⁸⁹ Norman Ration emphasized that although Native Americans are moving to urban areas in alarming numbers, “IHS does not ‘get it’ when it comes to addressing the health care needs of urban Indians.”¹⁹⁰ Kay Culbertson, executive director of the Denver Indian Health and Family Services, also stated that urban Native Americans have become invisible to federal policies, with services being geared toward tribal members living on reservations.¹⁹¹ She added that the health care needs of Native Americans living off reservation are as great or even worse than the needs of Native Americans who live on their homelands.¹⁹²

Contract Health Services Program

Through its Contract Health Services (CHS) program, IHS purchases primary and specialty health care services for eligible Native Americans when services are not available through IHS direct or tribal services.¹⁹³ For FY 2004, \$493 million has been requested for CHS, amounting to 25 percent of funds allocated for clinical services.¹⁹⁴

To receive contract health services, in addition to meeting IHS eligibility requirements, Native Americans must live within designated contract health service delivery areas.¹⁹⁵ Because of severe funding restrictions, IHS limits contract health care to those services determined to have medical priority.¹⁹⁶ According to Ed Fox, executive director of the Northwest Area Indian Health Board, these priorities are established locally and vary depending on the level of funding and the relative nature of the need.¹⁹⁷ In FY 2001, IHS deferred payment authorization for 111,620 recommended cases and denied care for 22,030 cases,¹⁹⁸ a 75 percent increase in denials

¹⁸⁷ Ibid.

¹⁸⁸ Ibid.

¹⁸⁹ Ration Statement, Briefing Transcript, p. 77; Culbertson Statement, Briefing Transcript, p. 277. Despite the apparent opposition of tribal and urban leaders in the quest for additional funding, there was general agreement that the question is not whether to provide health care to urban Indians or to the tribes, but whether additional funding is needed for *all* Native Americans. There seems to be a consensus that the battle for funding should not become a mechanism for division.

¹⁹⁰ Ration Statement, Briefing Transcript, p. 78.

¹⁹¹ Culbertson Statement, Briefing Transcript, p. 268.

¹⁹² Ibid., p. 276.

¹⁹³ This includes patients of IHS and tribally operated facilities. See Indian Health Service, “Glossary,” <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisGlossary.asp> (last accessed Dec. 18, 2003).

¹⁹⁴ HHS, “FY 2004 Budget in Brief.”

¹⁹⁵ Forquera, *Urban Indian Health*, p. 8.

¹⁹⁶ Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*.

¹⁹⁷ Fox interview.

¹⁹⁸ Northwest Portland Area Indian Health Board, “FY 2004 IHS Budget Analysis,” pp. 3, 41. Furthermore, these numbers are certainly low, as tribes frequently fail to report after denial is certain.

from 1998.¹⁹⁹ The denial rate has reached the point that the existence of a “loss of life or limb” rule is commonly recognized.²⁰⁰ Mr. Fox observed that by August, with several weeks remaining in the fiscal year, most facilities either defer or deny gallbladder surgeries and eyeglass prescriptions, as well as other services of equivalent urgency.²⁰¹ As an illustration, IHS officials identified one facility where only 14 of 45 cases needing referral for necessary services were even forwarded for CHS review.²⁰² Even fewer of those reviewed actually received contracted care.²⁰³ As a further impediment to accessing quality health care, IHS requires that other non-IHS sources be exhausted for payment before contract services are sought.²⁰⁴ In other words, the patient still receives a referral, but instead of IHS paying the bill, the referral lists the alternate health care provider as the payer, subject to any applicable restrictions. If the alternate provider requires any deductible or co-payment IHS may pay it, if funding is available.²⁰⁵

As discussed earlier, Contract Health Services programs require that patients live in certain contract health service delivery areas identified for their respective tribes. Accessibility to IHS contract health care services is effectively ended when individuals move from their home reservations to urban or rural locations, which are often outside contract health service delivery areas.²⁰⁶ Consequently, IHS-funded services are generally not accessible to the estimated 61 percent of Native Americans who live off reservations in urban areas. The exceptions are the estimated 150,000 with limited access to the 34 Urban Indian Health Programs.

As explained earlier, not all IHS and tribal hospitals provide a full range of specialty services such as cardiology, ophthalmology, and orthopedics. For these services, patients must use the Contract Health Services program, subject to the severe budgetary constraints discussed above. Contract services are usually restricted because most of CHS funding is consumed by emergency care.²⁰⁷ Those awaiting more routine care experience lengthy delays and unnecessary complications.²⁰⁸ Accordingly, while contract services provide health care otherwise unavailable through IHS direct or tribal providers, due to restricted funding, limited services, and lengthy delays in receiving services, Native Americans do not have full access to health care through the Contract Health Services program.

2. Poor Access to Health Insurance

Of the four major factors affecting access to health care, affordability is often considered the most formidable. Because the government has a trust responsibility to provide health care to

¹⁹⁹ ITU Budget Workgroup, “FY 2003 Needs Based Budget Presentation,” <www.npaihb.org/index.html> (last accessed Aug. 19, 2003).

²⁰⁰ *Ibid.* See also Jack Statement, Briefing Transcript, p. 26.

²⁰¹ Fox interview.

²⁰² Vanderwagen interview.

²⁰³ *Ibid.*

²⁰⁴ Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*.

²⁰⁵ *Ibid.*

²⁰⁶ Indian Health Service, “Health Care Away From Home Reservation,” <www.ihs.gov/GeneralWeb/HelpCenter/CustomerServices/CHSDA.asp> (last accessed Oct. 8, 2003).

²⁰⁷ Joe, “The Rationing of Healthcare,” pp. 539–42. See also Vanderwagen interview.

²⁰⁸ Joe, “The Rationing of Healthcare,” pp. 539–42. See also Vanderwagen interview.

Native Americans, the adequacy of federal funding becomes one measure of affordability, one measure of access to health care. Federal funding will be addressed in a later section of this summary. This section will address the individual Native American's contribution to funding health care as represented by enrollment in health insurance programs. Because Native American enrollment figures for job-based insurance and public insurance programs fall well below those for white Americans, the barriers to health insurance are the focal point for this discussion.

Data from the Kaiser Commission on Medicaid and the Uninsured indicate that 43 percent of Native Americans have access to employer-sponsored health insurance, compared with 72 percent of white Americans.²⁰⁹ This low figure may be partly attributed to high unemployment among Native Americans, 7.6 percent as opposed to 3.0 percent for white Americans,²¹⁰ and to the fact that many jobs available to Native Americans do not offer health insurance.²¹¹ In addition to those with job-based insurance, 27 percent rely on public health insurance, such as Medicaid, Medicare, the State Children's Health Insurance Program (SCHIP), and the Veterans Administration services.²¹² This leaves the remainder, nearly one-quarter of the Native American population, with no insurance at all.²¹³ For those individuals, IHS is the only obligated provider. If IHS is unable to provide services, the uninsured Native American must seek charity, or more frequently, go without health care until the situation requires emergency attention.

Of those who are uninsured some percentage are eligible for coverage but are not enrolled because they either lack access or they choose not to enroll. Many choose not to enroll based on the belief that the federal government is required to provide health care, without regulation or limitation, as a result of treaties and obligations created in court decisions and legislation.²¹⁴ The barriers to insurance that Native Americans face are numerous and substantial. They can be explained using three overlapping categories: social and cultural factors that limit enrollment, procedural factors that discourage enrollment, and factors that limit the collection of third-party funds to which Native American patients and/or IHS are entitled. The specific factors within each category are discussed in sequence below.

²⁰⁹ Kaiser Commission on Medicaid and the Uninsured, "Key Facts," June 2003, p. 12, <www.kff.org/minority/health/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=14366> (last accessed Dec. 30, 2003) (hereafter cited as Kaiser, "Key Facts"). Duane Jeanotte, director of headquarters operations, Office of the Director, IHS, explained that "the availability of insurance in the total Indian population is not known, but anecdotal information suggests that it's less than other groups." Jeanotte Statement, Briefing Transcript, p. 199. For the IHS and the tribal user population, Mr. Jeanotte estimates that 60 percent have some type of third-party coverage. *Ibid.*, p. 202.

²¹⁰ U.S. Census Bureau, "Employment Status 2000," *Census 2000 Brief*, p. 5, <www.census.gov/prod/2003pubs/c2kbr-18.pdf> (last accessed Sept. 22, 2003).

²¹¹ Kaiser, "Key Facts."

²¹² By some estimates as many as 40 percent of Native Americans are eligible for Medicaid, with more eligible for Medicare and SCHIP, and as many as 50 percent have private insurance (IHS estimates that 60 percent have some form of third-party insurance). Yet IHS estimates that only 25 percent of the money spent on Native American health care comes from non-IHS sources. *See* Kaiser, "Key Facts." The Veterans Administration's programs serve more than 165,000 Native Americans. *See* "VA and HHS to Improve Health Care for Indian Veterans," *Seminole Tribune*, Mar. 21, 2003, p. 4. Additional sources include the TriCare program with the Department of Defense, serving 12,800 Native Americans and their families (*see* "Hopi Mom Among Missing," *Newsday*, Mar. 30, 2003, p. W18); and state and federal correctional institutions, serving almost 29,000 inmates (*see* Bureau of Justice Statistics, "American Indians and Crime," 1997, <www.ojp.usdoj.gov/bjs/pub/pdf/aic.pdf> (last accessed July 11, 2003)).

²¹³ Kaiser, "Key Facts."

²¹⁴ Dupree interview.

Social and Cultural Factors

Many agree that the major factor preventing Native Americans from enrolling in public insurance programs is their belief that they are entitled to health care as a result of their unique relationship with the federal government.²¹⁵ From the perspective of many Native Americans, they purchased a service at heavy cost, on the order of 400 million acres of land, and full recovery should be neither costly nor burdensome for the individual patient. Therefore, these Native Americans see Medicare and Medicaid registration and enrollment procedures, as well as the accompanying rules and regulations, as burdens for which they did not bargain and with which they should not be required to comply.²¹⁶ Even the strong community interest in full collection from these programs is sometimes not enough to overcome this view.

The perception of burden derives from several factors, including requests for private information and the necessity for documentation to support the paperwork.²¹⁷ Additionally, Native Americans fear that participating in public programs will lead to the elimination of IHS.²¹⁸ This fear has been reinforced by budget proposals that have, in essence, deducted from appropriated funds the amount increased by collections from public insurance programs.²¹⁹ In fact, that dynamic has probably guided budgetary policy over the past seven to 10 years.²²⁰

Significantly, tribally operated facilities have proved to be more effective at increasing enrollment in and collections from public insurance programs than federal IHS facilities.²²¹ Native Americans are typically more comfortable releasing private information to other Native Americans; the tribal facilities are motivated to seek additional funds available to them; the tribal facilities use a different, more flexible billing system, which is capable of adapting to changing reimbursement requirements; and the tribal facilities experience less turnover, enabling the facility to build relationships with state government officials.²²²

Not completely separate from the view that Native Americans are entitled to health care is the stigma sometimes associated with public programs. Historically, stigma has centered on the perception others have of welfare recipients. Many beneficiaries of public programs feel that they are perceived as lazy and that they fail to get respect as a result of accepting public assistance.²²³ A study by George Washington University researchers has found that the actual

²¹⁵ Dupree Statement, Briefing Transcript, p. 216.

²¹⁶ Dupree interview.

²¹⁷ A study by the California Policy Research Center found that the requirement for the production of *any* documents or records to determine eligibility was problematic. Delight E. Satter, Steve Wallace, Trang Lee, and Andrea Zubiato, "Improving Health Insurance Coverage for American Indian Children and Families Under Healthy Families," SCHIP Final Report, June 2002, p. 15, <www.healthpolicy.ucla.edu/pubs/files/AIAN_report_062002.pdf> (last accessed July 14, 2003) (hereafter cited as Satter et al., "Improving Health Insurance Coverage"). See also Dupree interview.

²¹⁸ Satter et al., "Improving Health Insurance Coverage."

²¹⁹ Lovell Hopper, director, Division of Financial Management, Indian Health Service, interview, July 21, 2003.

²²⁰ Ibid.

²²¹ Dupree interview.

²²² Ibid.

²²³ Sara Rosenbaum, Karen C. Jones, Kathleen A. Maloy, and Jennifer P. Stuber, "Beyond Stigma: What Barriers Actually Affect the Decisions of Low-Income Families to Enroll in Medicaid?" July 2000, <www.gwu.edu/~chrsp/pdf/stig.pdf> (last accessed July 11, 2003).

stigma is even broader.²²⁴ Stigma is related as much to how recipients will be treated in the application process and how health care providers will treat those recipients once they are enrolled as it is to the mere perception of others.²²⁵ This stigma factor is amplified by several of the procedural factors discussed below.

Procedural Factors

Native Americans' perception that they are burdened by the requirement to enroll in public insurance programs is magnified by the confusing and difficult enrollment process.²²⁶ Very few Native Americans understand the Medicaid, Medicare, and SCHIP eligibility requirements; in fact, many IHS employees are equally confounded.²²⁷ One frequent misunderstanding involves Native Americans being asked for co-payments for programs such as SCHIP, when they are specifically exempt from the co-payment requirement.²²⁸ Any cost-sharing requirement impedes enrollment in public programs.²²⁹

Inconsistent guidance from the Centers for Medicare & Medicaid Services (CMS) compounds the problem. Policy is frequently promulgated by telephone from CMS headquarters, because CMS regulations on Native American health care are incomplete.²³⁰ The answer to a specific question, and consequently policy at the local level, may depend on who answers the telephone.²³¹

In other situations problems arise in the presence of very specific regulations and policies. One problem stems from the association of the 100 percent Federal Medical Assistance Percentage (FMAP) with the IHS facility, rather than the individual. In general terms, FMAP is the statutory percentage of Medicaid funds paid by the states but reimbursed by the federal government.²³² Under the current arrangement, full federal reimbursement for state expenditures is dependent on performance of services in an approved IHS facility. Contracted health care, long-term care, and home care do not qualify for the 100 percent FMAP.²³³ Essentially, the states

²²⁴ Ibid.

²²⁵ Ibid.

²²⁶ Dupree interview.

²²⁷ Ibid.

²²⁸ See Dupree Statement, Briefing Transcript, p. 212, and Dupree interview.

²²⁹ Dupree Statement, Briefing Transcript, p. 212

²³⁰ Dupree interview.

²³¹ Ibid. Fox interview.

²³² U.S. Department of Health and Human Services, Office of Health Policy, "Federal Medical Assistance Percentages," <<http://aspe.os.dhhs.gov/health/fmap.htm>> (last accessed Dec. 18, 2003).

²³³ Indian Health Service, "Speaking with One Voice IHS, Tribes, Urban," Draft Report on the Indian Health Service Regional I/T/U Consultation Meeting held February 1, 2, 1999, in Reno, Nevada, <www.ihs.gov/AdminMngrResources/reauthor/files/ihs-5ren.doc> (last accessed July 14, 2003) (hereafter cited as IHS, "Speaking with One Voice"). See Christian Richardson, "Federal Decision on Indian Health Care Reversed," *Aberdeen American News*, Oct. 4, 2003, p. A4. This may be expanding to include coverage of contracted services. On September 30, 2003, a federal judge in South Dakota (in an unpublished decision) ruled that the Centers for Medicare & Medicaid Services must reimburse the South Dakota Department of Social Services 100 percent of the costs of medical services provided under the CHS program for "essential" treatment. Ibid. See also Dupree Statement, Briefing Transcript, p. 211.

must contribute a portion if services are provided outside an IHS facility. Consequently, states are disinclined to provide assistance in enrolling Native Americans in public programs when increasing enrollment results in fewer services from the conventional tax base. By extending the 100 percent FMAP to all facilities, the disincentive is removed and states will be more likely to encourage Native American enrollment in public programs. One manifestation of this issue was addressed during the briefing. Because tribal nursing homes are not eligible for 100 percent FMAP, the state is less inclined to certify them.²³⁴ Uncertified facilities are ineligible for Medicare, making them unprofitable, particularly on or near reservations.²³⁵ Other procedural barriers include the coverage available under Medicare Part B and various technical issues associated with those eligible for Medicaid and Medicare, also referred to as “dual eligibles.”²³⁶

The shift to managed care in the past decade has also brought change to reimbursement from third parties. As the individual states have required citizens to work within a managed care system to receive Medicaid benefits they have chosen different methods for dealing with Native Americans, whose facilities frequently do not meet managed care requirements. Exemptions to mandatory enrollment come in the form of opt-in or opt-out programs, among other voluntary and mandatory programs.²³⁷ The response of Native Americans has not been uniform, as some tribes have sought further exemptions, while others are seeking ways to increase facility participation in the managed care provider networks.²³⁸

In addition to the system and facility requirements, individual eligibility requirements can also impose barriers. In the context of Medicare, the requirement for 40 quarters of Social Security-covered employment excludes many elderly applicants who would otherwise qualify for Medicare. With high unemployment rates on reservations and the disproportionately high number of persons failing to meet the 40-quarter requirement, tribes have sought a Native American exemption.²³⁹ Such an exemption would markedly increase Medicare eligibility. Furthermore, confusion and insufficient information about the availability of Medicaid to purchase Medicare Part B coverage have excluded an additional undefined number of elderly Native Americans.²⁴⁰

Collection Factors

Whether a Native American patient has health insurance is irrelevant to his or her eligibility to receive IHS health care. The existence of health insurance only affects the ability of IHS to seek reimbursement. To the extent that IHS is reimbursed for the care it provides, every dollar gained is one additional dollar available for health care for Native Americans. For many

²³⁴ Dupree Statement, Briefing Transcript, p. 224.

²³⁵ Ibid.

²³⁶ Ibid., pp. 213–14.

²³⁷ Centers for Medicare & Medicaid Services, “American Indian and Alaska Native Beneficiaries: Current Issues and News: June 22, 2000 Centers for Medicare & Medicaid Services Consultation Issues,” <www.cms.hhs.gov/aian/summiss.asp> (last accessed July 14, 2003) (hereafter cited as Centers for Medicare & Medicaid Services, “Current Issues”).

²³⁸ Ibid.

²³⁹ Ibid.

²⁴⁰ Dupree interview.

reasons, IHS collection from third parties has increased dramatically in the past 10 years.²⁴¹ This remarkable improvement in collections was achieved with a programmatic effort including “higher negotiated Medicare and Medicaid rates, new authority to bill under CHIP [Child Health Insurance Program] and more efficient business management practices, involving patient eligibility determination, documentation of services and processing of claims.”²⁴² Despite this significant improvement, barriers to full reimbursement remain.

One noteworthy barrier to full collection is a lack of data.²⁴³ As noted earlier, enrollment and eligibility data for public insurance programs are inaccurate and incomplete. With accurate data on eligibility and enrollment, IHS, CMS, and the tribes themselves would be able to redirect resources to where the need is greatest.

A second barrier is erected by the Medicaid reimbursement mechanism. For IHS facilities, reimbursement is calculated using an “all-inclusive rate” per encounter.²⁴⁴ This all-inclusive rate is a coarsely developed average, which may vary significantly from actual costs. This variance is problematic on its own, but the definition of “encounter” can magnify the problem. Depending on the nature of the encounter and the specific variance, the reimbursement amount may be significantly more or less than the amount anticipated or due.²⁴⁵

Many of the remaining barriers to increased collection overlap with barriers to enrollment. In attempting to simplify collection efforts, the resulting mechanism may reduce the amount collected.²⁴⁶ The lack of training that leads to a failure to enroll those eligible also leads to billing errors and inefficiencies.²⁴⁷ An administrator who does not know and is unable to determine which services are billable will inevitably neglect to bill for all covered procedures.²⁴⁸ Additionally, collecting improper or incomplete documents leads to a denial of benefits and necessarily fewer collections.²⁴⁹ During the briefing, Dorothy Dupree of the Centers for Medicare & Medicaid Services identified additional barriers, including high turnover in billing staff, high submission of incomplete claims or improper billing, failure to submit claims, little to no follow-up on pending claims, and difficulty in getting the right people through training workshops.²⁵⁰

²⁴¹ Indian Health Service, “Indian Health Service FY 2004 Performance Plan, FY 2003 Revised Final Performance Plan and FY 2002 Performance Report,” Sept. 13, 2002, p. 13, <www.ihs.gov/AdminMngrResources/Budget/downloads/FY_2004/GPRA%20Perf-Plan%20Report.doc> (last accessed July 14, 2003).

²⁴² *Ibid.*

²⁴³ Jeanotte Statement, Briefing Transcript, p. 199. The use of the all-inclusive rate, described below, also leads to data problems. One reason to use the all-inclusive rate is the minimal data-keeping requirement. *See* Dupree Statement, Briefing Transcript, pp. 211–14.

²⁴⁴ For a partial explanation of the all-inclusive rate calculation, *see* Jeanotte Statement, Briefing Transcript, p. 201, and Dupree Statement, Briefing Transcript, p. 214.

²⁴⁵ Centers for Medicare & Medicaid Services, “Current Issues.” *See also* IHS, “Speaking with One Voice,” and Dupree Statement, Briefing Transcript, pp. 215–16.

²⁴⁶ Dupree interview.

²⁴⁷ *Ibid.*

²⁴⁸ *Ibid.*

²⁴⁹ *Ibid.*

²⁵⁰ Dupree Statement, Briefing Transcript, p. 213.

Any barrier to enrollment, regardless of the reason, is necessarily a barrier to collection. Taken collectively, these barriers to collection affect an already overburdened IHS budget and magnify the inadequacy of current funding levels.

3. Insufficient Federal Funding

Inadequate federal funding has been consistently identified as a significant obstacle to providing adequate health care and eliminating disparities in health status for Native Americans. The need for additional funding is well supported, as advocates for Native American health care have developed a variety of measurements to verify the inadequacy of present funding levels. The following arguments have been made when requesting additional funding:

- Annual increases in IHS funding have failed to account for medical inflation rates and increases in population.
- Annual increases in IHS funding are less than those for other HHS components.
- Annual increases have effectively been reduced to reflect increased collection efforts despite express congressional intent that they not be reduced.
- Annual per capita expenditures rise to only 60 percent of the federal benchmark level for health care expenditures.
- Annual per capita expenditures fall below the level for every other federal medical program and standard.

Below are an overview of these individual measurements and specific identifiable needs, an explanation of what can be done with increased funding, and a look at the ramifications of not immediately providing appropriate funds.

As the primary health care provider for Native Americans, IHS receives the vast majority of funds appropriated for that purpose. For FY 2004, the President's budget request included \$2.9 billion for IHS, just 4.5 percent of a \$64 billion HHS discretionary budget and an even smaller 0.5 percent of the overall HHS budget of \$538 billion.²⁵¹ While other HHS components and programs do provide limited health-related services for Native Americans, their Native American expenditures are equal to 0.5 percent of IHS spending on Native Americans, less than \$20 million.²⁵²

Another HHS program, the Centers for Medicare & Medicaid Services (CMS), contributes significantly to the support of Native American health services, though indirectly, as all funding is distributed to IHS via individual state Medicaid and Medicare programs. The President's FY 2004 budget request estimated Medicaid and Medicare expenditures of \$439

²⁵¹ Indian Health Service, "President's Fiscal Year 2004 Budget Request Proposes 2.6 Percent Increase for Indian Health Service," press release, Feb. 3, 2003, <www.ihs.gov/PublicInfo/PublicAffairs/PressReleases/Press_Release_2003/Release_04_IHS_2004_Budget_Request.asp> (last accessed July 14, 2003) (hereafter cited as IHS, "President's Fiscal Year 2004 Budget Request"). See also U.S. Commission on Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, 2003, Tables 2 and 3 of Chapter 3 (citing the Budget of the United States Government, Fiscal Year 2004, Historical Tables, Table 5.4, pp. 103–04).

²⁵² See U.S. Commission on Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, 2003, Tables 2 and 3 of Chapter 3 (citing the Budget of the United States Government, Fiscal Year 2004, Historical Tables, Table 5.4, pp. 103–04).

billion.²⁵³ IHS estimated public third-party collections of \$517 million, or 0.1 percent of the combined annual Medicaid and Medicare budget.²⁵⁴ Because of the distribution mechanism used, CMS funds spent on Native Americans are seen as IHS collections or reimbursements, rather than budgeted appropriations. When IHS budget appropriations are combined with collections from CMS and private, third-party insurers, the total composes the program-level funding for IHS and provides a better picture of the overall federal government spending on Native American health care. For FY 2004, the President's budget estimates reimbursement in excess of \$560 million, for a total IHS program-level funding of almost \$3.6 billion.²⁵⁵

The overall IHS budget has grown at a rate slightly below the rate of inflation over the past several years. The \$2.9 billion budgeted for FY 2004 appropriations represents an increase of 2.6 percent from FY 2003,²⁵⁶ an amount far below that needed to maintain the current level of services.²⁵⁷ With only this limited increase, the actual spending power will decline due to the high specific medical inflation rate, the moderate health services and facilities inflation rates, and significant population growth in the Native American community.²⁵⁸ The Northwest Portland Area Indian Health Board estimates that \$360 million, a full 12.4 percent increase, would be needed simply to cover current services and mandatory costs.²⁵⁹

Comparing the current rate of increase with other HHS programs, IHS also falls short. The 2.6 percent increase for FY 2004 compares to a 5.5 percent increase for Medicaid and a 10.9 percent increase for Medicare.²⁶⁰ Over a longer period IHS fares no differently; it has the smallest rate of increase within HHS over the past five years.²⁶¹ When the annual IHS budget figures are adjusted for inflation it becomes apparent that the per capita spending power for IHS appropriations, in 1996 dollars, is roughly the same today as it was in 1991; IHS appropriations dropped from a high of \$1,439 in 1991 to a low of \$1,197 in 1998.²⁶²

Only enhanced collection efforts have made up the difference and prevented a continuous decline from 1991 until today, despite the intent that collections supplement rather than replace

²⁵³ HHS, "FY 2004 Budget in Brief."

²⁵⁴ IHS, "President's Fiscal Year 2004 Budget Request."

²⁵⁵ Ibid. This figure does not include reimbursement to tribal programs, as no nationwide data are collected. See Jeanotte Statement, Briefing Transcript, p. 201.

²⁵⁶ IHS, "President's Fiscal Year 2004 Budget Request."

²⁵⁷ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 2.

²⁵⁸ For FY 2004, the Northwest Portland Area Indian Health Board estimates the medical inflation rate for CHS at 12.5 percent, the health services inflation rate at 7.5 percent, the facilities inflation rate at 4.0 percent, and the population growth at 2.1 percent of the health services account. See Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 13. See also *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service).

²⁵⁹ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," pp. 9, 15. Mandatory costs include \$19.6 million for federal pay increases, \$16 million for tribal pay increases, and \$25.5 million to fund staffing and operating costs for new facilities. See also *The President's FY 2004 Budget for Indian Programs Before: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service).

²⁶⁰ HHS, "FY 2004 Budget in Brief."

²⁶¹ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 39.

²⁶² Indian Health Service, "Ten Year Funding Trends," <www.ihs.gov/nonmedicalprograms/ihtd2/Oldindex.asp> (last accessed July 3, 2003).

annual appropriations.²⁶³ IHS has raising collections as one of its long-term goals, and collections from alternate programs have risen considerably in the past decade. IHS officials estimate that collections could be increased by 25 percent; however, the current IHS infrastructure may not support an immediate 25 percent increase in services.²⁶⁴

From the CMS perspective, it is impossible to determine precisely current CMS expenditures with current data collection systems.²⁶⁵ Two factors contribute to problems tracking expenditures: tribal health programs are not required to report collection information to IHS, and collection figures for CMS services provided outside IHS facilities are dependent on self-reporting by patients. For reasons already discussed, many Native Americans are reluctant to report their status.

Even with a verified and complete third-party collection effort, it is unlikely that current program-level funding for Native American health care would be adequate. This adequacy was central to recent hearings before the Senate Committee on Indian Affairs. On February 26, 2003, and March 5, 2003, the committee conducted hearings on the President's FY 2004 budget request for Indian programs. Hearing participants addressed a wide array of Native American programs, including the Indian Health Service. Dr. Charles W. Grim, director of the Indian Health Service, described an increasing budget, demonstrative of government commitment to high-quality health care for Native Americans.²⁶⁶ In contrast, advocates described marginal budget increases woefully inadequate for bridging the divide between current funding and that necessary for Native Americans to receive the same medical care as other Americans.²⁶⁷

²⁶³ See 25 U.S.C. § 1641(a) (1994).

Determination of appropriations. Any payments received by a hospital or skilled nursing facility of the Service (whether operated by the Service or by an Indian tribe or tribal organization pursuant to a contract under the Indian Self-Determination Act (25 U.S.C. §§ 450f *et seq.*)) for services provided to Indians eligible for benefits under title XVIII of the Social Security Act (42 U.S.C. §§ 1395 *et seq.*) shall not be considered in determining appropriations for health care and services to Indians.

Id.

²⁶⁴ IHS executive staff, interview, July 21, 2003. IHS executive staff members who were present at this interview included Michel Lincoln, deputy director, Office of the Director; Duane Jeanotte, director of headquarters operations, Office of the Director; Robert McSwain, director, Office of Management Support; Gary Hartz, acting director, Office of Public Health; Paula K. Williams, director, Office of Tribal Self-Governance; Craig Vanderwagen, M.D., acting chief medical officer, Office of the Director; Michael Mahsetky, director of legislative affairs, Office of the Director; Lovell Hopper, director, Division of Financial Management, Office of Management Support; Cliff Wiggins, senior operations research analyst, Office of the Director; Jon Perez, Ph.D., director, Division of Behavioral Health, Office of Clinical and Preventive Services, Office of Public Health; Ron Demaray, division director, Self-Determination, Office of Tribal Programs, Office of the Director; and Kitty Marx, senior policy analyst/legislative affairs, Division of Regulatory & Legal Affairs, Office of Management.

²⁶⁵ Dupree interview.

²⁶⁶ See generally *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service).

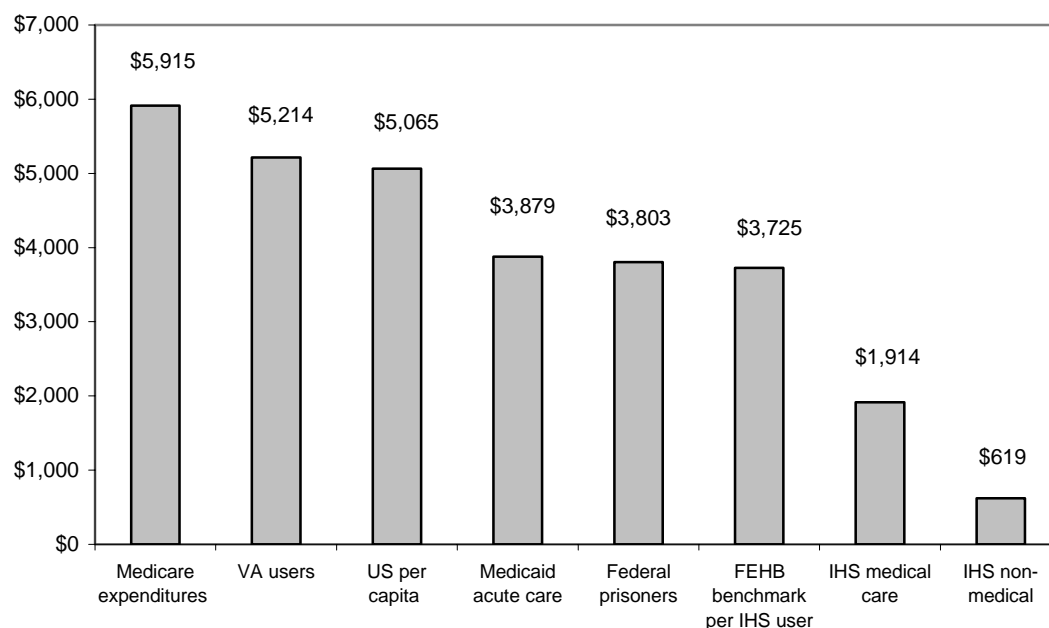
²⁶⁷ See generally *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statements of Tex Hall, president, National Congress of American Indians; Julia Davis-Wheeler, chair, National Indian Health Board; and Kay Culbertson, executive director, Denver Indian Health and Family Services).

Additionally, those testifying described an IHS budget shortfall of \$18 billion, money needed to extend IHS services to all Native Americans.²⁶⁸

Continued underfunding of IHS reflects the importance of the Native American program relative to all other federal medical programs. HHS estimates the annual per capita health care spending for the general population at \$5,065. In contrast, IHS spends \$1,914 per eligible user, or 38 percent of that spent by the general population.²⁶⁹

Figure 2 demonstrates that IHS expenditures are significantly less than every other federal benchmark and illustrates the inadequacy of federal funding for Native American health care.

Figure 2: Per Capita Health Care Expenditures



Source: U.S. Department of Health and Human Services, Indian Health Service, Office of Management Support, Division of Financial Management, "IHS Appropriations Per Capita Compared to Other Federal Health Expenditure Benchmarks," March 2003.

In addition to the funding disparities, specific funding deficiencies in the FY 2004 budget exist. The FY 2004 budget request includes \$493 million for Contract Health Services (CHS), a 5 percent increase over FY 2003. This represents a shortfall of more than \$500 million, and is

²⁶⁸ *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statements of Tex Hall, president, National Congress of American Indians, p. 7, and Julia Davis-Wheeler, chair, National Indian Health Board, p. 5). This number includes \$9–10 billion in annual expenditures and \$9 billion one-time facilities construction expenses. See also Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 2.

²⁶⁹ Indian Health Service, Office of Management Support, Division of Financial Management, "IHS Appropriations Per Capita Compared to Other Federal Health Expenditure Benchmarks," March 2003.

well below that necessary to even maintain the current level of services.²⁷⁰ Among all IHS programs, CHS is the most vulnerable to inflationary pressures.²⁷¹ It is estimated that between FY 1992 and FY 2003, CHS lost more than \$250 million to inflation alone.²⁷² At current deteriorating levels, only treatment for life-threatening conditions can be funded, particularly toward the end of the fiscal year. Failure to increase funding for CHS will lead to continued delays in delivering necessary, though not life-threatening, medical services. The budget request also includes no increase in contract support costs for the administrative infrastructure necessary for the tribal programs to function properly.²⁷³ An additional \$150 million would be necessary to enable scheduled expansion of these tribal programs.²⁷⁴ Urban health care has current unmet needs of more than \$1.5 billion. Nevertheless, advocates for urban health care request only an additional \$6 million for two compelling reasons.²⁷⁵ First, and perhaps most importantly, the current political and fiscal climate is unlikely to support substantial increases in funding. Second, the current IHS structure, including facilities and employees, cannot accommodate immediate full funding.²⁷⁶ Any attempt to fully fund urban Indian health care would require extensive structural change and sustained, gradual increases in funding.²⁷⁷

Tribal leaders and health care advocates have noted that more funding is needed to expand and improve health care for Native Americans. Tribal leaders have calculated the gains that they would realize for incremental changes in funding. For every \$100 million in purchasing power, IHS, tribal, and urban health programs could provide:

- 365,000 outpatient visits
- 13,000 inpatient days
- 115,000 dental services
- 10,000 mental health contacts
- 28,000 alcohol treatment visits
- 23,000 Contract Health Services outpatient visits

²⁷⁰ *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003), p. 6 (statement of Julia Davis-Wheeler, chair, National Indian Health Board).

²⁷¹ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 22.

²⁷² *Ibid.*

²⁷³ *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003), pp. 6–7 (statement of Julia Davis-Wheeler, chair, National Indian Health Board).

²⁷⁴ *Ibid.*

²⁷⁵ *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003), p. 9 (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services).

²⁷⁶ *Ibid.* See also Duane Jeanotte, director of headquarters operations, Indian Health Service, interview, July 21, 2003.

²⁷⁷ *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003), p. 9 (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services); ITU Budget Workgroup, "FY 2003 Needs Based Budget Presentation," p. 18, <www.npaihb.org/index.html> (last accessed Aug. 19, 2003).

- 16,000 public health nursing visits
- 29,000 health education services²⁷⁸

With a \$100 million increase in appropriated funding, an increase of approximately 3.1 percent, the Native American health care system could offer substantially more services. However, an increase in funding may well not be realized anytime soon. During the Commission's briefing, Myra Munson, an attorney and advocate for Native American health care issues, noted that "the ultimate policy document is always the budget document."²⁷⁹ With limited funds, IHS and other agencies are challenged to find creative ways to halt declining acceptability, availability, affordability, and accessibility of health services for Native Americans. Health care issues for Native Americans, however, are not only about IHS underfunding. In the words of Ms. Munson, they are also about "education underfunding, about housing underfunding, about roads underfunding, about justice underfunding, about the conditions in which Indian people live. If you take away all the things that allow people to be responsible for themselves and have a sense of hope, to have an opportunity, then health will suffer as well."²⁸⁰

4. Quality of Care Issues

Several factors, in addition to funding, affect a facility's ability to provide quality health services. Other factors include the ability to recruit and retain qualified health providers, accreditation status, the age of the facility's physical structures, and its capacity to deliver health care services in a culturally appropriate manner.

Ability to Recruit and Retain Health Providers

The ability to recruit and retain competent health care providers is one indicator of the quality of care at a health facility. In some cases, poor quality creates high turnover. Not surprisingly, highly trained medical personnel get frustrated at the inability to provide care at the level they were trained to provide. Additionally, overworked staffs quickly develop burnout.²⁸¹ In other situations, high turnover results in a poor quality of service. High turnover leaves gaps where facilities are undermanned and disrupts continuity of care. Historically, IHS has experienced shortages in doctors, dentists, pharmacists, and nurses.²⁸² IHS director Dr. Charles Grim stated that vacancy rates range anywhere from 8 to 23 percent.²⁸³ In 2001, his staff reported that the physician vacancy rate for IHS facilities was 10 percent, and the average length of service for IHS physicians was 8.1 years.²⁸⁴ Consequently, Dr. Grim stated the agency must hire

²⁷⁸ Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis."

²⁷⁹ Munson Statement, Briefing Transcript, p. 214.

²⁸⁰ *Ibid.*, p. 250.

²⁸¹ Open Session before the U.S. Commission on Civil Rights, Gallup Medical Facility, Gallup, NM, Oct. 16, 2003. Remarks of Dr. Jana Gunnell, New Mexico Department of Public Health.

²⁸² Restructuring Initiative Workgroup, *Transitions 2002*.

²⁸³ Grim Statement, Briefing Transcript, p. 61.

²⁸⁴ Indian Health Service, "Workforce," *Issue Summary*, February 2001, <<http://info.ihs.gov/infrastructure/infrastructure4.pdf>> (last accessed Sept. 25, 2003) (hereafter cited as IHS, "Workforce"). More recent figures list

almost 1,200 doctors to fill 900 vacant physician positions each year.²⁸⁵ IHS has had difficulty achieving this goal in some locations, which it primarily attributes to the remoteness of some sites.²⁸⁶ The vacancy rate for other health care professionals at IHS facilities also causes concern. For example, in 2001, IHS experienced a vacancy rate of 22 percent for dentists and 14 percent for optometrists.²⁸⁷ IHS also recognized that it is experiencing a shortage of registered nurses in inpatient and ambulatory care facilities, as well as pharmacists.²⁸⁸ On a local level, conditions can be even worse. The director of the Division of Health for the Navajo Nation reported nursing vacancy rates exceeding 25 percent.²⁸⁹

As an example of the impact of the lack of sufficient medical staff on the quality of care, Gregg Bourland and Harold Frazier, former chairman and vice chairman, respectively, of the Cheyenne River Sioux tribe in South Dakota, described the following situation at an IHS facility:

In January and February 2002, the Eagle Butte Service Unit [in South Dakota] on the Cheyenne River Sioux reservation has been swamped with children with Influenza A, RSV [Respiratory Syntactical Virus], and one fatal case of meningitis. There are only three doctors on duty, one Physician Assistant, and one Nurse Practitioner. The only pediatrician is the Clinical Director who will not see any patients, even though there is a serious need for the services of a pediatrician. Several of these children have presented with breathing problems, high fever, and severe vomiting. The average waiting time at the clinic has been [between] four and six hours. The average time at the emergency room is similar. Most babies have been sent home without any testing to determine what they have and with nothing but cough syrup and Tylenol. In at least three cases, the baby was sent home after these long waits two or more times with cough syrup, only to be life-flighted soon thereafter because the child could not breathe. The children were all diagnosed by the non-IHS hospital with RSV. . . . No babies have died yet, but the Tribe sees no justification for waiting until this happens when these viruses are completely diagnosable and treatable.²⁹⁰

Improvements in recruiting, training, and compensation are needed to reduce staff shortages. IHS has instituted a student loan repayment program to attract and retain Native American health professionals.²⁹¹ As a result of the program, the number of Native American federally employed health professionals has increased 195 percent and the proportion of the

average physician longevity at nine years. These numbers compare to an average of two to two and a half years in the 70s. *See also* Olson Statement, Briefing Transcript, p. 126.

²⁸⁵ Dr. Charles W. Grim, director, Indian Health Service, interview, July 21, 2003.

²⁸⁶ IHS, "Workforce."

²⁸⁷ *Ibid.*

²⁸⁸ *Ibid.*

²⁸⁹ Roanhorse Statement, Briefing Transcript, p. 143.

²⁹⁰ 149 CONG. REC. S. 4109, 4147 (daily ed. Mar. 20, 2003) (statement of Sen. Daschle). As part of his statement, Senator Daschle referred to a letter from the Cheyenne River Sioux tribe to IHS describing the situation at the Eagle Butte Service Unit. *See also id.* at 4147. Senator Daschle noted the following quality of care issues at the Eagle Butte Service Unit: The facility does not have an obstetrician; it is funded at 44 percent of the need calculated by the IHS; and although Eagle Rock has a birthing room and 22 obstetrical beds, only two to three doctors are available to staff the clinic, hospital, and emergency room. *Id.*

²⁹¹ IHS, "Workforce."

Native American professional staff has increased 104 percent since 1981.²⁹² Typically, many recipients of IHS scholarships work in tribal facilities and Urban Indian Health Programs. Despite these signs of improvement, a need for qualified medical and nursing staff remains at a number of IHS facilities, particularly those in remote locations.

Accreditation Status

As an important indicator of their ability to provide quality health services, health care facilities in the United States seek accreditation by nationally recognized organizations. All the large IHS facilities and some of the tribal health centers are accredited either by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) or by the Accreditation Association for Ambulatory Health Care.²⁹³

A certificate of accreditation from a recognized health care evaluating authority serves several functions. Most importantly, it instills public confidence in the quality of the services, satisfies safety standards and state licensure requirements, and supports recruitment and retention efforts.²⁹⁴ Accordingly, accreditation from JCAHO fulfills these requirements.²⁹⁵ Moreover, the Centers for Medicare & Medicaid Services (CMS) grants JCAHO “deeming” authority to consider each health care organization it accredits as meeting Medicare and Medicaid reimbursement certification requirements.²⁹⁶ As a result, JCAHO-accredited health care organizations are not subject to the CMS survey and certification process. Accreditation for Medicaid and Medicare reimbursement eligibility through this method is voluntary and seeking “deemed” status through accreditation is optional.²⁹⁷

Although other health care accrediting associations exist, JCAHO is considered the primary accrediting body responsible for establishing national health care standards on patient safety and quality of health issues and evaluating various types of health facilities for their

²⁹² Ibid.

²⁹³ Olson Statement, Briefing Transcript, pp. 129–30.

²⁹⁴ See Joint Commission on Accreditation of Healthcare Organizations, “How to Become Accredited,” <www.jcaho.org/htba/index.htm> (last accessed Sept. 25, 2003).

²⁹⁵ Joint Commission on Accreditation of Healthcare Organizations, “Facts About the Joint Commission on Accreditation of Healthcare Organizations,” *About Us*, <www.jcaho.org/about+us/jcaho/jcaho_facts.htm> (last accessed Sept. 5, 2003) (hereafter cited as JCAHO, “About Us”).

²⁹⁶ Joint Commission on Accreditation of Healthcare Organizations, “Federal Deemed Status and State Recognition,” <www.jcaho.org/about+us/government+relations/fed_st_rec.htm> (last accessed Sept. 25, 2003) (hereafter cited as JCAHO, “Federal Deemed Status and State Recognition”). In order for a health care organization to participate in and receive payment from Medicare or Medicaid programs, it must be certified as complying with the Conditions of Participation, or standards, set forth in federal regulations. This certification is based on a survey conducted by a state agency on behalf of the Centers for Medicare & Medicaid Services (CMS). However, if a national accrediting organization, such as the Joint Commission on Accreditation of Healthcare Organizations, has and enforces standards that meet the federal Conditions of Participation, CMS may grant the accrediting organization “deeming” authority and deem each accredited health care organization as meeting Medicare and Medicaid certification requirements. Ibid. See also Munson interview (stating that tribal facilities are now seeking JCAHO accreditation, in order to become eligible for funds from Medicaid and Medicare reimbursement).

²⁹⁷ JCAHO, “Federal Deemed Status and State Recognition.”

compliance with those standards.²⁹⁸ Since 1951, JCAHO has provided accreditation services for a variety of health care organizations, including hospitals (general, psychiatric, pediatric, rehabilitation, and critical care facilities), health care networks, assisted living facilities, ambulatory care centers, home care organizations, nursing homes, behavioral health facilities (including those that offer mental health and addiction services), and clinical laboratories.²⁹⁹

In 2002, JCAHO conducted accreditation surveys of 35 to 40 IHS facilities and found the overall quality of care in IHS facilities to be adequate. The survey included IHS ambulatory care and behavioral health facilities, laboratories, and critical access hospitals in Arizona, California, Minnesota, Oklahoma, North and South Dakota, and Utah.³⁰⁰ On a scale from 1 to 100 (with 100 considered full compliance), the scores for IHS facilities ranked from 97 to 100, compared with scores of 80s and 90s for comparable non-IHS facilities.³⁰¹ As an example, comparable non-IHS facilities scored worse in complying with the JCAHO standard “Assessing Competence,” which requires facilities to assess each staff member’s ability to meet the performance expectations stated in his or her job description. Here, 25.1 percent of non-IHS facilities did not satisfy this standard, as compared with a 14.29 percent noncompliance score in IHS facilities.³⁰²

Despite these rankings, JCAHO also identified standard problem areas for IHS facilities.³⁰³ A few examples include:

- “Environment of Care” (safety) Standard—14.29 percent of IHS facilities were not in compliance with hospital smoking policies, compared with a 2.7 percent noncompliance rate in comparable non-IHS facilities.
- “Initial Assessment” Standard—28.57 percent of IHS facilities did not assess patients’ functional status when warranted by their needs or conditions, compared with a 3.8 percent noncompliance rate for non-IHS facilities for this standard.
- “Anesthesia Care” Standard—14.29 percent of IHS facilities did not comply with the requirement to follow medical staff criteria for discharging patients from post-sedation or post-anesthesia recovery areas or provide a qualified licensed independent contractor to approve the discharge, compared with a 0.8 percent noncompliance rate for non-IHS facilities.

²⁹⁸ Mowll Statement, Briefing Transcript, p. 132; JCAHO, “About Us”; Charles A. Mowll, FACHE, executive vice president of business development, Government and External Relations, Joint Commission on Accreditation of Healthcare Organizations, interview, July 3, 2003.

²⁹⁹ Mowll Statement, Briefing Transcript, pp. 132–33; Joint Commission on Accreditation of Healthcare Organizations, *2002 Hospital Accreditation Standards* (Oakbrook Terrace: Joint Commission Resources, 2002), p. 13 (hereafter cited as JCAHO, *2002 Hospital Accreditation Standards*). See also *ibid.*, pp. 12–13 (JCAHO uses standards from several accreditation manuals associated with these areas).

³⁰⁰ See Mowll Statement, Briefing Transcript, p. 142; Mowll interview (These are smaller facilities that have referral agreements with larger hospitals. Critical access hospitals provide ancillary and support services to stabilize patients for a limited time before patients are transferred to a tertiary care facility for additional care).

³⁰¹ See Mowll Statement, Briefing Transcript, p. 142; Mowll interview (A few IHS facilities had survey scores that were considered as outliers on this scale. For example, a hospital in Oklahoma scored an 82, which indicated that the facility had more standards that were out of compliance than others).

³⁰² Joint Commission on Accreditation of Healthcare Organizations, “Indian Health Service Hospital Program—Top Standard Problem Areas, 1/1/2002 to 12/31/2002” (run date), June 19, 2003 (data provided in aggregate form).

³⁰³ *Ibid.*

- “Medication Use” Standard—14.29 percent of IHS facilities did not consistently have emergency medications available, controlled, and secured in the pharmacy and patient care areas, compared with a 2.8 percent noncompliance rate in comparable non-IHS facilities.³⁰⁴

Although these documented problem areas did not lower JCAHO’s overall rating of the IHS facilities, they affect the quality of care provided to Native Americans. The accreditation procedure that assesses the quality of a health facility must include all factors that affect quality. Panelists at the Commission briefing indicated that despite the JCAHO accreditation, the quality of health care provided by IHS does not always meet the standard of care acceptable to the Native American patients.³⁰⁵ As Dr. Richard Olson, director of Office of Clinical and Preventive Services at IHS noted, cultural competence is one measure of quality that JCAHO surveys do not evaluate. They also do not assess some of the major problems IHS is facing with high vacancy rates, aging and remote facilities, and rationing of services.

Importance of “Culturally Competent” Health Services

Ensuring that health care facilities satisfy national accrediting standards, recruiting and retaining qualified health care providers, updating and improving physical plants, reducing medical malpractice lawsuits, and eliminating the rationing of health services are essential ingredients in the delivery of quality health services. However, if health services are not offered to the targeted patient population in a culturally and linguistically appropriate manner, patient treatment will still be ineffective in eliminating racial and ethnic health care disparities.³⁰⁶

Public health authorities view providing culturally and linguistically appropriate treatment as “culturally competent” treatment. Cultural competence is defined as:

the demonstrated awareness and integration of three population-specific issues: health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy. . . . [P]erhaps the most significant aspect of this concept is the inclusion of and integration of the three areas that are usually considered separately when they are considered at all.³⁰⁷

The importance of culturally competent health services to the overall quality of health care is generally acknowledged.³⁰⁸ Dr. Grim noted that cultural and language barriers contribute to health disparities and limit access to health care.³⁰⁹ He added that IHS is working to make its programs more culturally relevant.³¹⁰ Authorities realize the necessity of offering health care that

³⁰⁴ Ibid.

³⁰⁵ See generally Jack Statement, Briefing Transcript, p. 24; Kathy Janis Statement, Briefing Transcript, pp. 293–94; Dan Jaco Statement, Briefing Transcript, pp. 301–04; Margaret E. Garcia Statement, Briefing Transcript, p. 306.

³⁰⁶ See generally Institute of Medicine, *Unequal Treatment*.

³⁰⁷ The Henry J. Kaiser Family Foundation, “Compendium of Cultural Competence Initiatives in Health Care,” January 2003, p. 6, <www.kff.org/content/2003/6067/6067v6.pdf> (last accessed Sept. 17, 2003).

³⁰⁸ See, e.g., Olson Statement, Briefing Transcript, p. 128.

³⁰⁹ Grim Statement, Briefing Transcript, p. 62.

³¹⁰ Ibid., pp. 62, 65.

recognizes the patient's values, beliefs, and traditions, in order to provide quality services for specific populations.³¹¹ According to the Department of Health and Human Services:

Health care providers typically presume they are color blind in their delivery of services. Few providers have thought about the biases they bring to patient encounters or about their own cultural/ethnic backgrounds, health beliefs, and health practices. These biases often result in both the system and its providers attempting to get the patient to conform to the mainstream instead of meeting a patient on her or his own cultural ground. Yet patient attitudes about health, religious views, and concepts of death often influence compliance, affect disease management, and alter health outcomes.³¹²

The Office of Minority Health in the Department of Health and Human Services published final national standards on culturally and linguistically appropriate services (CLAS) in health care in December 2000.³¹³ The CLAS standards are intended to address inequities in the provision of health services and to ensure that these services are more responsive to the needs of all patients and consumers.³¹⁴ The standards are specifically designed to address the concerns of racial, ethnic, and linguistic population groups that experience unequal access to health services, to eventually eliminate racial and ethnic health disparities, and to improve the health of all Americans.³¹⁵

The CLAS standards provide 14 principles and related activities to ensure culturally and linguistically appropriate services are integrated throughout a health care organization, in

³¹¹ U.S. Department of Health and Human Services, Public Health Reports, "Culturally Competent Health Care," *Public Health Report 2000*, by Jean Lau Chin, Ed.D., vol. 115, January–February 2000 (hereafter cited as HHS, *Public Health Report 2000*). See also Johnson interview. Dr. Emory Johnson, former director of the Indian Health Service, discussed what happens when cultural competency is not considered. He provided the following examples of the need to understand patients collectively, as a community or tribe, in order to build relationships and create acceptance:

Native Americans from a given tribe were opposed to the installation of sanitation lines. They had been living in homes, where every few years it was necessary to move the "privy." When offered permanent piping into their homes, their assumption was that they would need to build a new home when the "privy" at the end of the pipe was full. They had no intention of accepting a system that forced them to build a new home every few years. Consequently, it was necessary to understand the local sensibilities and educate them, first to understand and then to accept the sanitation program.

As further evidence, Dr. Johnson mentioned a Cornell University study, where a high-tech medical facility was placed in an impoverished rural setting. The study found that the high-tech program resulted in little improvement in health status, which was eventually attributed to a lack of understanding and acceptance in the rural community. Johnson interview.

See also "MPH Student Blends Native American and Modern Medicine to Address Health Disparities," *Harvard Public Health Now*, May 31, 2002, <www.hsph.harvard.edu/now/may31/student.html> (last accessed July 15, 2003); J. Patterson, "Meeting the Needs of Native American Families and Their Children with Chronic Conditions," *Families, Systems & Health*, vol. 15, no. 3, 1997, pp. 237–41. See generally USCCR, *Health Care Challenge*, pp. 44–45.

³¹² HHS, *Public Health Report 2000*.

³¹³ National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care, Notice, 65 Fed. Reg. 80,865 (Dec. 22, 2000).

³¹⁴ *Id.* at 80,873.

³¹⁵ *Id.*

partnership with the communities served by the facility.³¹⁶ The standards are organized into three categories: culturally competent care, language access services, and organizational support for cultural competence. The standards are required for all recipients of federal funds, recommended for adoption as requirements by federal, state, and national accrediting agencies, and suggested for voluntary adoption by health care organizations.³¹⁷

If culturally and linguistically appropriate health services are desirable to Native Americans based on their unique cultures and the unique relationship with the federal government, distinctive approaches to health care should also be included in the delivery of health services to this population. Many Native Americans continue to employ traditional medicines and practices either as their sole form of health care or as a component of their overall health care.³¹⁸ Accordingly, in March 2002, the Association of American Indian Physicians unanimously approved a resolution supporting Native American traditional healing and medicines as part of the spectrum of health care appropriate for Native Americans.³¹⁹ As part of this resolution, the association intends to work with traditional healers for the benefit of Native patients and community health.

In a study designed to identify what urban Indian family caregivers should inform health providers who work with Native American children with chronic health conditions about Indian culture, the caregivers concluded that providers should be aware of the role and importance of extended family members in a child's overall care, any traditional health beliefs and healing practices, and any cultural communication patterns.³²⁰ Specifically, health facilities should avoid excluding extended family members who might visit a child, since they also assist in serving as primary caregivers to Native American children.³²¹ Some Native American families may resist Western treatment recommendations and may want to use herbal remedies, healing ceremonies, and traditional healers as a primary or supplemental form of treatment.³²² Furthermore, the study indicated that health providers should be aware of the significance of nonverbal communication for some Native American patients, such as indirect eye contact and silence.³²³ These nonverbal signs often indicate respect for the "healer," which may cause some patients to refrain from asking questions or requesting health care services.³²⁴ Cultural competence, therefore, acknowledges the patient's perspective and inevitably improves the quality and delivery of care. Reaching that level of competence requires insight, extensive training, and a programmatic commitment to cultural sensitivity.

³¹⁶ *Id.*

³¹⁷ *Id.*

³¹⁸ Joe, "The Rationing of Healthcare," p. 537.

³¹⁹ Association of American Indian Physicians, "Resolution," Mar. 13, 2002, <www.aaip.com/about/AAIP_trad_med_resol_02.html> (last accessed July 15, 2003).

³²⁰ Ann Garwick and Sally Auger, "What Do Providers Need to Know About American Indian Culture? Recommendations from Urban Indian Family Caregivers," *Families, Systems & Health*, vol. 18, no. 2, 2000, p. 177. The study included a small sample of 30 Native American families from three tribes: 27 Ojibwe, two Lakota, and one Dakota in a large Midwestern city. The authors note that the results of this study may not be the same for families of other urban Indian tribes.

³²¹ *Ibid.*

³²² *Ibid.*

³²³ *Ibid.*

³²⁴ *Ibid.*

To explore whether IHS facilities were delivering culturally competent health services, a focus group of Native Americans was formed in Albuquerque, New Mexico, and revealed that participants were generally satisfied with IHS providers' awareness of Native American culture.³²⁵ However, despite that IHS provides training for non-IHS providers at contracted facilities,³²⁶ focus group participants cited biased behavior and cultural insensitivity toward the importance of traditional medicine by private sector health care providers.³²⁷ Findings from this focus group suggest that when IHS refers Native American patients to contracted health providers, these providers should be extensively apprised of and trained on the cultural and linguistic needs of all patients who seek their health services.³²⁸

Problem of Aging Facilities

IHS also faces the challenge of dealing with aging facilities. The average age of current IHS facilities is 32 years, compared with nine years for private sector facilities,³²⁹ indicating that a massive modernization program is urgently needed.³³⁰ New and properly designed facilities are needed to provide efficient space to deliver services.³³¹ Some older IHS facilities, however, tend to be "inefficient and haphazard in their arrangement of space," causing crowded waiting rooms, low productivity rates by providers, and ultimately patient dissatisfaction.³³² In addition, the oldest facilities may not comply with Occupational Safety and Health Administration or Americans with Disabilities Act standards.³³³ Unfortunately, because of financial constraints, IHS has been unable to renovate its older facilities. An IHS survey in November 2002 estimated a backlog of \$506 million in needed facilities repairs alone.³³⁴

³²⁵ Joe, "The Rationing of Healthcare," p. 538.

³²⁶ Grim Statement, Briefing Transcript, p. 66.

³²⁷ Joe, "The Rationing of Healthcare," p. 538.

IHS facilities and its leadership in many communities have always allowed patients and their families either time or a place (in a clinical setting) to consult with tribal healers or practitioners. The services provided by most of these tribal healers or practitioners are seen as complementing modern medicine and provide a source of spiritual help for many patients.

Ibid.

³²⁸ See, e.g., Anslem Roanhorse, Jr., division director, Navajo Division of Health, interview, Sept. 24, 2003 (For contracted services, Navajo-speaking staff are on call to provide translation services, if needed, on a 24-hour basis. Orientation and training about the Navajo culture are done for contracted providers).

³²⁹ See Indian Health Service, "Strategic Plan: Improving the Health of American Indian and Alaska Native People Through Collaboration and Innovation," p. 5, and Perez Statement, Briefing Transcript, p. 16.

³³⁰ Restructuring Initiative Workgroup, *Transitions 2002*.

³³¹ Indian Health Service, Office of Public Health, Division of Facilities and Environmental Engineering Health Care Facilities Engineering, *Millennium Report and Accomplishments Since 1954*, January 2000, p. 32.

³³² Ibid.

³³³ Roanhorse interview.

³³⁴ Results from Backlog of Essential Maintenance and Repair (Survey) as reported in Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 30.

5. Disproportionate Poverty and Poor Education

Not every disparity in health status for Native Americans can be attributed to care provided by a health care system. It is widely recognized that poverty and education can each contribute to the health disparities Native Americans experience.³³⁵ This fact is not lost on the tribes. During the Commission's briefing, Lyle Jack, a tribal representative, criticized current funding distribution formulas for failing to consider the role of poverty on Native American health status.³³⁶ The reasons for the causal connection, while seemingly common sense, are not well documented. Scholars, however, generally recognize that income relates to health status because it increases access to care, provides access to better housing with fewer environmental hazards, and generally increases the opportunities to engage in healthy lifestyles.³³⁷ Similarly, education relates to health in that it increases exposure to health-related information, equips individuals with the skills necessary to apply health-promoting behavior, and is typically associated with higher incomes.³³⁸

Unfortunately, Native Americans, like other people of color, are often poor and have lower levels of educational attainment. This section first details the link between socioeconomic status and health status; then follows with the link between educational attainment and health status. Because Native Americans have the highest poverty rate of any ethnic group and their educational attainment levels are significantly lower than the national average,³³⁹ it becomes apparent that their health status is compromised by these factors. On individual reservations, poverty levels are often significantly worse. Anslem Roanhorse, director of the Division of Health for the Navajo Nation, testified to the dire economic conditions the Navajo people face. Fifty-six percent live below the poverty level and 43 percent are unemployed. Additionally, more than 50 percent of homes rely on wood burning for heating, 32 percent lack adequate plumbing, and 60 percent lack telephone service.³⁴⁰

³³⁵ USCCR, *The Health Care Challenge*, p. 17. See also *Health Disparities: Bridging the Gap: Hearing Before the Subcomm. on Public Health of Senate Comm. on Health, Education, Labor and Pensions*, 106th Cong. (2000) (testimony of Ruth L. Kirchstein, acting director, National Institutes of Health); and E. Pamuk, D. Makuc, K. Heck, C. Reuben, and K. Lochner, *Socioeconomic Status and Health Chartbook. Health, United States 1998*, p. 25 (Hyattsville, MD: National Center for Health Statistics, 1998) (hereafter cited as Pamuk et al., *Socioeconomic Status and Health Chartbook*).

³³⁶ Jack Statement, Briefing Transcript, p. 24.

³³⁷ Pamuk et al., *Socioeconomic Status and Health Chartbook*, p. 29.

³³⁸ *Ibid.*, p. 30.

³³⁹ Native Americans have a poverty rate of 25.9 percent, compared with the national poverty rate of 11.3 percent. Among the other ethnic groups, the rates are 22.1 percent, 7.5 percent, 10.8 percent, and 21.2 percent, respectively, for blacks, white/non-Hispanics, Asians and Pacific Islanders, and Hispanics. See U.S. Census Bureau, Public Information Office, "Nation's Household Income Stable in 2000, Poverty Rate Virtually Equals Record Low," *Census Bureau Reports*, Sept. 25, 2001, CB01-158.

In 1990, 65.5 percent of Native Americans 25 and older had graduated from high school, compared with 75.2 percent for the total population. Furthermore, 9.3 percent of Native Americans 25 and older hold a bachelor's degree, compared with 20.3 percent of the total population. See National Center for Education Statistics, "American Indians and Alaska Natives in Post-Secondary Education," October 1998, p. 1-14. Other statistics demonstrate that Native Americans are twice as likely to drop out of high school as the national average. See U.S. Department of Education, Indian Nations at Risk Task Force, "Plans for Dropout Prevention and Special School Support Services for American Indian and Alaska Native Students," 1992.

³⁴⁰ Roanhorse Statement, Briefing Transcript, p. 139.

An array of figures are used to establish poverty level or socioeconomic status. Income level is most frequently used, but unemployment rates, enrollment rates for public benefits, and asset holdings can also illustrate relative ability to pay for health services. Regardless of which basis is used, statistics consistently support the proportional relationship between health and socioeconomic status. More specifically, Americans living near or below the poverty level suffer from worse health than their wealthier counterparts and at age 45 have a life expectancy three to seven years shorter than those with higher incomes.³⁴¹ While 27 to 37 percent of men living below the poverty line report being in fair or poor health, only 4 to 5 percent of high-income men report this. The results for women are similar.³⁴²

Mortality rates illustrate similar results. Low-income women are three times more likely to die from diabetes than their high-income counterparts, and the gradient is only slightly less steep for men.³⁴³ In addition, heart disease mortality rates for the poorest women are 3.4 times those for women with the highest incomes. Similarly, men earning less than \$10,000 are 2.5 times more likely to die from heart disease than men earning \$25,000 or more.³⁴⁴

One possible explanation for the higher mortality rate is that risk factors known to contribute to the identified health conditions are more prevalent among poor adults. For example, 31 percent of poor women suffer from hypertension, a risk factor for heart disease and stroke, compared with 19 percent of high-income women. Notably, hypertension in low-income women is almost twice as likely to be unmonitored and thus uncontrolled.³⁴⁵ Furthermore, poor men and women are about twice as likely to smoke as their high-income counterparts.³⁴⁶

Inadequate access to medical care is another factor contributing to poor health for those living in poverty. Men and women living below the poverty line are almost five times more likely to have an unmet need for health care than adults with high family income.³⁴⁷ Furthermore, poor women are three times as likely as high-income women to have gone without seeing a doctor in the past year; poor men are twice as likely as high-income men.³⁴⁸ This could account for the fact that rates of avoidable hospitalizations are 2.4 times higher for those living below the poverty level and for the fact that 33 percent of those living below the poverty level have some activity limitation due to injury or chronic condition, compared with 11 percent of those living in the middle- and high-income brackets.³⁴⁹

As alluded to earlier, income and education are closely linked. On a national level, accounting for all workers in 1999, high school graduates earned \$25,900 and college graduates earned \$45,400, while high school dropouts earned an average of \$18,900.³⁵⁰ Furthermore, high

³⁴¹ Pamuk et al., *Socioeconomic Status and Health Chartbook*, p. 88.

³⁴² *Ibid.*, p. 29.

³⁴³ *Ibid.*

³⁴⁴ *Ibid.*

³⁴⁵ *Ibid.*

³⁴⁶ *Ibid.*

³⁴⁷ *Ibid.*

³⁴⁸ *Ibid.*

³⁴⁹ *Ibid.*

³⁵⁰ U.S. Census Bureau, "The Big Payoff: Educational Attainment and Synthetic Estimates of Work-Life Earnings," July 2002, <<http://landview.census.gov/prod/2002pubs/p23-210.pdf>> (last accessed July 17, 2003).

school dropouts account for 12.9 percent of the working poor, more than double the rate of workers with a high school diploma.³⁵¹ For many, dire financial situations make finding employment, rather than seeking an education, a priority.

Conversely, wealthier, more educated people are more likely to have better access to medical care and safer home and work environments.³⁵² In addition, they may have more opportunities to engage in healthy activities and lifestyles, more awareness of health issues, and more time to pursue healthy behaviors.³⁵³ It stands to reason that there is also an emotional cost associated with being poor and uneducated that may lead to worse health or poor health practices.

Lack of education, considered alone, has historically been a very strong indicator of poor health. Among all racial and ethnic groups, men with less than 12 years of education are 2.5 times more likely to die from a chronic disease than men with more than 12 years of education.³⁵⁴ The ratio for women is 2.1, and similar rates are passed from generation to generation.³⁵⁵ Infant mortality rates almost double for infants whose mothers have less than a high school education.³⁵⁶

Death due to injuries and suicide is also more prevalent among less educated individuals. For example, the least educated men are over three times more likely to die of injuries than the most educated men, and the least educated women are more than twice as likely to die of injuries than their well-educated counterparts.³⁵⁷ Likewise, suicide rates are higher for those with less education, up to 3.7 times higher, depending on race and gender.³⁵⁸

Adults with less education are also more likely to exhibit risk factors known to contribute to chronic health problems and have more difficulties gaining access to medical care. For example, mothers with more education are 40 percent more likely to have received early prenatal care than mothers with less than 12 years of education.³⁵⁹ Less educated mothers are almost 10 times as likely to smoke during pregnancy as more educated mothers.³⁶⁰ Furthermore, heavy alcohol use, which can lead to cirrhosis, increased accident rates, and fetal alcohol syndrome, among other health problems, is 30 percent higher among adults with less than a high school education than it is among college graduates.³⁶¹

While health disparities between the educated and uneducated exist among all racial and ethnic groups, the disproportionate lack of educational attainment among Native Americans obviously results in more health disparities for that population. As explained above, the pattern

³⁵¹ U.S. Department of Labor, Bureau of Labor Statistics, "Profile of the Working Poor, 2000," March 2002, <www.bls.gov/cps/cpswp2000.htm> (last accessed July 17, 2003).

³⁵² Pamuk et al., *Socioeconomic Status and Health Chartbook*, p. 29.

³⁵³ *Ibid.*, pp. 29–30.

³⁵⁴ *Ibid.*, p. 90.

³⁵⁵ *Ibid.*

³⁵⁶ *Ibid.*, p. 52.

³⁵⁷ *Ibid.*, p. 29.

³⁵⁸ *Ibid.*, p. 100.

³⁵⁹ *Ibid.*, p. 46.

³⁶⁰ *Ibid.*

³⁶¹ *Ibid.*

holds true for disproportionate poverty levels in the Native American communities. Without a doubt, increasing the general educational level of Native Americans and raising their general standard of living will result in improved health status.

Consequently, any effort to improve the health status of Native Americans must necessarily address the high poverty rates and the disparate lack of education that afflict Native American communities, in addition to the access, funding, and quality of care issues described earlier. A significant portion of that effort involves the appropriations process, discussed in part earlier. A perhaps more achievable portion of that effort involves discrete statutory improvements as proposed in the Indian Health Care Improvement Act discussed in the following section.

REAUTHORIZATION OF THE INDIAN HEALTH CARE IMPROVEMENT ACT

Among the pending changes identified thus far, including the Medicare Prescription Drug, Improvement, and Modernization Act of 2003, the reauthorization of the Indian Health Care Improvement Act appears to hold the most promise.³⁶² The changes it proposes are expected to aid IHS and tribal leaders in making significant improvements to the health care provided to Native Americans.

The most recent version of the Indian Health Care Improvement Act (IHCIA) was passed in 1992 and authorized through FY 2000; Congress extended it through FY 2001. Anticipating the expiration of the IHCIA, IHS initiated regional consultation meetings with tribal leaders in 1998 to solicit input on changes to the act when the bill is introduced for reauthorization.³⁶³ The tribes formed a National Steering Committee (NSC) of tribal leaders to draft a comprehensive proposal to address concerns and unmet needs.³⁶⁴ The NSC sought to update the IHCIA to make it more responsive to current real-world needs, to increase opportunities for attracting more revenue into the health system, and to facilitate greater exercise of self-determination in health care program decision-making and regulations.³⁶⁵

In October 1999, NSC delivered a proposal to revise the existing law to the President and Congress.³⁶⁶ Reauthorization legislation was introduced during the 106th and 107th sessions of Congress that substantially reflected the NSC proposal; however, the bill never reached the floor of either the House or the Senate. Subsequently, in September 2002, the Bush administration

³⁶² According to Dr. Charles W. Grim, director, Indian Health Service, several items in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 will be particularly important to Native Americans, including a provision to increase rural ambulance reimbursement rates; a provision to compensate IHS for providing emergency assistance to undocumented aliens; a provision to require Medicare hospitals to accept Medicare rates as payment in full from IHS users; an expansion of Medicare part B services in IHS facilities; and changes to Critical Access Hospital reimbursement rates. *See* Indian Health Service, "IHS Director Grim Congratulates Bipartisan Passage of Medicare Bill; 'Bill Benefits All Americans and Has Specific Benefits for Indian Country,' Director Says," press release, Dec. 9, 2003, p. 1.

³⁶³ Indian Health Service, "Overview of Consultation Process," <http://www.ihs.gov/AdminMngrResources/reauthor/Our_Initiative.cfm> (last accessed Dec. 19, 2003).

³⁶⁴ *Ibid.*

³⁶⁵ Carol Barbero, Esq., partner, Hobbs, Straus, Dean & Walker, interview, Aug. 11, 2003; Munson interview.

³⁶⁶ The structure of the IHCIA has been retained in the various reauthorization bills introduced to Congress with new and revised language inserted in all eight titles.

voiced reservations about the costs associated with several sections of the bill.³⁶⁷ To address these budgetary concerns, NSC and Congress began negotiations to revise the draft bill. During these negotiations, in March 2003, Senator Ben Nighthorse Campbell reintroduced the bill as Senate bill 556.³⁶⁸ This bill is identical to earlier bills but does not include any revisions made pursuant to the NSC negotiations. The Senate Indian Affairs Committee conducted hearings in early 2003 to consider the bill.

In June 2003, Representative Don Young introduced reauthorization bill H.R. 2440, which includes revisions made by NSC to address the administration's earlier cost concerns.³⁶⁹ There are now numerous differences between the House and Senate bills.

There is no single change in the reauthorization of the IHCIA that will close the health status gap for Native Americans. Instead, the bills attempt to address the problems contributing to the gap, more specifically, access to appropriate health facilities, access to health insurance, inadequate federal funding, quality of care, and poverty and education. They accomplish this task through a series of procedural changes to the established system. Additionally, the reauthorization bills reflect changes in the landscape of Native American health care programs and the fundamental shift in the delivery of health care to Native Americans. Specifically, the bills recognize that many tribes have assumed responsibility for administering their own health programs under contracts and compacts.³⁷⁰ While tribes rely on government funding, the reliance is to varying degrees. Many tribes have found it necessary to access tribal money, charitable grants, and other funding sources. The reauthorization bills will allow for more flexible funding options.

Recognizing that tribes and tribal organizations now operate over half of IHS programs, there are six principal objectives of reauthorization. The first of these are health promotion objectives. The reauthorization will affirm the principle that the health status objectives for Native Americans must be the same as for all other Americans.³⁷¹ Previously, the only objective was to generally improve the health status of Native Americans.

The second objective of reauthorization is to ensure a continuum of care by providing a full range of health programs instead of relying on demonstration projects that isolate ideas in individual programs.³⁷² A flexible continuum allows the individual IHS, tribal, and urban Indian programs to use their own initiative in creating solutions that respond specifically to local needs.

Third, the reauthorization updates the act to focus on programs instead of facilities, responding to the evolution of health services from an inpatient model with lengthy hospital

³⁶⁷ In March 2001, the Congressional Budget Office (CBO) "scored" or estimated the federal budget impact of the mandatory spending parts of the Senate bill, S. 212. CBO estimated these would cost \$6.9 billion over 10 years. Munson interview.

³⁶⁸ Indian Health Care Improvement Act Reauthorization of 2003, S. 556, 108th Cong. (1st Sess. 2003).

³⁶⁹ Indian Health Care Improvement Act Amendments of 2003, H.R. 2440, 108th Cong. (1st Sess. 2003).

³⁷⁰ Today, tribes administer more than half of IHS funding through self-determination contracts or self-governance compacts. There are 265 tribes and tribal organizations that have contracts, and another 56 compacts representing 279 tribes.

³⁷¹ National Indian Health Board, "Reasons to Support the Reauthorization of the Indian Health Care Improvement Act H.R. 2440 and S. 556," <http://www.nihb.org/docs/ihcia_reasons_to_support.pdf> (last accessed Dec. 19, 2003) (hereafter cited as National Indian Health Board, "Reasons to Support the Indian Health Care Improvement Act").

³⁷² *Ibid.*

stays to a more ambulatory care model, where the physical location of services is less prominent.³⁷³ Frequently, third-party funding is not recovered because services do not fall within the specified categories of covered services, derived from inpatient care models.

Fourth, the reauthorization permits more flexible funding alternatives and interagency partnerships to address maintenance and construction delays.³⁷⁴ This is particularly true for new homes being built by the Department of Housing and Urban Development. For example, IHS and HUD would be allowed to enter into an interagency agreement to provide financial assistance for sanitation facilities and services.³⁷⁵

The fifth objective addresses behavioral health by authorizing the integration of mental health, substance abuse, and violence-prevention programs into a comprehensive behavioral health program. Combining programs will result in greater efficiency and a higher quality of care.³⁷⁶ Specifically, IHS, tribal, and urban Indian programs would be allowed to develop comprehensive behavioral health prevention and treatment programs that emphasize collaboration among alcohol, substance abuse, social services, and mental health programs.³⁷⁷ The development of tribal and local initiatives, instead of requiring the development of a single national plan, is encouraged.

Finally, the sixth objective is to maximize recovery from Medicare and Medicaid through, among other means, amending the Social Security Act.³⁷⁸

Viewed in its entirety, IHICIA reauthorization would be a dramatic step forward in the effort to erase current disparities. If passed, the IHICIA would enable significant improvement in the health care provided to Native Americans.

SUMMARY

As discussed throughout the briefing, many factors contribute to health care disparities among Native Americans. The examination of the structure and operation of the Native American health care delivery programs revealed that the location of health care facilities and the administrative framework of the delivery programs affect access to health care services for many Native Americans. The review of quality of services indicated that while IHS facilities have received adequate ratings in accreditation surveys, IHS faces significant problems with the retention and recruiting of qualified health care providers, and the maintenance of aging facilities. Furthermore, severely inadequate funding of IHS creates the majority of the access and quality issues. While not all access and quality issues may be resolved with additional funding, raising IHS funding levels to be comparable with mainstream health care organizations would eliminate many of the basic problems, while providing access to quality health care for Native Americans.

³⁷³ Ibid.

³⁷⁴ Ibid.

³⁷⁵ Indian Health Care Improvement Act Amendments of 2003, H.R. 2440, 108th Cong. § 302 (2003).

³⁷⁶ National Indian Health Board, "Reasons to Support the Indian Health Care Improvement Act."

³⁷⁷ Indian Health Care Improvement Act Amendments of 2003, H.R. 2440, 108th Cong. § 703 (2003).

³⁷⁸ National Indian Health Board, "Reasons to Support the Indian Health Care Improvement Act."

In addition, raising the health status of Native Americans to the level of the rest of the nation requires modification of the Indian Health Care Improvement Act of 1976. These modifications must reflect the current health status of the Indian population. But more importantly, they must recognize that health care for Native Americans is more than simply medical treatment; it involves a holistic approach, including lifestyle and behavioral considerations, education, housing, economic opportunity, as well as empowerment through self-determination and self-governance. The several objectives of the reauthorization listed above hold the promise for an approach that is more holistic.

In sum, the briefing revealed that it is through ongoing legislative efforts, a dramatic increase in funding, consulting with and involving Native Americans in health care decision-making, and developing creative ways to provide services in the absence of considerable funding increases will significant strides be made in erasing today's health care disparities experienced by Native Americans.