



AN
AMERICAN
DEBT UNPAID

Stories of native health

HEALTH RIGHTS ORGANIZING PROJECT

Edited by Julie Chinitz & Danisha Christian

Northwest Federations of Community Organizations

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NORTHWEST FEDERATION OF COMMUNITY ORGANIZATIONS
2009



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EXECUTIVE SUMMARY

When Native people arrive at the doctor's office, they come bearing the effects of discrimination and dispossession, which take a physical and mental toll. As a result, Native people in the United States bear an excess burden of disease, dying younger and often living sicker than members of other groups.

Yet Native people* often cannot get quality health care when they need it, despite the responsibility of the United States government to provide for Native people's health care. The infrastructure serving Native health needs is chronically underfunded, out-of-date, and understaffed. Native people have extremely high rates of uninsurance, and when they do make it into the clinic or hospital they often receive substandard care and biased treatment.

This storybook shares the experiences of Native people struggling to get health care they need. The contributors provide personal accounts of their efforts to be treated with respect by practitioners, as well as their fight to improve the health and wellbeing of their communities.

The stories touch on the following experiences:

- Battling stereotypes and disrespectful, dismissive treatment
- Being turned away for care
- Struggling to find affordable care in one's community
- Receiving substandard care
- Searching for care that respects one's traditions and practices
- Protecting and reviving practices that promote cultural renewal and health

It will take changes in U.S. federal policy to remove the many obstacles to good care and allow Native people to reclaim a tradition of health. To move toward its obligation for Native health, the federal government should take steps that recognize the full range of barriers to health and health care that Native people experience. In taking such measures, the federal government must respect the sovereignty, self-determination, and consultation rights of Native people. Among these measures are the following:

- Ensure full funding for the Indian Health Service
- Support improvements in the availability and quality of comprehensive health care for Hawaiians
- Increase enrollment of Native people in public health programs
- Support improvements in the quality of care for Native people
- Develop a larger, more diverse, and culturally competent health care workforce
- Support culturally appropriate research and data collection that advances the health of Native people
- Safeguard the rights of Native people—and their relationships with the federal government—in and through health care reform
- Reinforce health care infrastructures
- Support efforts to develop healthy food systems and economies in Native nations and communities

***In this storybook, we use the term “Native people” to refer to American Indians, Alaska Natives, and Native Hawaiians. Unless otherwise noted, the terms “white” and “African American” refer to non-Hispanic whites and non-Hispanic African Americans, respectively.**

THE OFFICIAL INVISIBILITY OF NATIVE HAWAIIANS

A note on data and terminology

This publication uses the term “Native people” to refer to indigenous people from the continental United States, Alaska, and Hawaii. Wherever possible, the information cited applies to all Native people.

However, data for Hawaiians often are not available. Historically, Native Hawaiians and Pacific Islanders were included in the category of “Asian and Pacific Islanders” (API) by the U.S. government. As a result, data and reporting on Native Hawaiians and other Pacific Islanders have been hidden within “API” data.¹ Though the federal government has issued a directive to disaggregate Native Hawaiians and Pacific Islanders, this directive is not enforced. For more on this issue, see Maile Tauali‘i’s comments on **page 40**.

When data apply to American Indians and Alaska Natives but not to Hawaiians, we note this in the endnotes or in the text. We use the term “Hawaiian” to refer to the indigenous people of Hawaii.

INTRODUCTION

When Native people arrive at the doctor’s office, they come bearing the effects of discrimination and dispossession, which take a physical and mental toll. As a result, Native people in the United States bear an excess burden of disease, often dying younger and living sicker than members of other groups.

Yet, despite these tremendous health challenges, Native people often cannot get quality health care when they need it. They face barriers that range from lack of adequate health care facilities and funding to outright bias and deep mistrust of the medical system. It will take changes in U.S. federal policy to remove these obstacles to care and allow Native people to reclaim a tradition of health.

This storybook shares the experiences of Native people from Maine to Hawaii. It is divided into three parts. The first discusses the health status of Native people and the difficulties they have getting good, timely, and respectful care. The second part shares the stories and commentaries of Native people and other experts in Native health. The third part offers recommendations for the federal government, so it may support improvement of the health of Native people and move toward fulfilling its commitments, debts, and obligations to them.

THE STATE OF NATIVE HEALTH

*“They made us many promises, more than I can remember,
but they kept only one; they promised to take our land, and they did.”*

RED CLOUD | 1822 – 1909

HEALTH CARE & THE RELATIONSHIP BETWEEN NATIVE PEOPLE AND THE UNITED STATES GOVERNMENT

Native people have unique relationships to the U.S. government, and these relationships are relevant to any discussion of the health of Native people.

INDIAN PEOPLE

In exchange for Indian nations' land, the United States government entered into treaties, issued court decisions, and passed legislation acknowledging a set of obligations to Indian nations. Among those obligations is the protection of the nations' sovereignty, remaining territory, and wellbeing. A responsibility for health care arises from this obligation. The Indian Health Service (IHS), a federal agency, was created as part of this trust relationship.³

INDIGENOUS PEOPLE OF ALASKA

The U.S. did not enter into treaties with Alaska Natives after acquiring Alaska from Russia in the 1860's, instead proposing to settle Alaska Natives' land claims through legislation a century later. However, the U.S. government acknowledges the sovereignty of Alaska Natives (though, like Indian nations, Alaska Natives must resist encroachment upon that sovereignty).⁸ Additionally, the U.S. government has recognized that it retains obligations toward Alaska Natives and includes them in the Indian Health Service system.⁹

HAWAIIANS

Hawaiians, too, have a unique relationship to the United States. In 1893, following decades of western colonization, the U.S. government facilitated the overthrow of the Hawaiian government, annexing Hawaii through legislation, rather than by treaty, five years later.¹⁰

In 1993, the U.S. government acknowledged the illegality of the overthrow, as well as Hawaiians' continued claim of sovereignty and land rights, and issued an apology.¹¹ The U.S. government also created a mechanism to fund Hawaiian health care systems.¹²

DATA SHORTFALLS FOR AMERICAN INDIANS AND ALASKA NATIVES

Data also remains a problem for understanding the full extent of poor health and difficulties getting health care for American Indians and Alaska Natives.

Indian people and Alaska Natives frequently have been subject to incorrect racial classification in public health surveillance data. This can result in an undercount of the number affected by a particular health condition, leading to inadequate resources.²

THE FEDERAL RECOGNITION PROCESS AND "TERMINATION" OF NATIVE NATIONS

Through federal recognition, the United States and Indian nations establish government-to-government relations. Federal recognition includes acknowledgment of both the sovereignty of Native nations and the U.S. trust responsibility for matters such as health care.⁴

However, the federal recognition process is fraught with difficulties. It involves extremely strict standards that are often impossible to meet, and it can take decades to complete.⁵

Furthermore, in 1953 the federal government adopted a policy of unilaterally "terminating" its relationship with Native nations, motivated by a desire to end the trust relationship and force assimilation upon Native people.⁶

"Essentially, this was an abrogation of the Federal government's numerous commitments, in treaties, laws, and executive orders...to protect [the] interests [of indigenous people]," writes the National Council of Urban Indian Health. "The results of termination were devastating."⁷ Among the outcomes was the loss of health services, other support, and land, leading to the collapse of many nations.

NATIVE PEOPLE SUFFER FROM POORER HEALTH

Native people bear more than their share of disease. Compared to most other groups, they suffer elevated rates of infant mortality¹⁴ and premature death from a major disease.¹⁵ They have the highest rates of diabetes in the country—almost twice the national average.¹⁶ They suffer from adult asthma attacks most frequently of all groups.¹⁷ And they are the most likely to report themselves in fair or poor health.¹⁸

It's not only physical illness that burdens Native people disproportionately. They also face alarmingly high rates of substance abuse¹⁹ and mental illness, such as psychological distress and hopelessness.²⁰ Depression is a major killer of Native people.²¹ And depression and physical illnesses like cardiovascular disease interact with one another, creating a cycle of worsening mental and physical health.²²



SUICIDE AMONG NATIVE YOUTH

In February 2009, the U.S. Senate Committee on Indian Affairs held a hearing on the alarming youth suicide rate in Indian country.

At the hearing, sixteen-year-old Dana Jetty described the death of her sister, Jami.¹³ “On November 3, 2008 I lost my sister and my best friend,” Ms. Jetty testified. “Suicide has left me feeling lost, lonely, and angry.”

“My mom did all the right things. She took [Jami] to the doctor, she talked to counselors, and she even had her evaluated by mental health professionals from Indian Health Service,” Ms. Jetty explained. “Those mental health providers dismissed my mom’s concerns and diagnosed my sister as being a ‘typical teenager.’”

Ms. Jetty urged Congress to support suicide prevention programs for Native youth. “It is not enough to put a counselor in a community,” she said. “We need trained professionals who really know how to help our communities.”

NATIVE PEOPLE, STRUCTURAL RACISM, AND THE SOCIAL DETERMINANTS OF HEALTH

“I can’t tell you the number of highway accidents I’ve seen from overturned cars, because people didn’t have the money to change their tires. It’s just tragic. So many health problems arise from these kinds of socioeconomic conditions, from the lack of a safe place to live, from the lack of jobs that pay well, from living next to contaminated waste sites.”

Dr. John Fogarty
Santa Fe, New Mexico

MIXED AFFILIATION AND HEALTH CARE

Many Native people have a background of mixed tribal affiliations that may not provide them with the amount of blood quantum from one tribe necessary for enrollment. Lack of enrollment can render that person ineligible for the Indian Health Service. Others may be members of tribe recognized in Canada or a terminated nation, also rendering them ineligible IHS services. Given the alarmingly high uninsured rates among Native people, these men and women often wind up completely shut out of the health care system.

The health disparities affecting Native people can not be explained as the result of individual choices or factors. Rather, they reflect the structural racism that often results in “conditions that are inadequate for living a healthy, dignified life.”²³

Structural racism shapes the lives of Native people in a number of ways. Colonization radically altered Native communities, and federal policies into the modern era have been “aimed either at dismantling tribal governments and assimilating Native people or at paternalistically isolating tribes to misappropriate their assets.”²⁴ As a result, Native people contend with a lack of economic opportunity, scarcity of nutritious food, environmental degradation, stress resulting from racial stratification, historical trauma, and cultural loss, and other inequities.²⁵

Such factors compromise the physical and mental wellbeing of Native people throughout their lives. These “social determinants” explain why Native people often have poorer health even before they see the doctor.

Diabetes illustrates this dynamic. The disease is especially prevalent among Native people. Not only do Native people suffer more frequently from diabetes; they also develop the disease younger and are more likely to die from it.²⁶ However, this has not always been the case. Native people have become more susceptible to the disease due to historic and current inequities they face.

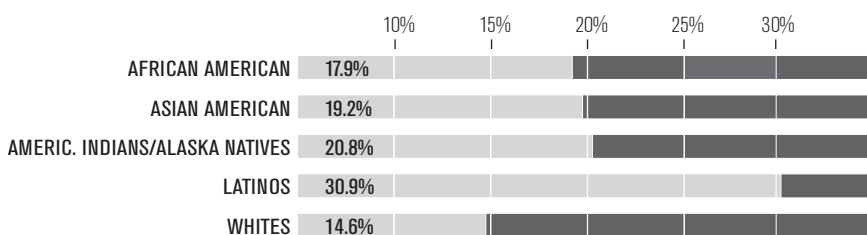
“There is a direct biochemical connection between living in poverty and the stress that people are under and blood sugar control,”²⁷ explains Dr. Donald Warne, Director of the Aberdeen Area Tribal Chairman’s Health Board. (Researchers also have linked poverty to other biological processes, such as inflammation, associated with higher risk of cardiovascular disease and other chronic conditions.²⁸) Therefore, loss of land, traditional economies, and indigenous food systems, which kept Native people healthy for generations, also leaves Native people vulnerable to conditions like diabetes.²⁹

These outcomes are not accidental. They resulted from federal policies such as relocation, urbanization, and forced boarding schooling policies that dispossessed Native people and intentionally disrupted Native practices.^{30, 31} Yet, though Native people carry an excess burden of disease as a result of such policies, they often must seek treatment from a health care system similarly characterized by racial inequity.

NATIVE PEOPLE GO WITHOUT NEEDED HEALTH CARE

Indian people and Alaska Natives do not receive all the health care they need. One fifth had no usual source of care in 2003-2004.³² They are the most likely of all reported groups to go without timely prenatal services.³³ And, from 1999 to 2003, they went without needed health care due to cost almost twice as frequently as did white people.³⁴

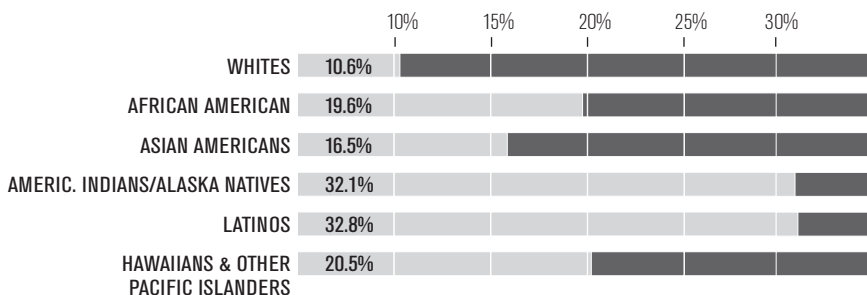
NO USUAL SOURCE OF HEALTH CARE: Adults 18-64 by Race, 2003-2004



Source: Kaiser Family Foundation, "Key Facts: Race, Ethnicity & Medical Care," January 2007. Figure 26, p. 22.

Little research or data is available on Hawaiians' access to the health care system, either in Hawaii or the continental U.S. Yet some data is available: Hawaiian women on O'ahu are less likely than others to see a doctor and more likely to have an emergency room visit.³⁵ They are less likely than white women to receive needed mental health or substance abuse treatment.³⁶ And Hawaiian women in Hawaii are more likely than others to go without early prenatal care.³⁷

UNINSURED RATES 2005-2007



Source: U.S. Census Bureau, "Income, Poverty, and Health Insurance Coverage in the United States: 2007," August 2008, Table 7, p. 23.

Though Native people have very high uninsured rates, this is not the only—or, in some cases, the primary—barrier to care for them.³⁸ A number of other obstacles exist, ranging from a poor or stressed health care infrastructure, to mistrust of the health care system, to lack of culturally competent care. The following sections address these obstacles.

"The doctors, nurses, and staff I've worked with in the Indian Health Service are some of the best and most dedicated anywhere, but they are working with so little. If the IHS were fully funded, I think it would be one of the best health care systems in the world. But after years of underfunding, the infrastructure is crumbling. We see the entire health care system collapsing beneath us.

Recently, the Santa Fe Indian Hospital, where I work, didn't have enough money to pay some of its contractors. As a result, we ran out of milk. We had sick children admitted to the hospital, and their parents had to go out and buy food for them. The hospital also has had trouble with the heating system, and we had elders with pneumonia bundling up under four or five blankets to stay warm. Our patients have been very kind and understanding – they know we're doing the best we can. But I think you have to ask, 'Is this supposed to be what health care in the United States of America looks like?'

Our patients often wait a minimum of three hours, but more typically five or six hours, to be seen. Many people just wind up leaving, even though there are few other options. One man – who was quite ill with undiagnosed hyperthyroidism – left the Santa Fe hospital to try the emergency room at the University of New Mexico in Albuquerque, where he waited thirteen hours and was never seen. He came back to Santa Fe the next day and waited four hours."

Dr. John Fogarty
Santa Fe, New Mexico

CHRONIC UNDERFUNDING OF THE INDIAN HEALTH SERVICE

The Indian Health Service delivers health care to Indian people and Alaska Natives in a number of ways. Services may be directly provided by the federal government in IHS facilities. Alternately, they may be delivered through tribally managed facilities, accounting for nearly half of IHS budget overall.³⁹ (Almost all IHS funding in Alaska is tribally managed.⁴⁰) Or, they may be provided by urban Indian health programs, which are private, non-profit Indian-run organizations that receive IHS funding.⁴¹ Finally, IHS patients may see outside clinics and doctors that contract with the IHS for certain services not available through IHS or tribal facilities, such as specialty or emergency care.⁴²

CONGRESS AND THE INDIAN HEALTH CARE IMPROVEMENT ACT

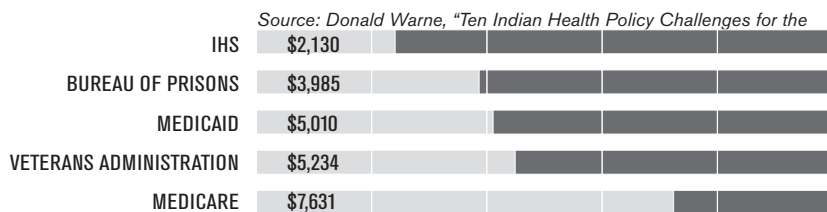
The Indian Health Care Improvement Act (IHCIA) was “originally enacted in 1976 to address the deplorable health conditions in Indian country.”⁵⁵ Along with other federal legislation, IHCIA provides the authority for delivery of health care services by IHS. However, the legislation has not been reauthorized since 1992,⁵⁶ and many provisions of IHCIA expired in 2001.⁵⁷

IHCIA reauthorization would provide mechanisms for updating infrastructure and care delivery systems, improving provider recruitment and retention, and increasing tribal decision-making.

The IHS is chronically underfunded. Unlike the budgets for Medicaid and Medicare, the IHS budget is discretionary, which “has produced a system that is insufficient and unreliable and is associated with ongoing health disparities.”⁴³ Spending for Indian health also grows at a smaller rate than for other programs, compounding the underfunding.⁴⁴

The federal government’s investment in IHS is “dramatically lower” than its investment in other public health programs.⁴⁵ The disparity is stark: in the 2005 federal budget, Medicare dedicated \$7,631 for each enrollee, compared to IHS’ \$2,130.⁴⁶ And, for nations that manage that their own health care, IHS has been failing to provide funding for all the costs associated with managing these health systems.⁴⁷

FUNDING DISPARITIES: per capita spending, 2005.



New Administration in 2009,” Wicazo SA Review, Spring 2009, p. 10.

HEALTH CARE CHALLENGES ON THE RESERVATION

As a result of IHS underfunding, patients often cannot get health care they need when they need it.⁴⁸ Not enough facilities exist, particularly in rural areas. Patients often must travel great distances and then wind up waiting hours and hours.⁴⁹ IHS facilities experience understaffing, high turnover of practitioners, and unfilled vacancies.⁵⁰ The average age of these facilities is forty years, and they “are often cramped and out of date.”⁵¹

Underfunding has also led to an explicit rationing of the services IHS contracts out to private clinics and hospitals. These contract health services are provided only to the extent of available funding, resulting in situations where patients have been denied even cancer treat-

ment.⁵² Furthermore, patients are eligible for contract services only if they live within their respective contract health services delivery areas,⁵³ creating often insurmountable eligibility barriers.

Despite these problems, IHS represents an existing infrastructure—much of it tribally managed—with experience in Native communities and positive impacts on Native people's health.⁵⁴

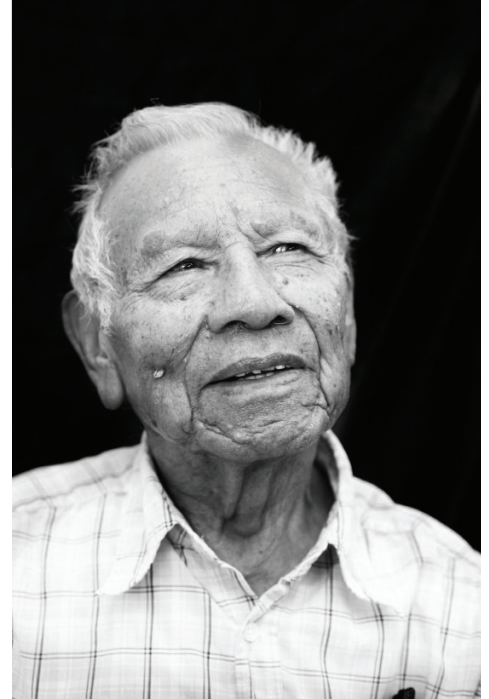
HEALTH CARE CHALLENGES AWAY FROM RESERVATIONS

The majority of Indian people and Alaska Natives do not live on reservations, as they once did. Today, 67 percent reside in or near cities.⁵⁸ This urbanization resulted from the 1950's policy of “terminating” Indian nations and relocation of Indian people to often faraway cities.⁵⁹ According to the Urban Indian Health Commission, “Today's urban Indians are mostly the products of failed federal government policies that facilitated the urbanization of Indians, and the lack of sufficient aid to assure success with this transition has placed them a greater health risk.”⁶⁰

American Indians and Alaska Natives are often shut out of the mainstream health care system. Thirty-two (32.1) percent are uninsured, compared to 10.6 percent of whites, making them more likely than any other racial group, except Latinos, to go without health coverage.⁶¹ And Indian people living away from reservations have reported being turned away by health care providers and told to receive services from the IHS.⁶²

Yet, most urban Indians do not receive IHS services.⁶³ Those who are members of federally recognized tribes may be IHS-eligible but live too far from reservations to receive care there.⁶⁴ Others belong to one of the 109 tribes “terminated” by the federal government in the 1950's, rendering them ineligible for IHS care.⁶⁵

As a result, Indian people living in urban areas often must turn to urban Indian health organizations (UIHOs) for their care. Proximity to UIHO clinics has been linked to decreased mortality from heart disease, the country's leading cause of death.⁶⁶ Yet these programs too are chronically underfunded, historically receiving only one percent of the Indian health budget. Consequently, UIHOs can serve only a fraction of the urban Indian population,⁶⁷ and, often, they cannot provide the full range of health care services their patients need—some can provide only outreach and referrals.⁶⁸



HAWAIIANS AND THE HEALTH CARE SYSTEM

Hawaiians are served by the Native Hawaiian Health Care Systems (NHHCS),⁶⁹ a statewide network of Native Hawaiian Health Centers that offer health promotion and disease prevention services, primary care, and assistance navigating the health care system. The NHHCS also provide traditional healing practices.⁷⁰

The NHHCS grew out of a 1987 federally funded health study that identified serious health disparities affecting Hawaiians. After the completion of this study, Hawaiians created Papa Ola Lokahi (POL), the Native Hawaiian Health Board, to address those challenges.

Community-led efforts also resulted in Congress' passage of the Native Hawaiian Health Care Improvement Act. This legislation provided funding to POL "to establish a Hawai'i statewide health infrastructure for enabling increased health care delivery for Native Hawaiians,"⁷¹ focusing on health promotion and disease prevention.

Five NHHCS now function in Hawaii. However, the legislation funding this infrastructure has not been reauthorized as required for its secure continuation.⁷² And, despite these advances, the federal investment in Hawaiian health still equals only an estimated \$28 per Hawaiian.⁷³

For the population as a whole, Hawaii's health care system is unique. All employers in the state are required to offer health insurance to employees that work at least twenty hours a week.⁷⁴ Hawaiians benefit from employer responsibility for insurance, but are more likely to be unemployed or underemployed than others in Hawaii, and therefore are more likely to fall through the cracks of the legislation.⁷⁵ Except for other Pacific Islanders, they have the highest uninsured rates in Hawaii (11%).⁷⁶

In addition to employer responsibility, Hawaii also has a relatively robust network of community health centers.⁷⁷ Yet demand for services at community health centers, which serve a majority-Hawaiian patient population, exceeds their capacity and resources, and the health centers do not have funds for expansion. The problem is particularly acute on neighbor islands.⁷⁸ These islands are home to a relatively higher population of Hawaiians⁷⁹ and have a lower-than-average ratio of primary care doctors, specialists, and surgical specialists to the population.⁸⁰

Hawaiians living away from Hawaii also face obstacles to health care. Approximately thirty-nine percent live in the continental United States.⁸¹ Nationwide, they have an uninsured rate of 20.5 percent⁸² and are more likely than the overall population to be poor,⁸³ suggesting that they run into financial barriers to health care.

NATIVE PEOPLE RECEIVE LOWER-QUALITY CARE*

Once they overcome numerous obstacles and enter the health care system, Native people receive lower quality care. Native Medicare patients with heart failure receive recommended hospital care significantly less frequently than do their white counterparts.⁸⁴ In nursing homes, they develop bed sores more often.⁸⁵ In hospice care, they often do not get adequate pain medication.⁸⁶ And they are less likely than almost all other groups to receive end-of-life care consistent with their wishes.⁸⁷

Not surprisingly, compared to whites, Native people are more likely to find their health care unsatisfactory. More than a quarter have reported poor communication with their doctor or other practitioner.⁸⁸ Moreover, the staffing problems at the Indian Health Service facilities lead to misdiagnosis, improper treatment, and inconsistent care.⁸⁹

*The statistics in this section apply to American Indians & Alaska Natives, but not to Hawaiians.

"The subjugation of a culture causes destruction not easily reversed. The result is an intense distrust of western ways, especially those not easily understandable, such as high-tech science and medicine. In the medical setting, that mistrust can be interpreted by Western caregivers as noncompliance.

Our Department of Native Hawaiian Health is analyzing how to improve compliance but also understand the causes—some would say the idea of compliance is western to begin with. Among Hawaiians, individual behaviors subjugate themselves to family loyalty and extended family. A lot of Hawaiians don't have to the same desire to live a long and potentially healthy life, not because they want short, unhealthy lives, but because that's not as important as commitment to family and community, and when we have finite energy, that's where the energy goes.

Almost forty percent of Hawaiians in Hawaii live on neighbor islands, where they're a disproportionately large segment of the population. On those islands, we have difficulty with primary care, but especially subspecialty care. When Hawaiians are diagnosed with cancer, if they have to fly to O'ahu three times a week for specialty care, they would have to pay \$750 each week. The patient frequently concludes, "If I have an illness that will drain my family funds that much, I'll go to a Hawaiian traditional practitioner instead—I'm not going to bankrupt my family for my care."

Dr. Kalani Brady

Dept. of Native Hawaiian Health,
John A. Burns School of Medicine,
University of Hawai'i at Manoa

BIAS AND DISCRIMINATION IN THE DOCTOR'S OFFICE

Many Native people continue to report instances of bias from health care practitioners, including overtly discriminatory and abusive treatment. In a study of Indian people in Missoula, Montana, forty-two percent of respondents said that a family member or friend “had been treated unfairly when seeking medical care specifically because of race.”⁹⁰

Finding bias and discrimination in IHS services, the U.S. Commission on Civil Rights related the example of a woman seeking pain treatment after a hysterectomy. The woman, according to the Commission, “informed her provider that she had two children. The doctor told [the woman] that she did not believe her because ‘no Indian woman only has two children’ and required her to undergo painful tests to confirm the hysterectomy.”⁹¹

In other cases, bias may be less visible but still compromise care. For instance, doctors and nurses have been found to “communicate lower expectations for patients of color and poor patients, including the expectation of medical resources and assistance [and] expectations of improvement in their medical condition.”⁹²

HEALTH CARE OFTEN IS DISCONNECTED FROM NATIVE CULTURAL PRACTICES, TRADITIONS, AND LANGUAGES

Culture and language are both important factors in health care. Native patients are not the only ones “with culture”: health care professionals and their patients alike have their respective cultural perspectives. For example, they may have different concepts of health and what it means to be healthy.⁹³ When treatments reflect the cultural framework of only the practitioner, they are less likely to be effective. For instance, patients may not follow through on treatments that do not make sense in their lives.⁹⁴

Native people often approach the health care system with a historic mistrust.⁹⁵ This mistrust is confirmed and compounded by encounters in which practitioners express disregard for, misunderstanding of, or bias against Native cultural practices, including traditional healing practices.⁹⁶

In 2004, the U.S. Commission on Civil Rights criticized the IHS for failing to require adequate cultural competence training among its providers, particularly contract providers.⁹⁷ As of 2004, IHS did not

“Hawaii has a mechanism in place to support research that’s performed in an ethical way in Hawaiian communities. There’s a Native Hawaiian Institutional Review Board. If researchers want to work with the Native Hawaiian Health Care Systems, they must have proposals reviewed by the IRB that focuses on Native Hawaiians. And our medical school has a Department of Native Hawaiian Health, which provides a Native Hawaiian focus, so everyone who goes through the medical school knows something about Native Hawaiian health. That’s another important mechanism.

When research comes from within communities or represents their interests, that’s very positive. Research shouldn’t be just for academic researchers; communities have their own questions they want answered, although this tends to focus less on research for academic publication and more on answer-seeking to address their issues.”

Maile Tauali'i
Papa Ola Lokahi

provide its patients formal language services, such as interpretation and translation, even though many Indian people and Alaska Natives have a primary language other than English.⁹⁸ And there also exists “a general lack of cultural competency and understanding of Native Hawaiians in the providing of health care services, teaching and education, and in conducting research.”⁹⁹

Nonetheless, there are many examples of progress. Hawaiians have made important advances in developing culturally relevant health promotion strategies. And, in Alaska, in the 1990’s the Southcentral Foundation (SCF), an Alaska Native-owned health care system delivers primary care with integrated care teams that fully incorporate tribal doctors or traditional healers as well as chiropractors, massage therapists, and acupuncturists.”¹⁰⁰ The Southcentral Foundation and other Native-run health programs show that it is possible to integrate culture into health care and health promotion for Native people. But they do not yet account for all, or even most, care received by Native people.

Delivery of care by Native providers could address many of the shortfalls in cultural competence, continuity, and trust.¹⁰¹ Yet, there continues to be a lack of Native practitioners, who represent less than one percent of medical school graduates¹⁰² and are underrepresented among registered nurses.¹⁰³

THE HUMAN FACE OF HEALTH INEQUITIES

Health inequities are about more than data and statistics. They affect real people, harming their health and shortening their lives.

The next part of this publication presents the stories of Native people and their struggles to get health care they need, be treated with respect by practitioners, and improve the health of their communities.

STORIES

"I'm sharing my story because no one should have to go through what we've gone through. We should feel that our doctors are listening to us, treating us as human beings, and giving us care that we can trust."

Claudette BLACKHAWK

"My hope is that sharing our stories will lead to unity and affirm a commitment to affordable health care for all. It is a basic human right."

Andrew IRON SHELL

PAST & PRESENT

Sidney STONE BROWN

Blackfeet

Denver, Colorado

Sidney Stone Brown, PsyD., is a Child and Family Therapist, completing a post-doctoral study on Native Self Actualization Placement Assessment.



I WILL CONSIDER SURGERY ONLY if it's a matter of life and death. This reflects the historical trauma experienced by American Indians and Alaska Natives, which has caused deep mistrust of health professionals and medical procedures.

One day after World War I, when my father was a young boy on the Blackfeet Nation Reservation in Montana, all the schoolchildren were herded into the hospital, which was then run by the Bureau of Indian Affairs. As my father stood in line, listening, he realized what the doctors were doing—something awful. He ran home to tell his parents what was about to happen to his younger brother. “They’re going to scrape his eyelids!” he said.

When my grandparents arrived, it was too late. Their younger son developed scars on his eyelids, which led to a lifelong disability, all because the BIA had authorized medical research on Indians. At the expense of Native American children, an eye doctor from back east—we heard from New York City—became a famous researcher.

My grandparents didn't have the right to refuse their son's participation in the study. They weren't deemed competent to make decisions for their children. As wards of the government, they weren't even informed of the study. My father escaped the experiment by running away, but he didn't really escape harm. His brother was legally blind, and my father blamed himself—he felt he should have saved his brother.

As a young adult, my aunt was admitted to the BIA hospital during World War Two. She was married, she and her husband had a toddler daughter, and they planned on having more children. She went into surgery to have her appendix removed. When she was released she was told she'd had a complete hysterectomy. Many physicians, and the U.S. government, believed there were just “too many Indians.” As it was told to me by elders, providers were instructed to sterilize American Indian women to reduce the population.

These forced sterilizations were still being done when I worked in Rapid City, South Dakota, in 1973. Doctors often decided to sterilize Lakota women in the Indian Health Service hospital for being “just” alcoholics. At that time, people in need of treatment were sent to residential care only if they had cirrroses, the final stage of the disease. You may think this story is outdated, but not much has changed for Native Americans.

My family and tribe are not unique. Most tribal families have stories of malpractice, maltreatment, and abuse of power by individuals with authority in medical and social service settings. People have lost their lives and suffered immensely as a result, and we've passed the traumatic memories of these experiences from one generation to the next in an effort to intervene and prevent ongoing harm.

THE WORD ALOHA IS A SERIOUS WORD in our culture. We are people of this place, and because of our culture, we welcomed other people at the height of colonialism. Those who came brought western cultural traits, such as individualism and private economy.

Many Hawaiians died as an immediate result of colonization—about eighty percent of the population was decimated by infectious diseases like influenza, small pox, and measles. When Hansen's disease* arrived, the Kingdom, filled with immense fear and not knowing the transmission route, thought the disease could spread throughout the entire population.

A remote place was chosen to house people believed to have the disease: the Kalaupapa peninsula is separated from the rest of Moloka'i by a sheer cliff, which fulfilled the needs of the Board of Health and the Kingdom. There was no template for creating a quarantine station, so they borrowed the penal code, and suspected patients were put on trial.

This happened not just to adults but also—if you can imagine—to children, many of them girls. The patient was brought into a room wearing a smock, in front of a room of male, Caucasian physicians, and put on a pedestal in the center of the room. The nurse told the patient to drop the smock. They'd have to stand there, naked, while the doctors examined them, with tugging and pulling on body parts, including genitals. Imagine a twelve-year-old girl who has to do that in front of a bunch of male strangers. If the council of physicians believed the patient had Hansen's, with no lab test and surely plenty of misdiagnoses, they were convicted and sentenced. Ninety percent of those sentenced were Hawaiian.

For almost six years, I've been part of a group of doctors treating the last Hansen's patients at Kalaupapa. I live there two days a week and am on call for the nurses who are there around-the-clock. Our work there is the result of the vision of Dr. Emmett Aluli, who's been very active putting forward an agenda around Hawaiian health, culture, and land. His vision was to have a group of Hawaiians caring for the Hawaiians at Kalaupapa.

I was worried when I first started there, because I was a newcomer who'd lived on O'ahu most of my life. What I didn't bank on was that I have a television show in Honolulu, and the people in Kalaupapa are avid t.v. viewers. I'd been in their bedrooms once a week for eight years. They said, "Kalani, we know you. We see you on t.v."

Over the years, we've built real trust. In Hawaiian culture, trust develops with a person, not an ethereal institution. And, with my Hawaiian patients generally, I think having a Hawaiian practitioner makes a difference, because of the ability to relate and communicate in Hawaiian culture, as opposed to Ha'ole or Caucasian culture.

*Hansen's disease has also been known as leprosy.

S. Kalani BRADY
Hawaiian
Honolulu, Hawaii

Kalani Brady studied public health at the University of Hawaii and medicine at the University of Pennsylvania. He is an Associate Professor in the Department of Native Hawaiian Health at the John A. Burns School of Medicine, University of Hawai'i at Manoa.



John COMPTON
Sicangu-Lakota
 Denver, Colorado

John Compton is a seventy-nine-year-old elder enrolled in the Sicangu-Lakota (Sioux) nation located on the Rosebud Sioux Indian Reservation in South Dakota. He lived in the reservation until 1949, until he moved away to attend the University of Kansas. He has a Masters in Social Work.



MY FIRST EXPERIENCE WITH WESTERN MEDICINE came through the Bureau of Indian Affairs, as part of its treaty obligations. To end the military conflict between the U.S. and Indian nations in the 19th Century, the U.S. government agreed through treaty to provide health care and other services, and Indian people were confined to reservations. I lived on the reservation and was raised in a traditional extended family headed by my paternal grandparents.

We were treated with disrespect and sometimes derided by the doctors and nurses there, almost all of whom were Anglo. In hindsight, I think they hated their jobs and did not like living on the reservation. As a child and then as a youth I hated going to the doctor because of these attitudes and the limited treatment provided.

We didn't have dental care in those early years. We just had a circuit-rider type dentist that came one or two days every several months. I had my first extraction when one of my teeth got infected. A general practitioner treated me. He didn't know how to do it, though, and the pain of the extraction was worse than the toothache. To this day, I have difficulty trusting and relating openly to medical professionals!

In those early days, we secretly used tribal medicine practitioners and tribal medicine, even though the U.S. federal government prohibited many healing and spiritual ceremonies. Some people, especially younger adults, used both Anglo and Indian medicine at the same time.

During my childhood in the 1930's and 1940's, most deaths of young and old people alike were due to tuberculosis, water and sewage-borne disease, accidents, and alcohol. We had no safe water or sewage systems, or, for that matter, electricity. We had outhouses and had to haul water from local white farmers and ranchers with wells. Our nutrition was also very poor, because there were no jobs and we depended on rations for food. These consisted mainly of dried foods like rice, beans, sugar, flour, coffee, and the like. We had no refrigeration. Sometimes we received canned vegetables, evaporated milk, corned beef hash, and, for a short period, canned mutton.

I left the reservation in 1949. Since then, I've had good health insurance, first through college, then the Air Force, then my employment. Now I receive my health care through Medicare with supplemental coverage. I think this is an effective and reasonably low-cost model that should be considered by health care reformers.

LIFE & LAND

ALMOST EVERYONE IN MY FAMILY has diabetes—my mother, my aunts, my sister. I had one uncle who died right on the operating table, waiting for an amputation. And my sister was put on dialysis, because her kidneys don't filter her blood properly. So, now she has to depend on a machine for her life, because of diabetes. I have diabetes, too, even though I'm not even forty yet.

This disease has become an awful fact of life for Tohono O'odham. But there's nothing "biological" about diabetes in my community. Up to the mid-1900's, the Tohono O'odham grew our own food and drew on our own traditions. Diabetes was unheard of. No member of our nation had diabetes until 1960. It turns out that traditional O'odham food helps the body regulate sugar levels.

But the federal government introduced policies that ended all that. O'odham were encouraged to work on large, irrigated cotton farms. They had to stop farming their own land. Children were forcibly sent off to the boarding schools, where they were punished if they spoke their own language. And federal food programs replaced traditional food with lard, refined flour, and sugar, all processed foods linked to diabetes.

We're still paying the consequences of these policies. Now the Tohono O'odham nation has the highest rate of adult diabetes in the world, and even children as young as four have been diagnosed with it. People feel like diabetes is unstoppable.

Diabetes isn't unstoppable, but our history shows that the epidemic isn't about choices that individual O'odham make. We need to bring the entire community together to make healthy food available and reconnect people to their culture.

At Tohono O'odham Community Action, we're creating that system change. We support traditional food, products, and cultural practices to create healthy community—in other words, the Tohono O'odham nation is coming up with solutions based on our own resources.

We have farms where we cultivate our traditional foods. We teach people how to grow these crops, and we market them in our community and beyond—including hospitals, schools, and lunch programs for seniors. We've started a basketweavers' organization and a cooperative marketing system. This creates sustainable economic development and community self-sufficiency. And, recently, I launched "The Walk Home," a three-thousand mile journey on foot to spread the word among Native and non-Native people about traditional foods and wellness. These are just some examples of the actions we're taking to make real change from within our community.

Some U.S. government policies continue to discourage the consumption of healthy, traditional foods, in favor of unhealthy, processed food. We know that an alternative exists. And Tohono O'odham can offer solutions, not just for our nation, but for all people.

Terrol DEW JOHNSON

Tohono O'odham

Sells, Arizona

Terrol Dew Johnson is an artist and co-founder of Tohono O'odham Community Action, a community-based organization dedicated to creating a healthy, sustainable and culturally vital community on the Tohono O'odham Nation. He is recognized as one of the top Native American basketweavers in the United States.



John FOGARTY
Santa Fe, New Mexico

Originally from Iowa, **John Fogarty** studied medicine at the University of Washington and moved to New Mexico for a family practice residency. He joined the Indian Health Service in the mid-1990's and moved to Crownpoint, in the Navajo Nation, in 1999. He now practices medicine with the Indian Health Service in Santa Fe, where he treats Pueblo people. John Fogarty is also a co-founder and co-director of New Energy Economy.

FOR TOO LONG, NATIVE COMMUNITIES have been treated as energy colonies. For example, uranium mining ended twenty-five years ago on Navajo Nation, but one-third of the mines have never been cleaned up and the waste is contaminating communities and water supplies. People who've worked in and around the mines suffer high rates of diseases, such as lung cancer and pulmonary fibrosis, or scarring of the lungs. And drinking uranium leads to kidney disease.

I took care of a family in which the father used to come home after working in the uranium mines covered in yellow dust. Although uranium is radioactive and highly toxic, the company didn't tell workers it was harmful, nor were the workers given any protective clothing or respirators. So, this gentleman would come home covered in toxins, shake off his clothing, and it ended up contaminating his family, too. He and his wife both wound up using oxygen. They were wonderful people, bright spirits, and the company maximized its profits at the expense of their health.

The uranium companies knew uranium was highly hazardous when they began mining on Navajo Nation. Studies dating back to the 1800's have linked it to cancer and "mountain sickness," the term then for pulmonary fibrosis. Yet, when I moved to the Navajo Nation in 1999, I learned that a large multinational company planned to mine uranium right in Crownpoint. The community and the Navajo Nation have been fighting this for fifteen years and the case is still in the courts. Given the go-ahead, this company will use in situ leach mining and destroy the only source of drinking water for thousands of people and their livestock. There's no other source of potable water for almost 100 miles.

I think I was pretty naïve when I moved to Navajo Nation. When I learned that uranium mining might start again, I thought the Nuclear Regulatory Commission and the federal government had overlooked something. I believed that, given the opposition and the scientific evidence, the government would change course and say, "Of course, we won't let this community be destroyed." Yet, unfortunately I think many of the systems that destroyed tribes in the 19th Century are still in place.

I have worked with the Indian Health Service for twelve years, and I am amazed to see a growing movement that could turn things around on many of the Reservations. Right now there's a huge effort on Navajo Nation to develop a green economy based on renewable energy, green building, and sustainable agriculture. Young people have seen the impacts from uranium mining, from coal-fired power plants and they know there's a better way. In South Dakota they are working on creating large-scale wind farms, which will create hundreds of new jobs and bring in revenue for the tribes. These developments give me hope.

MY PARENTS WERE ACTIVE IN the Native social justice movement in the 60's and 70's. In Oklahoma, my father was involved with a group of families that would gather and talk about issues and work for change.

There was uranium processing facility in eastern Oklahoma adjacent to the Cherokee Nation. The facility processed uranium that was mined in Indian communities in New Mexico then transported to another Indian community, where it was turned into yellow cake. The byproduct, called raffinate, was used to fertilize grain in the surrounding fields, and livestock also picked it up. We knew that wasn't good for people's bodies, and I protested the licensing of the facility when I was sixteen or seventeen.

Then, in 1990, I attended Protecting Mother Earth Conference in Dilkon, Arizona, where Native people gathered to discuss environmental issues. There was a big "aha" moment for a lot of us. We talked about how tribal communities were targeted for mixed waste incinerators, medical waste incinerators, landfills, and nuclear waste—sometimes multiple facilities in one community—and the same companies came up again and again. We started to connect the dots, think about the health effects, and became outraged.

I became involved in the creation of the Indigenous Environmental Network as a youth representative. Later, I worked with Greenpeace's Native Lands Toxics Campaign, helping Native communities explore the link between the toxics and health problems. Chemicals had leached into farmland, and people were having ailments that hadn't been present before. The incidence of asthma had climbed in some communities, along with more breast cancer and mercury poisoning. Families were being told not to eat the fish in their traditional streams and rivers and not to breastfeed.

Eventually, the Navajo Nation outright banned uranium mining, but it's not easy for an indigenous nation to make that transition away from these harmful activities. The Navajo Nation, for example, sustains its health care system, affordable housing, and social services, much of it dependent on revenue from coal mining. Solar and wind aren't competitive yet. The U.S. government needs to create a system where these forms of energy are competitive. And, when we look at the impacts of a facility, we need to look not just at the impact of that individual facility, but the cumulative impact of multiple facilities affecting a single community. Native communities have been burdened by environmental destruction for too long.

Bineshi ALBERT
Yuchi/Chippewa
Albuquerque, New Mexico

Bineshi Albert helped found the Indigenous Environmental Network in the 1990's. Among other activities, she currently works as a field organizer with the Center for Community Change.

STRUGGLING FOR HEALTH CARE RESOURCES

Solomon BULL SHOWS

Crow
Hardin, Montana

Solomon Bull Shows is twenty-two years old. He lives on the Crow Reservation with his mother, father, and three brothers.



AFTER I GRADUATED HIGH SCHOOL in 2005, I moved down to Colorado to work at my uncle's HVAC company, which installs heating, ventilation, and air conditioning systems. But, because of back pain, I lasted just two years.

The pain started in my left leg. It got worse and worse with time, until it moved up to my back. Finally I went back home to Hardin. I needed to get it checked out. Early in 2009, I went to a chiropractor who did shock treatment and suggested I get x-rays at the Indian Health Service. A few days later, I went to IHS.

The doctor I saw there couldn't really help me, which is one thing. But he seemed irritated by not knowing what was wrong, and he treated me like a nuisance, instead of like a patient. Then, when I was having the x-rays taken, the technician said to me, "You're not the only one who wants to go home for the day," as if I were just trying to get out of work. In the end, the doctor told me I needed to see the orthopedic specialist from Billings, who came to the reservation twice a week. In the meantime, he prescribed me Tylenol with codeine, which didn't do much to numb the pain.

About six weeks later, I got in to see the orthopedic specialist. He thought I had a herniated disk and referred me to a back specialist in Billings, so I could get a CT scan. But that's where I had problems with contract services—IHS uses outside doctors and you can't get services unless there's an emergency. I hit a brick wall—they wouldn't pay.

Then I got lucky. My father went for a check-up with his doctor, who happens to be with the Area Health Board. My father told his doctor that I'd been denied contract health, and his doctor went to the Board the next day and looked at case. And then, well, I got approved—just because my father said something to a doctor in a position to help.

After I got the scan and a myliogram, I learned that I have a herniated disk, and, on top of that, I have a twelve centimeter cyst. When I was just one-year-old, I had back surgery to remove a growth, and the cyst is right at the spot where I had that surgery. The back specialist in Billings told me he'd never seen anything like it in his life. He referred me to a neurosurgeon. After a month, I had that appointment. He told me I needed surgery to have the disk repaired and the cyst removed.

I scheduled my surgery for April, but I didn't get it. I wound up getting denied again by contract health services. Now I'm on another appeal and waiting for my life to come back to normal. I'm an active person – I love to play basketball, love to fish on the Big Horn River. But I haven't been able to work. I can't do even basic things. My girlfriend has to help me get dressed in the morning, put my socks on for me, and I'm only twenty-two. None of this makes sense, and I know it doesn't have to be this way.

In May, Solomon Bull Shows received approval for his back surgery. He underwent surgery later that month.

TO UNDERSTAND THE HEALTH NEEDS of Native people, first you need to take a step back and understand how much U.S. federal policy has shaped our lives.

My grandparents were taken from their homes and prevented from speaking their language. My grandfather was from Laguna Pueblo and when he was a little boy, he was sent off to the Albuquerque Indian School. My grandmother was from Ohkay Owingeh Pueblo. She was sent off to the Indian School, too, and that's where they met as teenagers. They didn't get married right away. First my grandfather went to the Carlisle Indian School in Pennsylvania, then he went back for my grandmother and they wound up living off the reservation in Santa Fe, where they worked at the Indian School.

This wasn't just a decision my grandparents made, though. The United States government removed young people from their families to, as they put it, "civilize or assimilate" them—and removal was not voluntary. It was forced upon them. And it often accomplished the federal government's goal: to sever young Native people from their families, their communities, and their culture.

When the youth were taken away, it was for years, and they couldn't go back and visit their families during that time. Their hair was cut, they lost their language, they stopped wearing moccasins and the clothing they were used to. There aren't words to describe what this did to them.

This history has a lot to do with our health. The link between racism and health is indisputable, and being cut off from our culture is stressful and contributes a lot to disease and behavioral health issues. But people living off reservations often can't get health care, even though we've paid for it through the transfer of our land to the United States.

In 2005, the Indian Health Service decided to close urgent care services at the Albuquerque Indian Health Center. It was a funding issue, but where would people go if they sprained an ankle, had an accident, came down with some sort of infection?

For many Native people in Albuquerque, the Albuquerque Indian Health Center was the place to go if you got hurt or sick. These services wound up being contracted to a hospital next door. But the eligibility for contract health services is very limited, and many people no longer qualify.

We began to organize people in our community. Nine of us met at the Village Inn in Albuquerque and formed the Native Health Care Council of New Mexico. From there we organized picnics and community meetings to make sure that we had a voice in major policy decisions. In the meantime, people wound up putting off care or getting huge bills because urgent care services were no longer available. One man

Roxane SPRUCE BLY
Pueblo
Albuquerque, New Mexico

Roxane Spruce Bly helped establish the Native Health Care Council of New Mexico.

took his son, who'd broken his leg, to the local public hospital. But the hospital told him they needed payment upfront. He wound up taking his son all the way to the Santa Fe Indian Hospital.

In the end, we weren't able to get our urgent care services back. But we learned something important: as a community we need to be making decisions for our health care. We pushed for legislation to create the Off Reservation Native American Health Commission for Bernalillo County, where Albuquerque is located. That's a first step. But we shouldn't forget why the Albuquerque Indian Health Center closed its urgent care services—money. Health care services for Indian people are the responsibility of the federal government and should get the funding necessary to provide services to all Indian people—just like the VA or other entitlement programs. The Indian Health Service is hugely important for Native people, and it shouldn't be necessary to slash basic care because of budget shortfalls.

Urban Indian health programs shouldn't be left out of the funding priorities. Part of the healing they provide is cultural. When I was a student at the University of Michigan, I'd drive to the urban Indian health program in Detroit, because it provided a sense of community that I really needed. That's an important part of care for Native people, especially given how cultural and social displacement affects our health.

Electa HARE
Pawnee
Tulsa, Oklahoma

Recently, **Electa Hare** completed her Masters in Social Work at Washington University in St. Louis, where she was a Buder Scholar. Currently interning at the Tulsa Indian Health Care Resource Center, she plans to return to Pawnee, Oklahoma, to serve her community.



I'D ALREADY APPLIED TO SOCIAL WORK school when my cousin, Pamela Feathers, died in a car accident. People from many different nations came to the funeral: Pawnees, Creeks, Cherokees. As I looked at those gathered, I saw many of the problems we experience in Indian Country—the effects of meth, of Post-Traumatic Stress Disorder in families with veterans.

But, I also saw our strengths. So many people had shown up to share our grief. Wilma Mankiller, an important leader, came to the funeral and cried with us. That was very powerful. And it hit me: we look out for each other. When we put my cousin in the ground, we drew on a very strong bond. I realized how important it was for me to go away to study and return with new skills for supporting my community.

There's so little information for people about the services they should be getting. There's also a big gap between the U.S. government's trust responsibility and the services that are available. I've been lucky. I've used IHS all my life, and I've been healthy and never had a problem. But as a student, I've seen and learned more and more.

I learned that there's no urban Indian health center in St. Louis, and no way for many Native people there to get health care they need. Last spring, I interned at a hospital in St. Louis. One day, the social workers got a phone call from a Seminole family whose son had just been in a real bad car wreck. He was going to need rehab, and his family wanted to know where the Indian Health Service facilities were.

The social workers had no idea what to tell them. Everyone was scratching their heads. Then they said, "Let's ask Electa." They figured, "She's Native, she's a Buder Scholar, she'll know." I had to tell the family that there was no facility nearby. They didn't have insurance. They'd have to go all the way to Lawrence, Kansas, or to Nashville.

I've also worked as an extern at an IHS clinic in Oklahoma. That clinic opened at eight and closed at five, and if you needed help before or after, you were out of luck. In Indian country especially, people don't keep regular hours. Most of the doctors, and a few of the nurses, weren't from the tribe or the community. They drove in and out. The practitioners that were most successful, I think, were the ones that raised their kids where they worked, the ones who kept it real with people, who joked but were also honest with their clients.

A lot of Native people find the health care system confusing and alienating, and that makes sense—it's so complicated! I want to be a bridge for them, a link between families and doctors, so they can understand the system, get what they need from it, but also change it. That role should be part of health care system, and respected.

AT THE SEATTLE INDIAN HEALTH BOARD, we provide primary care, but we're also more than a clinic. Our service area includes members of more than two-hundred and fifty tribes and different levels of assimilation. We have people whose families came to Seattle four generations ago to work at Boeing, and we have people just arriving from their reservation. The clinic is a cultural and social hub. It's also a place where people can get some respite from living in a city.

For people coming from reservations, having that respite is very important. We had one older gentleman who was having headaches and anxiety attacks. We found out that the noise was bothering him. He'd lived mostly on a rural reservation where the sounds were all natural—birds, crickets, and so on. So, we gave him earplugs as part of his care.

Native people run into a number of obstacles to health services. First among these is the financial challenge. We focus on primary care and have a significant number of people who need treatment beyond what we can offer. That's the biggest frustration of this sort of work—knowing that as much as you do, it may not be enough. We're now involved in a cancer screening project. The first question I asked when we started talking about this was, "If we find a woman has a lump, can we guarantee we can get her in to evaluate and treat that properly?" In this town, there's no guarantee. Then the question becomes an ethical question: do we screen? So, we need to remove the financial barrier and change the way we pay for health care.

American Indian people also have a historical mistrust of the health care system. Many people think of the hospital as the place you go

Ralph FORQUERA
Juaneño Band of Mission Indians,
Acjachmen Nation
Seattle, Washington

Ralph Forquera is the Executive Director of the Seattle Indian Health Board. He obtained his Masters in Public Health degree from the California State University, Northridge, and he has served as chair of the American Indian, Alaska Native, and Native Hawaiian caucus of the American Public Health Association.



to die. Developing trust is an especially important part of health care delivery for Native people. Some health care professionals are not familiar with the cultural differences, especially in the sub-specialties—they don't see many Native people, because Native people don't make it that far. So, there needs to be some training and targeted programs.

And, as the country looks at health care reform, we need to make sure that whatever changes are made don't disrupt what Native people currently have, which goes beyond medicine. It also includes traditional practices and ceremonies. There are also a lot of cultural beliefs around health that we need to recognize—along with the fact that Indian people bring historical experiences to the encounters they have now with medicine. For one thing, the trust responsibility for health care is important in Indian country, but it's mostly ignored.

In the end, how communities adapt to changes will be the responsibility of institutions like ours. Walking people through the health care system is an important part of healing people, and it should be valued and compensated like any other service. Healing is about the whole person, the larger community, and our entire society.

DO NO HARM?

BACK IN 1987, I HAD GALL BLADDER surgery and a tubal ligation. I had no reason to think anything had gone wrong with that operation. More than twenty years later, though, I found out what had really happened.

I went to see a doctor at the Indian Health Service in January, 2008. I'd noticed that my arms were getting thinner and my belly was growing larger. That seemed very strange to me. I explained my concerns to the doctor. He said, "It's something that just comes with age," and told me it was all in my head. I left with Zantac, an antacid.

When my ring slipped right off my finger in May, I knew it wasn't just in my head. I went to the doctor again, but I didn't go to IHS. I went to the Billings Clinic instead.

The doctor I saw there took me seriously enough to send me to a gynecologist. He said, "Claudette, I don't want to scare you, but just looking at you I have a feeling you have a tumor." The next day, I had fluid taken from my right side. But I had to have more fluid taken, because the first time they didn't get enough to test. Six days later, I had fluid taken from my left side. That came back positive. It turned out I had fibroids in my uterus.

I went in for a hysterectomy at the end of June. They also removed seven liters of fluid and found a tumor, which had grown from the stub of my appendix and spread to my left ovary. I say stub, because I didn't have a full appendix, which I was very surprised to learn – it turned out that, back in the 1980's, when the surgeon was removing my gall bladder, he took part of my appendix, too.

At first, IHS didn't want to pay for the procedures, because I hadn't asked for authorization to see the doctor at the Billings Clinic. I filed an appeal, though, because I don't have insurance—and because I knew I had made the right choice. I didn't accept that my symptoms were all in my head, and I didn't accept that my concerns shouldn't be taken seriously.

I wish I could say this was just a fluke, but something similar happened to my daughter. She felt very sick, went to the Crow IHS, and was treated for the flu. Later, she went to the Hardin Clinic and found out she had kidney failure. She's been on dialysis ever since.

I'm sharing my story because no one should have to go through what we've gone through. We should feel that our doctors are listening to us, treating us as human beings, and giving us care that we can trust.

Claudette BLACKHAWK
Crow
Wyola, Montana

Claudette Blackhawk has four children and eight grandchildren. She lives on the Crow nation, where she works at the Apsáalooke Nation Housing Authority and practices bead craft.



Carmen DAVIS
Makah
 Seattle, Washington

Carmen Davis is an enrolled member of the Makah Nation. She is the President of Reach the Rez, an outreach program that serves reservations and Native communities across the country. She is also the Vice-President of Native Style Clothing and Litefoot Enterprises.



Jennifer CHASING HAWK
Crow
 Crow Agency, Montana

Jennifer Chasing Hawk lives on the Crow Reservation. She shares her story and the story of her fiancé, George G. Reed, III.



I TRAVEL INDIAN COUNTRY from coast to coast, and I've heard more horrible health care stories than I can even remember—after a while, they just become the norm. Personally, I will never use Indian Health Service again. There have been times over the years that I've been uninsured and had health issues arise, and still I avoided IHS.

The final straw for me came when we were on the road and my son got sick. He was only three-years-old, I'd never seen him that sick, and we were driving through South Dakota, so we stopped at the IHS clinic there. They did a bunch of tests. During the blood test, they practically butchered his arm. They put so many holes in it that, instead of using a needle, they squeezed his arm to get the blood out and into the vial. They couldn't even do a simple blood draw!

My husband and I were trying to stay calm so our son wouldn't become completely unglued. But we could not believe the incompetence of these practitioners, to whom we'd entrusted our child.

This wasn't our first traumatic experience with IHS. My husband had such bad dental care growing up that it took him fifteen years to see the dentist again. My mother-in-law went to the hospital and left with a hysterectomy that she didn't need—and that she hadn't even consented to. She's just one of many stories of forced sterilization to control Native people in this country.

Impoverished nations or not—Native people are not well. Some tribes have the resources to create wellness programs and offer more than just tiny, run-down clinics. But our health issues encompass more than just economics. Our health issues are the manifestation of five hundred years of oppression, warfare, and genocide.

BACK IN 1989, MY FIANCÉ AND I went to a concert in Billings and decided to drive back after the sun came up. I fell asleep at the wheel, and the car rolled off the highway. I was pretty much fine, but George got thrown from the car and landed on a rock. He wound up spending five weeks in intensive care, mending five broken ribs.

He was a cowboy, and tough, and went back to work on Littlehorn Sunlight Ranch from June through November. After that, he went from ranch to ranch herding cattle, spending three to four weeks at a time in the wilderness. Meanwhile, I learned that I was pregnant.

By January, we were living with my mother. One evening, I got sick and was given a sedative at the hospital. Late that night, my mother noticed George awake, sitting in the dark kitchen. Traditionally, mothers-in-law and sons-in-law do not speak to each other, but that night my mother asked George what was wrong, because he was so clearly in pain.

He said he had a bad stomach ache and took Tagamet, but when it didn't get better, my mother told me to take him to the Indian Health Service hospital. We waited two or three hours before he was seen there. The doctors ran test after test and couldn't figure out what was wrong. I went home for a short time, and then returned to stay with

George. He just kept feeling worse, but there was no doctor then at the hospital.

The next day, a Saturday, I went home to get some clothes for George, thinking soon he'd be getting better and would be released. When I returned, he was on heavier pain killers and in even worse shape. On Sunday, the doctor on call finally came in at 2 PM. She was a pediatrician and at first tried to take his blood pressure with a child's cuff. Then she said, "Everyone's BP goes up when they're sick. It doesn't mean anything."

At this point, George couldn't lie down and had shortness of breath. He had to sit at the edge of the bed, rocking back and forth, to deal with the pain. The doctor gave him an even stronger pain killer. By then, he was in so much pain, and so heavily drugged, that he was delusional. I was the only person he recognized. He thought his father was his brother and his brother was his father. Next, they gave him Demerol. He'd wake up briefly, say, "Jen, I love you," and pass out. Every hour, he got a dose of Demerol.

His pain got worse, and the doctor started giving him morphine. He got five doses of that on Sunday night. Just after midnight, he woke up and said to me, "I love you." He was in my arms, and he just fell.

I screamed, and the doctor kicked me out of the room to do CPR. I went to the car to get my mother, and when we returned, they were still doing CPR, while George was partially on his side. The doctor told me George had died. Then, for some reason, she started to laugh, as if trying to make light. I just lost it—I punched the doctor in the face, grabbed her hair, and kicked her in the back.

George's death certificate said he'd died from Acute Alcohol Abstinence Syndrome. But the autopsy showed that in the car accident he'd broken a sixth rib, which had punctured his lung, causing it to collapse. George's family filed a wrongful death suit, which they settled out of court. Our daughter, Holly, was born shortly after he died.

Five years later, I was having my own stomach pain. I went to IHS three times in five months. Each time, they told me it was in my head and I was having anxiety attacks. They gave me nausea medication. Finally, I got fed up. I moved in with my grandmother in Rocky Boy, an eight hour drive from Crow, and was admitted to the ER there. They sent me to Northern Hospital in Havre, where I waited for three hours while they did tests.

The tests showed I had a ruptured gall bladder and my kidneys and liver were severely swollen. I went straight into surgery. The doctor told me I might have died if I'd waited another day.

WHEN MY SON KENNINGTON was four, he fell on a toy dart. The suction cup rammed the inside of his throat and hurt him pretty badly. So I rushed him to the ER at the IHS hospital on the Crow reservation, where we live.



George G. Reed, III.

Summer FITZPATRICK
& Kennington KALINE
Crow
Ashland, Montana

Summer FITZPATRICK
& Kennington KALINE

Crow
Ashland, Montana

Summer Fitzpatrick works at the tribal office of the Crow Nation. She lives on the Crow reservation with her husband, her two sons, ages nine and seven, and her three-year-old daughter.



The attending doctor told me that Kennington was just “stressed out” and “colicky,” because his grandmother had died recently. I just didn’t trust that assessment. I thought he had been injured, and I took him back every day for the next six days. Each doctor repeated what the original attending physician had told me and noted in the chart. I knew, though, that he’d been hurt. For one thing, he’d stopped eating.

Finally, on the seventh day, a pediatrician saw Kennington, recognized that he had a fever, and ordered that he be sent to the ER in Billings. Within an hour of arriving at the ER, he was on his way to the operating room – the surgeon had to clean out the infection that had developed in his esophagus. He’d gotten the infection because the force of suction cup had led to an abscess in his throat. During the surgery the doctor placed him on a feeding tube.

The doctor at the Billings Clinic told me that it all could have been avoided if Kennington had just received an antibiotic when he’d first arrived at the IHS. And the operation Kennington had that day was just the first of many.

He had his second surgery two days after the first to repair the hole in his throat and continue cleaning the infection. In January, he got strep throat, the infection returned, and IHS sent him to the ER in Billings where they had to do a third surgery. Three or four days later, he had the fourth surgery. By then, his ear, nose, and throat specialist said Kennington’s tissue in his throat was damaged from all the infection. There wasn’t anything more the specialist could do for him. So, the next day, he sent him by medical plane to the children’s hospital in Salt Lake City.

Four more surgeries followed, three to clean out the infection and one in which tubes were inserted in his ears. The tubes were so he could do hyperbaric treatment, which the doctor ordered to lower his white blood cell count and raise his red blood count and fight the infection. He continued his treatment on Crow.

In all, Kennington saw nine doctors at IHS, all non-Native. He wound up having eight surgeries. Kennington’s father and I went through tremendous stress and worry. And IHS wound up paying for all the treatment because of the error—we don’t have insurance, so I certainly couldn’t have paid. Now, we are treated better at IHS because of what happened. But it never should have happened.

All this could have been avoided if the doctor had taken Kennington seriously to begin with. Instead, he was dismissed. The doctor simply assumed his symptoms were psychosomatic and failed to notice he was running a fever. And the initial mistake was repeated again and again.

Now, Kennington’s overall health is good, and he’s a curious boy who loves studying government. He learns as much as he can about the President, because President Obama was adopted as a Crow. This experience has affected him, though. Recently, he was watching an infomercial on television and said he wanted “scar-be-gone” for his neck. I didn’t even notice the scars anymore. But they won’t go away.

BEING TURNED AWAY

I BEGAN MY HEALTH CARE WORK as a provider, but I could not stand to see so many patients die due to a simple lack of health care—deaths that could have been prevented. I had to take a break and heal myself, because seeing these things happening to my people took such an emotional and spiritual toll. When I came back to work for the tribes, I took an administrative role. Now I manage the Tribal Clinic for the Fallon Paiute-Shoshone Tribe.

Back in 1986, the only Indian Health Service hospital in Nevada was shut down. Since then, for emergency and specialty care, all the tribes have had to use contracted services at facilities off the reservation. Some reservations, like the one where I work, have opened clinics to try to meet their people's needs. But resources are very limited. On the Walker River Reservation, where the old IHS hospital was, there's now a small clinic operating in a building that was condemned years ago. It's just so sad.

Contracting services out has just created a whole new set of problems. For a while now, I've been tracking the patients my clinic refers out. Every week, ten to fifteen of them get turned away. This is because the IHS is so far behind in paying its bills that the facilities and practitioners do not want to see patients from the IHS system. Legally, they aren't supposed to turn people away, but they do it all the time!

There's a myth out there that Indian people are being taken care of, that their health needs are being met. At my clinic, though, we don't go a week without seeing medical negligence. It's criminal. How can people think we're being taken care of?

I've sent patients to the emergency room, just to have the ER release them prematurely, sending them home to die. Every week I have people return to the ER because I think they've been released too soon. Only yesterday, one of my staff members started to not look well. I sent her to the ER. Her blood work showed a white cell count so low I wondered how she was alive. But they couldn't figure out what was wrong with her, and they sent her home. I was terrified she would die on my watch, so I told her to go back to the hospital. They had to airlift her to another hospital, where they gave her fluids and antibiotics—only to release her a few hours later! I'm still very worried about her.

This just discourages people even more from going to the doctor. Native people are already so reluctant. By the time people come to my clinic, they're really sick, often with multiple conditions. There are a lot of reasons people don't want to see the doctor. We have to deal with stereotypes before we're even seen. And people don't want to go to doctors off the reservation, because of the way they've been treated in the past. Plus, a lot of Native people, myself included, were raised traditionally and don't want to take western medicine. Instead, we rely on traditional medicines like teas, practice ceremonies, and live in a good way. Many doctors don't understand this.

I understand how people feel. I myself would not use the IHS unless I were dying.

Cynthia OCEGUERA
Paiute/Miwok
Nevada

Cynthia Ocegüera is Health Director of the Fallon Paiute-Shoshone Tribe. She was raised on the Walker River Reservation and has worked in public health for thirty years.



ANONYMOUS
Seattle, Washington

I WANT TO SHARE THE STORY of a little girl I know, who I'll call Liz, the adopted daughter of friends of mine. Born addicted to meth and cocaine, Liz had a lot of lung problems in her first two years and was constantly using inhalers and a nebulizer.

Once, her mother told me, they had to rush her to the hospital near the reservation where they live. After asking for insurance information, the admitting nurse refused to let Liz be seen—despite her turning blue from not being able to breathe—because Liz is in the Indian Health Service system. Finally, Liz's parents took her to the next closest hospital fifteen minutes away.

When Liz was five, I was with her when she broke her ankle playing on a trampoline. Her mom said that she knew it was serious, because Liz never cries from pain! We drove to a hospital twenty or thirty minutes away, because Liz's mom was afraid the closer one would turn her away again. During the drive, we gave Liz herbs to help her relax, and when we got the ER she was no longer crying.

At the hospital, they didn't believe her ankle was broken because she wasn't crying. They didn't want to do x-rays. We had to insist. Even then, they just scheduled an appointment for x-rays the next day!

They wouldn't even give us an exam room to see Liz. They came out to the waiting room and took Liz's vitals right there. They even wanted to take her temperature rectally right there! My friend asked if they could do it in her ear or mouth instead. The nurse said "Oh, we'll just skip it then!" Liz got the x-ray the next day, and her ankle was in fact broken.

I've had my own problems with the medical system. I was sixteen when my grandma died. Despite having diabetes, which she managed well, she was healthy. One day she had a fall and hurt her back. The doctor said she was healthy and strong enough for surgery. I visited her afterward, and she was her normal silly self. But one of the nurses in the hospital put her in a bathtub with stitches in her back, and she caught a virus or infection that attacked her central nervous system. It traveled to her brain, and she eventually went into a coma.

There were clear medical instructions: they were not supposed to put her in a bathtub! I can't help but wonder: if she weren't an old brown woman, would she have received better care? When she went into the coma, I used the traditional teachings I had, and made her a bundle of medicine that I prayed with, and I beaded a nice little bag for it to go in. I put it on my grandma in the hospital. When I went back to visit her, the bundle was gone. For one reason or another, one of the hospital staff had taken it. There was a total lack of respect for our religious/spiritual ways.

This wasn't an isolated incident. Just a few months ago, I had surgery to remove a massive tumor. I told my doctor that I wanted to take the tumor afterward. He laughed at me. I told him I was serious. He didn't think it could be saved. I had to go through all sorts of channels to fight to have this tumor saved for me. The hospital finally agreed, but I'd have to wait two whole months before I could come pick it up. I had forms drawn up and spoke to all the appropriate parties. Yet, after all was said and done, they didn't save the tumor. I wasn't able to handle it the way I was supposed to according to my cultural and spiritual traditions.

RESPECTING CULTURE & COMMUNITY

AT ONE POINT, OUR PRIMARY CLINIC was in San Francisco, one of the relocation centers under the federal urbanization policies. Thousands of people came into the city, mainly young, single people—no elders. As they got older, they began having families, and they began moving to the East Bay because the rents were cheaper. So, we moved east, too.

Providing good health care is about more than just what happens in the examining room. It also involves an array of services for addressing the needs of our community. That's something we don't get in a western model—an approach that includes not just physical, dental, and mental care, but also the need to be culturally connected, to get child care, to be able to leave a situation of domestic violence, to get out of poverty.

One of the causes of health disparities is lack of adequate housing. A physician can't just say to a patient, "Take this medication and go home and rest," if the patient lives in a small, crowded apartment. You can't raise a child without safe housing. And a car is not a healthy place to live. So, we've helped members of our community find housing. We've helped people buy homes if they're in a position to buy them. And, when we built a new clinic in Oakland, we included two floors of apartments—thirty-eight units that are now filled.

It's also very important for people to have a place to come together as a community. Back in the early 1980's, we did a needs assessment, and people told us, "We need a place to gather that's not bars." At that time, there were about seven or eight American Indian bars here, and we embarked on a sobriety initiative. Today, there are no bars. Are we healthier as a result of that? I would say so.

But, we've also provided an alternative. People can come to our clinic just to be part of the community. When someone comes into a new city from South Dakota or the Navajo reservation they always ask where the Indian health clinic is. We've tried to make our new clinic very welcoming, with open space and ceremonial ground. When you come in, you'd swear it wasn't a clinic. I always ask people, "Does this feel like a clinic?" They say, "No." And I say, "Great. That's exactly what we want."

Martin WAUKAZOO
Lakota
Oakland, California

Martin Waukazoo is the CEO of the Native American Health Center (NAHC), which has health care clinics and other services in Oakland, San Francisco, and Sacramento. Originally from South Dakota, he moved to the Bay Area in 1973.

Chii EVANS
 (as told by his mother, Bineshi Albert)
Navajo/Yuchi/Chippewa
 Albuquerque, New Mexico

Chii Evans is seven-years-old and lives with his mother, brother, and sister. He will enter second grade in the fall.

This helps us build not just community, but trust, too. We've been encouraging Native people to go into the health professions, but we also want our non-Native providers to be in the community and not just the exam room. Cultural understanding and trust are very important. We have a health run, and this lady came running up to one of the doctors and said she hadn't had a drink in six months. She wanted to tell her doctor that because of the relationship they'd developed.

WHEN CHII WAS JUST TWO OR THREE years old, he had problems with his teeth. We were enrolled in Medicaid at the time, and it took a month to get a dentist appointment. It turned out he had five cavities, and, because he was so small, he needed a special procedure with sedation. It was going to take a month to get an appointment with the anesthesiologist, then another month for the procedure.

While we waited, I had to recertify for Medicaid, and it turned out we no longer qualified. I thought that was okay, because by then I had insurance through work, but the insurance wouldn't pay for the procedure. They said it was a preexisting condition.

In the end, I had to drive four hours away to Navajo Nation, where my ex-husband is from, so Chii could have the procedure done there. By then, he had eleven cavities. Fortunately, once we got him to the Northern Navajo Medical Center, he was in and out. We met with an anesthesiologist in the morning, and it was done that same day.

I was happy to have my son treated there. I'd been a patient there, and when I used to go, they had a campaign to get everyone a primary care doctor, someone who'd be there for a long time, because up to that point people were used to always having a different doctor. They also require their doctors to learn Navajo language and culture, and the hospital has incorporated a lot of cultural beliefs and values.

When my daughter was born, she was born in that hospital. I had the option of midwife or doctor, and I had both. They and the nurses were very knowledgeable about Navajo customs around birth. In the maternity ward, all of the beds face east, so the babies can be born to the east. They also had fixtures from the ceilings so women could use traditional woven sash belts and stand to give birth, as it's traditionally done in hogans. They asked me if I wanted to take the placenta, I said yes, and they carefully packed it with ice for me.

When my son was born in the city, they refused to give me the placenta. They said it was a biohazard. "How can it be a biohazard?" I said. "It just came from my body." It's a very different experience when you receive health care in accordance with your values, traditions, and beliefs.

CULTURAL AND SPIRITUAL TRADITIONS have an important role to play in healing for Native people. If I have a Native patient and they have traditional practice, we can speak that language together. I might suggest the use of herbs, spiritually or medicinally, in conjunction with their spiritual practice. Not all my Native patients practice their spiritual tradition—many are Christian. But, if they want to incorporate traditional practice into their healing, I can help them do that.

Native medicine and practices have a lot to offer. There's a medicine wheel program for addiction and recovery that's often used on reservations. I share that with my Native patients if they're interested in a spiritual approach that isn't Christian or twelve-step.

There's also a medicine wheel diet based on traditional foods, and I use it with all of my patients. For Indian people, though, it's helpful to see this diet and remember, "This is the way my ancestors ate." When you're eating those sacred foods, especially in a ceremonial setting, you're putting that essence into your life. That's feeding your spirit.

There's a wealth of medicinal information that, unfortunately, is being lost. A lot of Native healers with knowledge of herbs are either gone, or no one in their family is interested, or they don't want to share their information, because they think non-Native people will abuse the information.

One example of using a traditional medicine would be, instead of using Metformin for moderate diabetes, using devil's club. Northwest coastal tribes have been using devil's club for hundreds of years. It's a treatment I'd offer any of my patients, but a Native person can think, "My ancestors used this," and it helps them feel good and complete, which is an important part of their health.

AS A RESEARCHER, I'VE STUDIED a number of important public health issues. A major area of my work involves researching biological, psychological, and socio-cultural factors, and their interplay in affecting the health of Native Hawaiians. Another initiative I belong to is now gathering data on whether having Hawaiian behavioral health practitioners affects the willingness of Hawaiians to seek and stay in treatment.

I became a psychologist and researcher by accident. I was never very studious in high school—I barely graduated—and I wasn't planning on attending college. But five years out of high school, I decided to learn the Hawaiian language. This was during the centennial of the overthrow of the Hawaiian kingdom and there was a second revival of Hawaiian culture. Like most Hawaiians, I wasn't raised speaking our language. One grandparent on each side of my family spoke it but didn't pass it down.

To study Hawaiian, I started taking some free night classes after work, and the teacher said, "If you're really interested in learning the

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Sioux
Portland, Oregon

Dr. Marleen Haverty, ND, LAC, received her Doctor of Naturopathic Medicine and Masters of Science in Acupuncture from Bastyr University. She has practices in Portland, Oregon and Kingston, Washington, where she treats members of the Port Gamble S'Klallam Tribe and other Native people.



J. KEAWE'AIMOKU KAHOLOKULA
Hawaiian
Honolulu, Hawaii

Keawe'aimoku Kaholokula completed his doctorate in psychology at the University of Hawaii. He now is a member of the Department of Native Hawaiian Health at the John A. Burns School of Medicine, University of Hawai'i at Mānoa.



language, you need to go to university." I decided to study the language at the community college, but it was so popular I couldn't get in. I enrolled in other classes to get priority for the Hawaiian class, but the next semester it was still full. By the time I finally started Hawaiian, I had taken four other classes and had A's in all of them.

I decided to stay in and transferred to the University of Hawaii to finish my B.A. From there, I went to graduate school in psychology and was involved in an NIH-funded research project looking at disparities in diabetes and cardiovascular risk factors. Along the way, I received scholarship support, including scholarships to support the development of Hawaiian professionals. Some of the scholarships I received included payback service.

Thanks to these kinds of initiatives, we're beginning to develop a new breed of scholars and professionals that are cultural practitioners themselves. Being Hawaiian, we can have our feet in both worlds, offer a unique perspective, and be from the communities we serve. So, we've made some advances, but we still have a way to go when it comes to developing scholars, researchers, and health professionals from within our community.

ORAL HEALTH

GROWING UP, WE USED Indian Health Service when we had to. It was terrifying, and I've been afraid of doctors and dentists ever since. It was scary enough that the doctors were military providers and the facilities were old, but nothing was as frightening as the dentists. They didn't offer gas or even numbing cream before injections. Now, I go to the doctor only if it's an absolute emergency, and I won't use IHS at all.

I got injured at work last year, and I had to take time off for therapy. Being off work, and without enough money to survive, I became really depressed. My teeth hurt, my back hurt, I'd lost weight, and I couldn't get out of bed for nearly a month. A friend who's not Indian stopped by to see me and was very upset with my condition. She told me I looked like "walking death." Since my teeth hurt so much, she asked me, "Why don't you go to the dentist? It would be free at Indian Health."

I told her, "You're not Indian and you don't know what it's like. For what I need done, they'd just give me a referral, and then I'd have to pay for it." My friend called members of my family and told them I really needed help, and they came up with the money for me to go to the dentist. I think I got good treatment there. Then my mother took me home to Pendleton so I could go to the doctor.

I used all my tax refund money to get my entire top row of teeth pulled and to pay for the denture plate. Now that I'm back to work, I make payments to the denturist for the bottom plate, and I've been saving for the \$700 I need to have the last of my bottom teeth pulled. I hope to have a new smile by the end of the summer. It's cost a lot of money, but at least I didn't have to go through the horror of IHS.

I think that people deserve quality health care that's affordable. Native Americans shouldn't have to suffer with less. It's not right. Our treaties guarantee health care, but using IHS seems like more of a death sentence.

FOR MORE THAN FORTY-FOUR YEARS, I've relied on Indian Health Services, and I've had a lot of struggles. Luckily, I've managed to stay healthy overall. But, now, I have some serious dental problems, and IHS hasn't been able to help.

Getting to see a doctor or dentist at the IHS clinic in Rapid City takes patience. You can't call ahead for an appointment. The clinic opens at twelve and by eleven you see a long line of people, all waiting. You have to arrive a couple hours beforehand if you want to be seen, and if you're not one of the first eight or ten people, you may be out of luck.

Over the years, I haven't been able to get good dental care. Plus, I'm still afraid of dentists, who traumatized me when I was a kid—they worked on me with no Novocain or anesthetic and didn't give me any preventive care. With time, my teeth have really gotten bad. They've decayed and hurt every day. I can't eat anything hot, cold, salty, or sweet.

Martine HOERNER

Umatilla

Lewiston, Idaho

Martine Hoerner is a member of the Umatilla Tribe, from Pendleton, Oregon. She moved to Idaho with her husband twelve years ago. Currently, she works at an ATK/Blount bullet factory.



Andrew IRON SHELL

Eastern Cherokee/Sicangu Lakota

Box Elder, South Dakota

Andrew Iron Shell is a Community Organizer with the Western South Dakota Native American Organizing Project. Previously, he has served with the Rosebud Sioux Tribe Community Health Representative Program, on the Native Communities HIV/STD Prevention Guidelines Task Force, and with the Office of Minority Health Resource Center.

I made it into the IHS clinic in Rapid City last spring, and that's where I had problems with contract services. Here I should explain something about the federal budget: the IHS clinic doesn't offer all the services a person needs. A lot they contract out to private doctors or dentists. But funding runs out in the first five months of the year—then they won't pay for contract care unless your life is at stake. At the Rapid City IHS clinic, they told me I had to have all my teeth pulled, but they couldn't send me for dentures until the next year, because the funds had ended. I'd have to go with no teeth at all for eight months!

They suggested one alternative: I could go to the IHS hospital on the Rosebud Reservation for surgery instead. That's 198 miles away, over roads with potholes, and I drive an '87 van. This would have involved several trips, each one costing \$80 to \$90, since my van's horrible on gas. Plus, I'd have to take someone along because of the anesthetic. So, that wasn't an option. At least I have a car, though. A lot of people in my community don't—we're one of the poorest counties in the country—or they have a real old one.

This situation made me depressed, and pretty hopeless. Then, luckily, I got health insurance through work—the first time I've ever had insurance. I'm going to have the surgery. I'm so relieved. I've had a couple of teeth pulled, and already my mental health has improved—now I know the problem will be fixed. But people shouldn't have to struggle like this for the health care so many other Americans take for granted.

My case is just one example. IHS simply doesn't have the resources to serve the Indian community. Rosebud has the facilities and equipment of a real hospital, but doesn't have the funding to staff it. When my daughter was about to be born, we wanted her to be delivered in her ancestral homeland, on the Rosebud Reservation. There weren't any obstetricians that day, though, so we had to go to Nebraska for a doctor!

Later, my daughter started having difficulty breathing. Only after a year of persistence, while it got worse and worse, did we get the right diagnosis: asthma. It's been a year now, she's receiving treatment and doing well, but, again, people shouldn't have to fight so hard.

Part of the problem is that you always see a different doctor and can't develop a trusting relationship. Almost all the doctors are white. Many have trouble communicating with us, aren't familiar with our culture, and need cultural competence training. It would help to have Native doctors familiar with our home environments. For example, a lot of houses have black mold, which causes health problems. A doctor from this community would know what our houses are like and think to ask about the mold.

There are many great people within IHS, but they can do only so much with the limited resources provided them. This represents a failure of the U.S. government to fulfill its obligations under the Fort Laramie treaty and its trust relationship with American Indian people. My hope is that sharing our stories will lead to unity and affirm a commitment to affordable health care for all. It is a basic human right.

HEALING THE MIND & SPIRIT

BETWEEN 2004 AND 2008, I LOST MY MOTHER, my father, and my brother. I miss them so much. The story of our family is like the story of our people in many ways—our struggles, and our hopes.

My mother was an alcoholic and was beaten by my father. My father went blind twice from his drinking. My brother choked to death right in front of my father. You would think that my father would have noticed my brother was blue in the face, but he thought Cody had just passed out from drinking. It wasn't until the next day that he realized my brother had died.

Many of us turn to drinking because of how hard life is for Native people. And after I lost so many of my family so quickly, the doctors wanted me to turn to chemicals, too—Prozac. But I don't believe in just taking pills. I needed to face my grief, the same way that my family needed to face the difficulties of their lives, and the same way we need to face our difficulties as a people. Drinking and pills don't get to the root of the problem. Settlers yesterday and doctors today push things that only make the situation worse.

Pow Wows, spiritual gatherings, AA groups on reservations where we can talk to each other—these are the things that make a difference, and this is the kind of care we need. Self-respect and faith are not things you can write prescriptions for, but you can't be healthy without them.

Very often I still feel depressed and miss my family terribly, especially on the holidays. But because I have faced my grief, felt the strength of my culture, and believe in God, I can live my life with hope. And, finally, I believe that when all races can come together across our differences, we will rely on each other more than on medicine. All of us have gone through hardship, and when we learn to share each other's struggles, so many of the problems that medicine tries to fix won't be around anymore.

I RUN AN ORGANIZATION THAT has an inter-tribal camp in the wilderness. Native people come to the camp to live, practice ceremonies, and connect with other Indians.

I want to share the story of one of the men—who I'll call Richard—who lives in the camp. We found Richard living on the streets, trying to survive with a bad leg and mental illness. We helped him move here and gave him a tiny trailer with no running water. Because he has strong anti-social behavior, this is about as integrated as he can be into society. But, in time, we got to know Richard and learned his story, and though he's very isolated, he still has needs that aren't being met.

Richard is a veteran and fought in a special unit. When parachuting during an invasion, he met gunfire, and his unit scattered. Richard ran

Stoney EAGLE BARTLETT
Maine



ANONYMOUS

in one direction, and the guys who ran in the other direction were killed. He got shot, too, though, and had to have surgery on his leg when he finally made it to a military hospital.

He's had knee problems and mental health problems ever since then. He became homeless not long after leaving the military. He sought help from the Indian Health Service, which said his care was the responsibility of the Veteran's Administration. At one point, they asked Richard to show his tribal ID, but he didn't have one. Meanwhile, the VA said they were reviewing his case, but they weren't providing him any services.

When I came on as Richard's advocate, we pushed for the VA to take some kind of action. After all the appointments and exams, the VA concluded that Richard was only 10 percent disabled. Just 10 percent! Richard has to be forced to bathe and groom—he's completely cut off from society and can't function in it. If we hadn't pushed, the VA would have said he wasn't disabled at all. Now he gets a monthly check for \$112, and more than half of this goes to child support. He certainly doesn't get any health care.

Richard is one of the Native people who are really falling through the cracks. I don't know if he's enrolled Apache or not, but he was raised traditionally by his grandfather, learning skills like tracking, desert living, shelter-making, and hunting. When he was a teenager, his grandfather left him in the wilderness to live and came back after one year—Richard jokes that his grandfather returned just as Richard was finally getting a good system down! He is connected to his Native culture, and he also bears the effects of everything that's been done to Indian people, but none of his needs are being met.

I know personally what that's like. I'm Native but of mixed background. I'm from one tribe that's recognized in Canada but not here, and I don't have enough "blood quantum" to be enrolled in the other.

I used to go to a clinic funded by IHS. Once I went in to have a cyst removed from my scalp. The doctor told me he wasn't sure he could do it. But, because I had no insurance—there's no way I can pay for it on my earnings—I talked him in to doing it anyway. I had no other options. Finally, he agreed.

He started removing the cyst. Then, he sent the nurse out to go find a cauterizing unit, because he couldn't stop my bleeding. The nurse went running out to search for it but came back empty-handed. She couldn't find it. The doctor had me press my own head while the two of them went to find the machine. They found it, but it didn't work. In the end, they gave me stitches so big they looked like football laces. I looked like I'd survived a major accident.

There's no good reason for the clinics that serve Native people to be so underfunded that they don't have proper equipment or qualified doctors. But, as it turns out, now I can't even go to this clinic. Later, when I went, I was asked for a roll number, which I don't have, because of my mixed background. This leaves me shut out of the Indian health system in the United States.

BATTLING STEREOTYPES & DISRESPECTFUL TREATMENT

I WENT TO THE EMERGENCY ROOM at the IHS hospital early one evening in 2007, with my back hurting, pain in my chest, and trouble breathing. I'd also been vomiting. After almost half an hour, the nurse on duty took my vitals, then sent me back to the waiting room. That was when I heard her call me "just a pill popper."

This comment burned. It was insulting and unprofessional. I thought, "After this, I'll never come back again."

I continued to wait. Forty minutes went by. I was finding it harder and harder to breathe. Finally, I approached the window. The same nurse—the one that had called me "just a pill popper"—took my vitals again. She told me that I was just hyperventilating, to breathe slowly, that I would be okay. I told her, no, I was having real trouble breathing. She said, "There are four people ahead of you."

She sent me back to the waiting room, where I waited another hour until I was called and the nurse led me to an examining room. I don't know how long I waited in the exam room. The pain in my back and lungs was so strong. After a time, I passed out. When I came to, I was startled. I tried to get up for help.

That was when the doctor came in. "I can't breathe," I told him. "I need help." He asked, "What nurse put you in here?"

I couldn't answer him. I just couldn't. I was in too much pain. I was wheeled into another examination room, given an IV and pain medication, and then I passed out again. Later that night, while I was unconscious, I was flown to St. Vincent's Hospital in Billings. There I was diagnosed with double pneumonia.

I arrived at the hospital about twenty minutes after five o'clock. I was air-lifted to the hospital in Billings about ten minutes before ten o'clock. I went in for emergency treatment. Instead, I was insulted, accused of seeking drugs, and placed in danger. People wonder why Indian people are afraid of seeing doctors and put off going to the hospital. This is why.

Johnny STOPS

Crow

Crow Agency, Montana

For more thirty years, **Johnny Stops** worked with the Bureau of Indian Affairs. He retired as supervisor of the road maintenance program at Crow Agency, after having coordinated or assisted in road surface sealing, fire suppression, and irrigation projects.



Juanita GEORGE
Fallon Paiute-Shoshone
Nevada

JUANITA GEORGE HAS WORKED as a Contract Health Clerk the Fallon Tribal Health Clinic for the past nine years.

I've always been in the best of health. Recently, I fell terribly ill: headache, bodyache, chills, 105-degree fever, vomiting, diarrhea, loss of appetite, and sleeplessness. I went to the Fallon Tribal Health Clinic, where they said I needed emergent care. They referred me to the local hospital, Banner Churchill Community Hospital. The hospital took one look at me and felt I needed to be careflighted to a medical center in Reno, where they had a specialist available.

Once I got to the medical center in Reno I was wheeled into a room and left there until finally a doctor came in. He told me I was very sick, with a high fever and a white blood count that was "wiped out." But they couldn't figure out why. The doctor then wrote me a prescription for antibiotics and headache medication. Then he said I was fine to go home. He told me if I was still sick the next day to come back.

I was shocked that I was being released so quickly, after being careflighted to Reno and feeling very, very ill. I asked, "Shouldn't I stay overnight for observation, or have more tests to find the solution to my problem?" I was told being at home and taking the medication prescribed should be sufficient, and any CT scans or MRI's would just lead to nowhere. I reluctantly picked up my things and headed home.

The next day my fever continued to climb and the headaches increased. I began to show signs of an allergic reaction to the antibiotics, so once again I returned to the medical center. They drew more blood and did a CT scan of my head. The tests came back negative. They wrote more prescriptions and sent me home once again. I was feeling weak, ill, and in so much pain—not to mention frustrated at being brushed aside with no answers.

That following Monday, I still felt very sick. I went back to our clinic seeking help. They were very kind and worried that I hadn't been admitted to the hospital. Dr. Mabunda at our clinic started some IV's, drew blood, and tested me again for the flu and strep throat. He got the paperwork together and sent me back to the medical center in Reno.

I once again went to the ER there. I sat and waited what seemed like an eternity. Finally I was admitted to the hospital—after the ER doctor read a letter Dr. Mabunda had sent with me.

Being at that medical center was a nightmare! Thank goodness I had family members there to help me get up and use the restroom. I was constantly up and down vomiting and with my diarrhea. I couldn't walk on my own because I was weak and dizzy. But I rarely saw a nurse. And my arms wound up full of holes because, when nurses did come in, they couldn't get the IV in correctly. My IV perforated twice and both my right and left arms were swollen. It was such a terrible experience!

The last night they woke me up at 1:00 am and told me they were moving me to another room. There were two other patients there, and the room was so filthy, I was afraid to stay there with my weak immune system.

The next day one of the physicians told me he was sending me home, since they didn't have answers to why I was so sick. He told me that a lot of the time they have patients coming in seeking pain medications or running from their stressors. He said, "You have kids at home. Don't you want to go home and take care of them?"

I couldn't believe he was actually saying these things to me. It made me so angry. Hearing him say those things to me I just wanted to leave. I didn't care how sick I was I just wanted to get out of that place!

Now they have me scheduled to follow up with an infectious disease doctor, but I'm seriously thinking about canceling that appointment. I don't look forward to being treated like I'm faking my illness, or there to seek medication. My whole experience with that medical center was a nightmare and left me feeling disgusted. If I ever get sick again I don't want to go back there. I'll die at home.

I FEEL THAT I SAW A LOT OF incompetent care, and disrespectful treatment, while I was working as an LPN with IHS. Once I was with a woman going into labor, and the attending physician told her to handle it herself, because he was busy.

Another time, I told the doctor that a patient was in severe pain. The doctor said, "So you think you're a doctor, now? Who are you to say what he is or isn't feeling?" That patient had to be flown to Billings with a ruptured gall bladder.

Guinea pigs to experiment on—that's how we've been treated. In the 1980's, an IHS nurse told me she'd been sent to the reservation because, as she put it, "You Indians are incapable of thinking for yourselves." And a doctor once said to me, "You Indians make things up. It's in your nature to tell lies."

I've had many of my own health struggles: diabetes, deafness in my left ear from a mini-stroke, asthma, head trauma after an assault. Because I was an LPN, I received special treatment, treatment other people would be very lucky to have. But I've also often felt like doctors didn't listen to me closely, and I've felt like racism has interfered with my care and the care of Indian people generally.

Brenda PRETTY WEASEL
Crow/Sioux/Irish
Crow Agency, Montana

Brenda Pretty Weasel currently works for the Census Bureau. In the 1990's, she worked for two years as a Licensed Practical Nurse (LPN) with the Indian Health Service. She hurt her back while working and later lost her job—due to the pain, she could no longer perform her duties. In her spare time, she reads mystery novels.



RESEARCHING NATIVE HEALTH

Maile TAUALI'I
Hawaiian
 Honolulu, Hawaii

Maile Tauali'i received her Ph.D., in Health Services, Public Health Informatics, from the University of Washington. She directs the Native Hawaiian Epidemiology Center at Papa Ola Lokahi. Previously, she served as Scientific Director of the Urban Indian Health Institute.

ON ALMOST EVERY FRONT, Native Hawaiians suffer the worst health disparities of any group in the United States, from infant mortality to chronic conditions, to infectious disease. But that reality is masked by the lack of data. When data is available, it's very limited and sometimes people feel they can't use it, so it gets excluded. This makes us invisible in many respects, and that invisibility is a huge problem.

The biggest issue I'm championing now is the aggregation of data under the "Asian Pacific Islander" category, originally driven by the U.S. federal government. This categorization masks health disparities because Asians make up over ninety percent of that category and Hawaiians only a tiny percentage. When combined with Asians, our health status looks better than that of almost all races. Yet, when you model our health data, it's more in line with American Indians than any other group. We share what I believe is the number one health determinant: colonization.

The Office of Management and Budget has issued a directive, which applies to any data collection funded by federal dollars, that Native Hawaiians and Pacific Islanders are to be separated from Asians. But there are no teeth to the directive. Researchers revert to the historical collection method, which is API, because the directive included no penalty and no incentive.

If we were able to demonstrate the extent of our health disparities, it would drive policy decisions and create funding mechanisms. When we don't exist, there are no services, no programs, and no resources to address the issues we face.

CONCLUSION & RECOMMENDATIONS

Despite over 200 years of subjugation and the efforts of others to conquer us to the point of (for some tribes) extinction, we have managed to survive. We have been able to do so because of our deeply rooted value that we exist in a Tiospaye (family circle). As part of that circle, our practice of ancestral cultural traditions and values have kept us alive, hecel oyate kini pi kte (so that our people may live)."

Colette KEITH, LAKOTA

ACROSS THE UNITED STATES, the public is engaged in a debate about how to improve the health care system and ensure access to quality, affordable health care for everyone in the country. This debate acknowledges the widespread shortfalls of the health care system and the need for reform. Yet not all people in the United States join the health care reform conversation at the same starting line.

Native people in the U.S. come to the health care reform discussion with an excess burden of disease, a crumbling or stressed health care infrastructure, and mistrust of a health care system that has failed to provide quality, culturally competent care. They also come to the health care discussion with unfulfilled promises, debts, and obligations based on their unique relationships to the United States government. These obligations exist independently of the mainstream health care reform discussion.

To move toward fulfilling its obligation for Native health, the federal government should take steps that recognize the full range of barriers to health and health care experienced by Native people. In taking such measures, the federal government must respect the sovereignty, self-determination, and consultation rights of Native people. The recommendations below provide examples of such steps.

Ensure full funding for the Indian Health Service

The health care infrastructure funded through the Indian Health Service budget needs updating, expansion, and modernization. The federal government should reverse the history of chronic underfunding of IHS and provide the resources needed to bring IHS facilities, health information technology, and service delivery into the 21st Century. It should also ensure that tribes have the authority to explore innovative ideas for addressing facility needs and the flexibility to use existing facilities fully and efficiently. Moreover, Urban Indian Health Program clinics and programs need full funding, support, and expansion to all urban centers with sizeable Indian communities. Finally, the IHS system should be transparent and responsive to patients' complaints and concerns.

Support improvements in the availability and quality of comprehensive health care for Hawaiians

Hawaiians, as one of this country's Indigenous Peoples, need to have universal access to the full range of health care, including physical, behavioral, and oral health. Traditional health practices also need to be available when appropriate and validated by Western-trained medical practitioners. Some of the issues surrounding current health care for Hawaiians include: the lack of 100 percent Federal Medical Assistance Percentage legislation for Hawaiians; the low reimbursement rates for providers of care to Hawaiians; the inability of Hawaiians to access specialty care providers in a timely fashion; the lack of long-term care options for Hawaiians; the lack of Hawaiian providers practicing in Hawaiian communities on the continental United States and the lack of cultural understanding of providers generally; and the higher costs of treatment for Hawaiians generally because of multiple health issues. Each of these issues needs to be addressed by appropriate federal action and/or federal agencies.

Increase enrollment of Native people in public health programs

Despite high rates of disability, poverty, and health disparity American Indians and Alaska Natives have low rates of enrollment in key public health programs such as Medicaid, Medicare, and the Children's Health Insurance Program. Health care reform should include increased outreach and enrollment efforts for American Indians and Alaska Natives, including using Fast Track enrollment at Indian health providers as well as other enhanced enrollment methods. Moreover, Medicaid eligibility should be expanded.

Support improvements in the quality of care

The federal government should ensure the availability of integrated services that address the full range of Native people's health needs, whether physical, mental, or behavioral. All services should be provided in a culturally and linguistically appropriate manner—with emphasis on prevention, health promotion, and the whole person. Payment reform should encourage the integration, rather than segregation, of health services so that patient-centered health care home models of care (and other models that integrate all aspects of care) are the norm.

Furthermore, Native peoples often have distinct and unique approaches to health and wellness often based upon their respective cultural values and traditions. For Hawaiians, a number of health and wellness programs have been structured around voyaging and sailing and relationships with the land. Health programs and projects utilizing these relationships, and other culturally-based programs, need to be supported and expanded upon for Native communities by the U.S. federal government.

Develop a larger, more diverse, and culturally competent health care workforce

The federal government should increase financial support for the training, recruitment, and retention of American Indian and Alaska Native health care practitioners. Pipeline incentives and reimbursement reform should be implemented to attract, train, support, and retain a diverse, culturally competent workforce. Similarly, the Native Hawaiian Health Scholarship Program has begun to make a major impact on the underrepresentation of Hawaiians in the health and allied health professions. This program should be expanded, along with expansion of other federal efforts, such as loan repayment programs, so they include specific Hawaiian initiatives.

The federal government should also support the use of health care navigators and other professionals that help ensure that Native people receive needed care and services in an appropriate and timely way. The Community Health Representative Program developed under the Indian Health Care Improvement Act, and modeled upon community health workers, is an ideal way to support necessary community involvement to address access issues.

Support culturally appropriate research and data collection that advances the health of Native people

Best practice research and development must be community-informed, community-based, and representative of actual populations involved. Data, public health surveillance, and research systems and guidelines must be updated, implemented, and enforced to guarantee the full and accurate representation of American Indians, Alaska Natives, Hawaiians, and other indigenous people. The federal government should expand support for Native community-based Institutional Review Boards and support the development and training of Native health researchers.

The undercounting of American Indians and Alaska Natives must be remedied. And federal agencies, state governments, and private foundations need to evaluate their reporting standards to assure their compliance with Office of Management and Budget revised standards regarding racial and ethnic data, including correctly identifying Hawaiian data. Moreover, the Native Hawaiian Epi Center—which identifies and tracks Hawaiian health status nationally and provides programmatic guidance in meaningful health care initiatives to public and private entities—should receive comprehensive and consistent federal funding.

Safeguard the rights of Native people—and their relationships with the federal government (including sovereignty and the trust responsibility)—in and through health care reform

- Protect American Indians and Alaska Natives from cost-sharing or monetary penalties, which would violate the federal trust responsibility and Indian people's right to health care. Furthermore, as a matter of sovereignty, Indian tribes as employers must be protected from financial penalties related to the provision of coverage.
- Guarantee automatic eligibility of American Indians and Alaska Natives for all federal or state health plans and services, as well as access to associated subsidies.
- Apply protections for American Indians and Alaska Natives in Medicaid, including Medicaid managed care, to their participation in any health insurance plan under health care reform.
- Provide the choice of a public health insurance plan (as an alternative to private insurance) to address the high rates of both uninsurance and underinsurance among Native people.
- Include a standard for health benefits that covers both preventive and curative interventions.
- Protect the ability of Native health programs to integrate traditional health care practices into their prevention/wellness programs.
- Ensure representation of Native nations in all bodies created under health care reform.
- Guarantee the ability of Hawaiians to consult with the federal government around areas of mutual concern and interest, including health care.
- Ensure the federal government's support for and commitment to Native Hawaiian health care as identified in current 100 percent FMAP legislation and the Native Hawaiian Health Care Improvement Act reauthorization.
- Advance the ability of all Hawaiians to access timely and appropriate health care regardless of their abilities to pay.
- Ensure the ability of Native Hawaiians to administer and direct their own health care initiatives, including those providing traditional healing practices and health promotion practices, with federal support.
- Include Hawaiian representation in all bodies established under new health care reform legislation.

Reinforce health care infrastructures

Mechanisms must be implemented to support safety net institutions and quality improvement initiatives in all health care settings. These include: expanding and strengthening culturally competent health care providers such as Urban Indian Health Programs and Community Health Centers; prioritizing investment in the primary care infrastructure, including facilities, equipment, and health IT; and promoting the adoption of patient-centered health care home models of care.

Support efforts to develop healthy food systems and economies in Native nations and communities

Many health solutions for Native people lie outside the health care system. Across the country, Native people are developing strategies to build green economies and sustainable food systems. These strategies have the potential to benefit not only Native communities but also the population as a whole. The federal government should provide support for these efforts by helping open access to broader markets and revising programs to encourage sustainable, rather than unsustainable, practices.

SOURCES

- 1 Carolyn Melenani Kualii, "Navigating Our Way Towards Health & Wellness: A Native Hawaiian Perspective," n.d.
- 2 Jeanne Bertolli, et al., "Racial Misidentification of American Indians/Alaska Natives in the HIV/AIDS Reporting Systems of Five States and One Urban Health Jurisdiction, U.S., 1984-2002," Public Health Reports, May – June 2007.
- 3 Brett Lee Shelton, "Legal and Historic Roots of Health Care for American Indians and Alaska Natives in the United States," Henry J. Kaiser Foundation, February 2004. [Hereinafter referred to as Shelton.]
- 4 National Congress of American Indians, "Federal Recognition," viewed at: <http://www.ncai.org/Federal-Recognition.70.0.html>.
- 5 Ibid.
- 6 Christopher K. Riggs, "Dual Citizenship and the Struggle for American Indian Voting Rights in the Southwest in the 1940's," April 2006, viewed at: <http://www.lcsc.edu/criggs/documents/votingrights1.pdf>.
- 7 National Council of Urban Indian Health, "The Legal Status of Urban Indians Under Federal Indian Law," October 23, 2006.
- 8 Carl H. Johnson, "A Comity of Errors: Why John V. Baker Is Only a Tentative First Step in the Right Direction," Alaska Law Review, June 2001.
- 9 Erik Bruce Smith, "Dental Therapists in Alaska: Addressing Unmet Needs and Reviving Competition in Dental Care," Alaska Law Review, June 2007.
- 10 Melody Kapilialoha MacKenzie, "Native Hawaiians and the Law: Struggling with the He'e," Asian-Pacific Law & Policy Journal, Winter 2006.
- 11 Ibid.
- 12 Native Hawaiian Health Care Act of 1988, Pub. L. No. 100-579, 102 Stat. 296 (1988); Kekuni Blaisdell, "Update on Kanaka Maoli (Indigenous Hawaiian) Health," In Motion, 1997.
- 13 Dana Lee Jetty, Written Comment & Testimony, Youth Suicide in Indian Country, U.S. Senate Committee on Indian Affairs, February 26, 2009.
- 14 National Center for Health Statistics, Health, United States, 2008, 2009, Table 22, pp. 194-195; Office of Minority Health, "Native Hawaiians/Other Pacific Islander Profile," viewed at: www.omhrc.gov.
- 15 National Center for Health Statistics, Health, United States, 2008, 2009, Table 29, pp. 211-212. Table provides figures for "years of potential life lost before age 75 for selected causes of death, by sex, race, and Hispanic origin: United States, selected years 1980-2005." Statistic applies to American Indians and Alaska Natives. Hawaiians in Hawaii are more than twice as likely to die of cardiovascular disease as the state's overall population. Rosanne C. Harrigan, et al., "Oral health Disparities and Periodontal Disease in Asian and Pacific Island Populations," Ethnic Disparities, 2005. Hawaiians in Hawaii have a cancer death rate 50 percent higher than that for the total state population, a death rate from kidney disease that is 140 percent higher, and a death rate from chronic lower respiratory disease that is almost 50 percent higher. Hardy Spoehr, Testimony the House Ways and Means Committee, Subcommittee on Health, June 10, 2008; Moreover, Hawaiians have the lowest life expectancy of any group in Hawaii. Lana Sue I. Ka'opua & Charles W. Mueller, "Treatment adherence among native Hawaiians living with HIV," Social Work, January 2004.
- 16 Eighteen percent of American Indians/Alaska Natives aged 20 or over have diabetes. The rate for the same-aged overall population is 9.6 percent. Holly Mead, et al., Racial and Ethnic Disparities in U.S. Health Care: A Chartbook, The Commonwealth Fund, March 2008, p. 32. Hawaiians in Hawaii are 50 percent more likely than whites to die of diabetes. Hardy Spoehr, Testimony the House Ways and Means Committee, Subcommittee on Health, June 10, 2008.
- 17 Kaiser Family Foundation, "Key Facts: Race, Ethnicity & Medical Care," January 2007, p.35. Adult asthma attack statistic applies to American Indians and Alaska Natives. Hawaiians have the highest rate of asthma in Hawaii. Office of Hawaiian Affairs, Native Hawaiian Data Book, p. 98.
- 18 National for Health Statistics, "Summary Statistics for U.S. Adults: National Health Interview Survey" Table 2, "Age-adjusted percent distributions (with standard errors) of respondent-assessed health status, by selected characteristics: United States, 2007. Statistic applies to American Indians and Alaska Natives.
- 19 Sadie Willmon-Haque & Dolores Subia BigFoot, "Violence and the Effects of Trauma on American Indian and Alaska Native Populations," Journal of Emotional Abuse, 2008. Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States," 2006, p. 4.
- 20 Patricia M. Barnes, et al., "Health Characteristics of the American Indian and Alaska Native Population: United States: 1999-2003," National Center for Health Statistics, April 27, 2005, p. 5; Holly Mead, et al., Racial and Ethnic Disparities in U.S. Health Care: A Chartbook, The Commonwealth Fund, March 2008, p. 43; Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States," 2006, p. 4.
- 21 American Indians and Alaska Natives have a rate of suicide 60 percent higher than for other groups in the United States. Association of American Indian Physicians, American Indian/Alaska Native Facts-at-a-Glance Guide, n.d.; Sadie Willmon-Haque & Dolores Subia BigFoot, "Violence and the Effects of Trauma on American Indian and Alaska Native Populations," Journal of Emotional Abuse, 2008.
- 22 Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 11.
- 23 Nancy Krieger, "Unnatural Causes: Ask the Experts Forum – Divided We Fall," 2008, p. 6.
- 24 Sherry Salway Black, "American Indian Tribes and Structural Racism," Poverty & Race, November/December 2008, p.1.
- 25 Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007; Marjorie K. Mau, et al., "Environmental Factors of Obesity in Communities with Native Hawaiians," NIH Public Access, published in final form in Hawaiian Medical Journal, September 2008 (study found that "[c]ommunities with a higher proportion of [Native Hawaiians] had a greater proportion of fast food outlets and the least number of exercise facilities per 10,000 population."); Sadie Willmon-Haque & Dolores Subia BigFoot, "Violence and the Effects of Trauma on American Indian and Alaska Native Populations," Journal of Emotional Abuse, 2008, p. 57; Joseph Keawe'aimoku Kaholokula, et al., "Pacific Islanders' Perspectives on Health Failure Management," Patient Education and Counseling, February 2008, p. 6 (cost of nutritious food identified by study participants as a barrier to heart failure care); Lori A. Colomeda & Eberhard R. Wenzel, "Medicine Keepers: Issues in Indigenous Health," Critical Public Health, April 2000; Monica K. Mau, "A history of Native Hawaiian Health," Senior Talk, UCLA Internal Medicine-Pediatrics Residency, January 15, 2009.
- 26 Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 2.
- 27 California Newsreel, "Unnatural Causes: Bad Sugar," 2008.
- 28 Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 12.
- 29 Daisy Hernández, "Got Tradition?: American Indians use native foods to fight diabetes and revive Indian culture," ColorLines, Summer 2005.
- 30 Association of American Indian Physicians, AI/AN Diabetes Resource Guide, pp. 6-7; Rebecca Adamson, et al., "Asset Building in Native Communities: An Asset Building Framework," First Nations Development Institute, 2004, p. 7; Sherry Salway Black, "American Indian Tribes and Structural Racism," Poverty & Race, November/December 2008.
- 31 Sherry Salway Black, "American Indian Tribes and Structural Racism," Poverty & Race, November/December 2008, p. 6.
- 32 Kaiser Family Foundation, "Key Facts: Race, Ethnicity & Medical Care," January 2007, p. 22. Data includes non-elderly population. Statistic is for American Indians and Alaska Natives in the 2003-2004 period.
- 33 Kaiser Family Foundation, "Key Facts: Race, Ethnicity & Medical Care," January 2007, p. 24; Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States," 2006, p. 3.
- 34 Patricia M. Barnes, et al., "Health Characteristics of the American Indian and Alaska Native Population: United States: 1999-2003," National Center for Health Statistics, April 27, 2005. Statistic is for American Indians and Alaska Natives.
- 35 Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States, 2006," p. 2. Figure includes Hawaiians and Other Pacific Islanders.
- 36 Van M. Ta, et al., "Disparities in Use of Mental Health and Substance Abuse Services by Asian and Native Hawaiian/Other Pacific Islander Women," Journal of Behavioral Health Services & Research, January 2008.
- 37 Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States, 2006," p. 3.
- 38 Sabrina T. Wong, et al., "Rural American Indian Medicaid Health Care Services Use and Health Care Costs in California," American Journal of Public Health, February 2006. This study found lower use of Medicaid services by American Indians and Alaska Natives, compared to whites also enrolled in the program.
- 39 Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004.
- 40 Indian Health Service, "Welcome to the Alaska Area Office of IHS," viewed at: <http://www.ihs.gov/facilitieservices/areaoffices/alaska/>.
- 41 Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 7.
- 42 Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004.
- 43 Timothy M. Westmoreland & Kathryn R. Watson, "Redeeming Hollow Promises: The Case for Mandatory Spending on Health Care for American Indians and Alaska Natives," American Journal of Public Health, April 2006.
- 44 Timothy M. Westmoreland & Kathryn R. Watson, "Redeeming Hollow Promises: The Case for Mandatory Spending on Health Care for American Indians and

- Alaska Natives," *American Journal of Public Health*, April 2006, p. 602.
- ⁴⁵ Timothy M. Westmoreland & Kathryn R. Watson, "Redeeming Hollow Promises: The Case for Mandatory Spending on Health Care for American Indians and Alaska Natives," *American Journal of Public Health*, April 2006, p. 600.
- ⁴⁶ Donald Warne, "Ten Indian Health Policy Challenges for the New Administration in 2009," *Wicazo SA Review*, Spring 2009, p. 10.
- ⁴⁷ Donald Warne, "Ten Indian Health Policy Challenges for the New Administration in 2009," *Wicazo SA Review*, Spring 2009, p. 14. ("In addition to increased local control and flexibility, the IHS is required to provide contract support costs to the tribes, which are essentially funds for administration of the '638 contract.' Unfortunately, funding for contract support costs has not been increased to keep up with the demand as more tribes have exercised their rights to manage their own health systems under self-determination law.")
- ⁴⁸ Government Accountability Office, "Health Care Services Are not Always Available to Native Americans," August 2005.
- ⁴⁹ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, p. 70-76.
- ⁵⁰ Amnesty International, *Maze of Injustice: The Failure to Protect Indigenous Women from Sexual Violence in the USA*, 2007, p. 76; Eugene DeLorne, J.D., Director, Indians into Medicine, Assistant Professor in Family Medicine, Statement to the Select Committee on Indian Affairs, United States Senate, May 21, 1998.
- ⁵¹ Amnesty International, *Maze of Injustice: The Failure to Protect Indigenous Women from Sexual Violence in the USA*, 2007, p. 76.
- ⁵² U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, p. 66.
- ⁵³ Donald Warne, "Ten Indian Health Policy Challenges for the New Administration in 2009," *Wicazo SA Review*, Spring 2009, p. 13.
- ⁵⁴ Stephen Zuckerman, et al., "Health Service Access, Use, and Insurance Coverage among American Indians/Alaska Natives and Whites: What Role Does the Indian Health Service Play?" *American Journal of Public Health*, January 2004.
- ⁵⁵ National Indian Health Board, "Indian Health Care Improvement Act," viewed at: www.nihb.org, May 6, 2009.
- ⁵⁶ National Congress of American Indians and National Indian Health Board, "Reauthorization of the IHCA: Bringing Indian Health Services into the 21st Century," February 2006.
- ⁵⁷ National Indian Health Board, "Indian Health Care Improvement Act," viewed at: www.nihb.org, May 6, 2009.
- ⁵⁸ Carrie Tracy, "Montana's Urban Indians Face Health Barriers," Northwest Federation of Community Organizations, n.d, p. 5.
- ⁵⁹ National Urban Indian Family Commission, "Urban Indian America: The Status of American Indian and Alaska Native Children and Families Today," n.d.
- ⁶⁰ Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 1.
- ⁶¹ U.S. Census Bureau, "Income, Poverty, and Health Insurance Coverage in the United States: 2007," August 2008, Table 7, p. 23. Uninsured rates are an average for 2005-2007.
- ⁶² Carrie Tracy, "Montana's Urban Indians Face Health Care Barriers," Northwest Federation of Community Organizations & Montana People's Action/Indian People's Action, n.d.
- ⁶³ Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004.
- ⁶⁴ Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 8.
- ⁶⁵ Urban Indian Health Commission, "Invisible Tribes: Urban Indians and Their Health in a Changing World," 2007, p. 1.
- ⁶⁶ Urban Indian Health Institute, "Fact Sheet: Health Status for Urban American Indians & Alaska Natives," n.d.
- ⁶⁷ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 62-65.
- ⁶⁸ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 68.
- ⁶⁹ "Native Hawaiian Health Care Systems," *Niu Maka*, Spring 2005, p. 1.
- ⁷⁰ Papa Ola Lokahi, "Native Hawaiians and Health," n.d., on file with the editors, p. 2.
- ⁷¹ Papa Ola Lokahi, "Native Hawaiians and Health," n.d., on file with the editors, p. 1.
- ⁷² Hardy Spoehr, Executive Director, Papa Ola Lokahi, Interview with the editor, May 13, 2009.
- ⁷³ Papa Ola Lokahi, "Native Hawaiians and Health," n.d., on file with the editors, p. 2.
- ⁷⁴ Sylvia A. Law, "Health Care in Hawaii: the Agenda for Research and Reform," *American Journal of Law and Medicine*, 2000, p. 206.
- ⁷⁵ Hardy Spoehr, Executive Director, Papa Ola Lokahi, Interview with the editor, May 13, 2009.
- ⁷⁶ David MKI Liu, et al., "Health Disparities in Hawaii: Part 1," *Hawaii Journal of Public Health*, p. 11, viewed at: <http://hawaii.gov/health/hjph/HJPH/PAGES/article.html>.
- ⁷⁷ Sylvia A. Law, "Health Care in Hawaii: the Agenda for Research and Reform," *American Journal of Law and Medicine*, 2000, p. 206.
- ⁷⁸ Helen Altonn, "Need strains isle health clinics," *Honolulu Star-Bulletin*, September 3, 2007.
- ⁷⁹ Marjorie K. Mau, et al., "Renal Disease Disparities in Asia and Pacific-Based Populations in Hawaii," *Journal of the National Medical Association*, October 2003, p. 961.
- ⁸⁰ Megan Inada, et al., "Health Workforce Assessment of Hawaii Physicians: Analysis of data from the DHHS Health Resources and Services Area Resource File, 2001," *Californian Journal of Health Promotion*, 2005.
- ⁸¹ Hardy Spoehr, Testimony the House Ways and Means Committee, Subcommittee on Health, June 10, 2008.
- ⁸² U.S. Census Bureau, "Income, Poverty, and Health Insurance Coverage in the United States: 2007," August 2008, Table 7, p. 23. Uninsured rates are an average for 2005-2007. Figure is for Native Hawaiians and Other Pacific Islanders.
- ⁸³ Asian Pacific Islander American Health Forum, "APIAHF Health Brief: Native Hawaiians in the United States, 2006," p. 2. Figure includes both Hawaiians and Other Pacific Islanders.
- ⁸⁴ Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," 2007, p. 53. Statistic applies to American Indians and Alaska Natives.
- ⁸⁵ Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," 2007, p. 69. Includes "long-stay high-risk nursing home residents." Statistic applies to American Indians and Alaska Natives.
- ⁸⁶ Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," 2007, p. 72. Statistic applies to American Indians and Alaska Natives.
- ⁸⁷ Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," 2007, p. 73. "Asian Pacific Islanders" have a higher rate of receiving hospice care inconsistent with their wishes. Again, because of aggregation, the rate of Hawaiian dissatisfaction with end-of-life care remains unknown.
- ⁸⁸ Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004.
- ⁸⁹ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 80-81.
- ⁹⁰ Carrie Tracy, "Montana's Urban Indians Face Health Barriers," Northwest Federation of Community Organizations, n.d., p. 17.
- ⁹¹ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, p. 31.
- ⁹² U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 30-31.
- ⁹³ Lana Sue I. Ka'opua & Charles W. Mueller, "Treatment adherence among native Hawaiians living with HIV," *Social Work*, January 2004; Juliet McMullin, "The Call to Life: Revitalizing a Healthy Hawaiian Identity," *Social Science & Medicine*, August 2005.
- ⁹⁴ Lana Sue I. Ka'opua, Diane B. Mitschke, Karen C. Kloezeman, "Coping with Breast Cancer at the Nexus of Religiosity and Hawaiian Culture: Perspectives of Native Hawaiian Survivors and Family Members," *Journal of Religion & Spirituality in Social Work: Social Thought*, 2008, p. 278.
- ⁹⁵ Kapuola Gellert, et al., "The 'Ohana Day Project: A Community Approach to Increasing Cancer Screening," *Preventing Chronic Disease: Public Health Research, Practice, and Policy*, July 2006.
- ⁹⁶ Carrie Tracy, "Montana's Urban Indians Face Health Barriers," Northwest Federation of Community Organizations, n.d.; U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 35-36.
- ⁹⁷ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, pp. 35-36.
- ⁹⁸ U.S. Commission on Civil Rights, *Broken Promises: Evaluating the American Health Care System*, September 2004, p. 37.
- ⁹⁹ Hardy Spoehr, Testimony the House Ways and Means Committee, Subcommittee on Health, June 10, 2008.
- ¹⁰⁰ Katherine Gottlieb, et al., "Transforming Your Practice: What Matters Most," *Family Practice Management*, January 2008, p. 33.
- ¹⁰¹ Eugene DeLorne, J.D., Director, Indians into Medicine, Assistant Professor in Family Medicine, Statement to the Select Committee on Indian Affairs, United States Senate, May 21, 1998.
- ¹⁰² Edna Francisco, "Preparing Native Health Professionals," *Tribal College*, Summer 2007.
- ¹⁰³ Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," 2007, p. 90. Statistic applies to American Indians and Alaska Natives.



ABOUT THE ORGANIZATIONS RELEASING THIS REPORT

The Health Rights Organizing Project is a collaboration of grassroots community organizations around the country. The project is co-coordinated by the Northwest Federation of Community Organizations and the Center for Community Change. Each member organization is committed to securing quality, affordable health care for all.

MEMBER ORGANIZATIONS INCLUDE:

Alliance to Develop Power
California Immigrant Policy Center
California Partnership
Coalition for Humane Immigrant Rights of Los Angeles
Colorado Progressive Coalition
Connecticut Citizen Action Group
Faith Action for Community Equity
Granite State Organizing Project
Grassroots Organizing
Idaho Community Action Network
Indian People's Action
ISIAAH
Korean Resource Center
Maine People's Alliance
Make the Road New York
Michigan Gamaliel
Montanans for Health Care
National Korean American Service & Education Consortium
Nebraska Appleseed
New York Immigration Coalition
North Carolina Fair Share
Northeast Action
Ocean State Action
Ohio Gamaliel
Oregon Action
Organization of the Northeast
Progressive Leadership Alliance of Nevada
South Carolina Fair Share
South Dakotans for Health Care Solutions
Sunflower Community Action
Tying Nashville Together
United Action of Connecticut
Virginia Organizing Project
Washington Community Action Network



NORTHWEST FEDERATIONS OF COMMUNITY ORGANIZATIONS
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