# Leveraging Culture to Address Health Inequalities: Examples from Native Communities: Workshop Summary

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Karen M. Anderson and Steve Olson, Rapporteurs; Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities; Board on Population Health and Public Health Practice; Institute of Medicine

# LEVERAGING CULTURE TO ADDRESS HEALTH INEQUALITIES

## Examples from Native Communities

Workshop Summary

Karen M. Anderson and Steve Olson, *Rapporteurs*

Roundtable on the Promotion of Health Equity and the
Elimination of Health Disparities

Board on Population Health and Public Health Practice

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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*"Knowing is not enough; we must apply.*
*Willing is not enough; we must do."*
—Goethe

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*IOM Staff*

**KAREN M. ANDERSON,** Senior Program Officer
**ANDRÉS GAVIRIA,** Research Associate (until August 2013)
**ALEJANDRA MARTIN,** Research Associate (until July 2012)
**DORIS ROMERO,** Financial Associate
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This workshop summary has been reviewed in draft form by persons chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

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**Loretta J. Fuddy,** Hawaii Department of Health
**Tom Granatir,** American Board of Medical Specialties
**Elena O. Nightingale,** Institute of Medicine
**David Pryor,** NBC Universal

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Ned Calonge.** Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the authors and the institution.

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APPENDIXES

# Abbreviations and Acronyms

| | |
|---|---|
| ACA | Patient Protection and Affordable Care Act |
| AI | American Indian |
| AN | Alaska Native |
| DHAT | dental health aide therapist |
| FSM | Federated States of Micronesia |
| IHS | Indian Health Service |
| IOM | Institute of Medicine |
| MRI | magnetic resonance imaging |
| NCAI | National Congress of American Indians |
| OHSU | Oregon Health and Science University |
| SAMHSA | Substance Abuse and Mental Health Services Administration |
| SEARHC | SouthEast Alaska Regional Health Consortium |
| UN | United Nations |
| VA | Department of Veterans Affairs |

# 1

# Introduction and Themes of the Workshop[1]

In Native American tradition, the medicine wheel encompasses four different components of health: physical, emotional, mental, and spiritual (see Figure 1-1). Health and well-being require balance within and among all four components. Thus, whether someone remains healthy depends as much on what happens around that person as on what happens within.

On November 14, 2012, the Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities of the Institute of Medicine (IOM) held a workshop in Seattle, Washington, to explore the ideas at the heart of the medicine wheel. Titled Leveraging Culture to Address Health Inequalities: Examples from Native Communities, the workshop brought together more than 100 health care providers, policy makers, program administrators, researchers, and Native advocates to discuss the sizable health inequities affecting Native American, Alaska Native, First Nation, and Pacific Islander populations and the potential role of culture in helping to reduce those inequities. The Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities was created to enable dialogue and discussion of issues related to (1) the visibility of racial and ethnic disparities in health and health care as a national problem; (2) the development of programs and strategies to reduce disparities; and

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[1] The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, are not necessarily endorsed or verified by the Institute of Medicine, and they should not be construed as reflecting any group consensus.

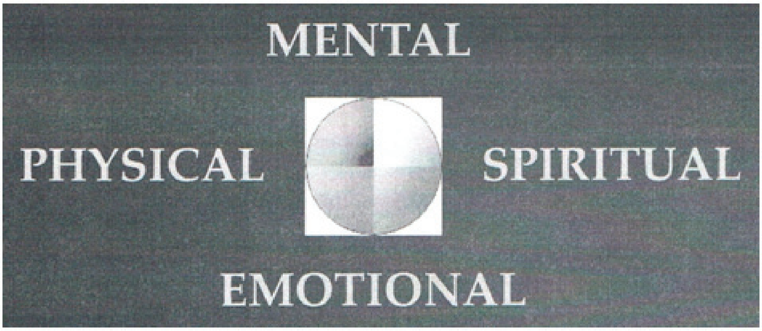

**FIGURE 1-1** In the medicine wheel, health has physical, mental, spiritual, and emotional components.
SOURCE: White Earth Nation.

(3) the emergence of new leadership. All three objectives were achieved at the Seattle meeting.

"Culture is so important in our well-being," said Ralph Forquera, executive director of the Seattle Indian Health Board, in his opening remarks at the workshop. Native Americans have struggled and continue to struggle to find their identity and place in Western society. Yet, they have inherited strong and enduring cultural traditions that continue to evolve in response to new circumstances. The resulting cultural dichotomies have become a defining element in the effort to use culture to improve the health prospects of Native people. "This searching for culture, this searching for identity, the searching for belonging transcends many of the social factors that are oftentimes viewed as being important characteristics of the health dilemma," said Forquera.

## ORGANIZATION OF THE SUMMARY

This summary of the workshop describes the observations, conclusions, and recommendations made by the individual presenters at the workshop and by individual workshop participants during the rich discussions that followed the presentations. Chapter 2 summarizes the keynote address made by James Knibb-Lamouche, director of research for the Blue Quills First Nations College, who wrote a commissioned paper for the workshop (see Appendix A). Chapter 3 addresses the broad role of culture in contributing to and ameliorating health inequities. Chapter 4 probes more deeply into the effects of culture, looking at issues such as the training of clinicians and researchers and the effects of federal policies. Chapter 5 provides case studies that examine three programs aimed at diabetes prevention and management. Chapter 6 presents case studies for cancer prevention and treatment programs. Finally, Chapter 7 summarizes comments made in the final discussion session, when workshop participants were invited to identify lessons they had drawn from the day's presentations and discussions.

## KEY THEMES

Over the course of the day, several prominent themes emerged from the individual presenters' remarks that framed much of the subsequent discussion. These themes are presented here not as conclusions or recommendations from the workshop but as a way of organizing the material summarized in this report.

- Many factors affect health, including factors such as social environments, education, and responses to colonialism that are subsumed under the broad label of culture.
- Any efforts to understand the culture of Native peoples should take into account the historical trauma and loss of land suffered by these groups.
- Culture varies greatly across communities, yet a common denominator across communities is that unbalanced cultural forces can produce ill health.
- Similarly, culture can be a powerful force for good health when cultural forces are aligned with the traditions and beliefs of a community.
- Cultural safety, in which the services provided are based in the culture of the individuals seeking the services, is the ultimate goal for the health care system.
- Culture is also an important factor in research on communities, given that communities need to be involved in the planning and performance of research for that research to be useful.
- Members of Native communities can be essential partners in community-based research even if they lack research training. Partnerships are seen as essential to research conducted with tribes.
- Governmental and institutional policies should reflect traditional medicine and cultural advocacy for the staff who provide services.
- More pathways into health care, better academic preparation, more culturally aware faculty, and continual mentoring are all needed to increase the number of Native clinicians and researchers.
- Diabetes prevention and management, as an example of a health issue prominent among Native peoples, require an integrated and multifaceted set of activities and programs that can leverage Native traditions to improve health.

- Similarly, cancer prevention and treatment programs should reflect the characteristics and needs of local communities if they are to be successful.
- Every program should be tailored to the local community, because every community is different.

> "This searching for culture, this searching for identity, the searching for belonging transcends many of the social factors that are oftentimes viewed as being important characteristics of the health dilemma." —*Ralph Forquera*

# 2

# Culture as a Social Determinant of Health

In his keynote address, James Knibb-Lamouche, director of research for Blue Quills First Nations College, highlighted several observations and recommendations made in the paper he was commissioned to write for the workshop. (Appendix A provides the full text of the paper.) The observations and recommendations were his alone, but they established the context for many later discussions at the workshop.

## THE BROAD DETERMINANTS OF HEALTH

The medical model of health has had fantastic successes, Knibb-Lamouche began. It has produced new diagnostic technologies, medications, and health care delivery systems. The reductionist approach at the center of the model has been a foundational methodology for gaining new knowledge.

But all systems have limits. The proliferation of technologies and medications has run up against cost limits in all developed nations. Parts of communities have access to these resources, but other parts do not, which increases inequity. Also, the reductionist approach has been a victim of its own success. Relying on this approach alone reduces the ability of the system to respond to chronic diseases such as diabetes, cancer, and heart disease, which disproportionately affect indigenous and minority communities. A reductionist framework also can lead to the denigration of other forms of knowledge, including the indigenous knowledge present in communities that can be used to address these problems.

Many factors affect health, including income, social support, education, and social and physical environments. Collectively, such factors are often referred to as the social determinants of health, but Knibb-Lamouche advocated taking an even wider perspective on these factors. In indigenous communities, the broader determinants of health include cultural continuity, responses to colonialism, and responses to the "new colonialism"—globalization—which he described as seeking reduced diversity because it is cheaper to provide goods and services to a uniform market. These broader determinants also include the relationship of indigenous people to their territories and former territories. The forced migration of indigenous peoples away from their territories has been a major contributor to the poverty that afflicts many of these communities. Self-determination and control over territories are politically charged topics, he acknowledged, "but any serious attempts to deal with the amelioration of health are going to have to face them at one point or another."

## INDIGENOUS CULTURES

The importance of culture can be masked by the tremendous diversity of indigenous peoples (see Figure 2-1). Canada has more than 600 different First Nations. The United States has more than 1,000. These groups have different languages, different cultural practices, and different histories.

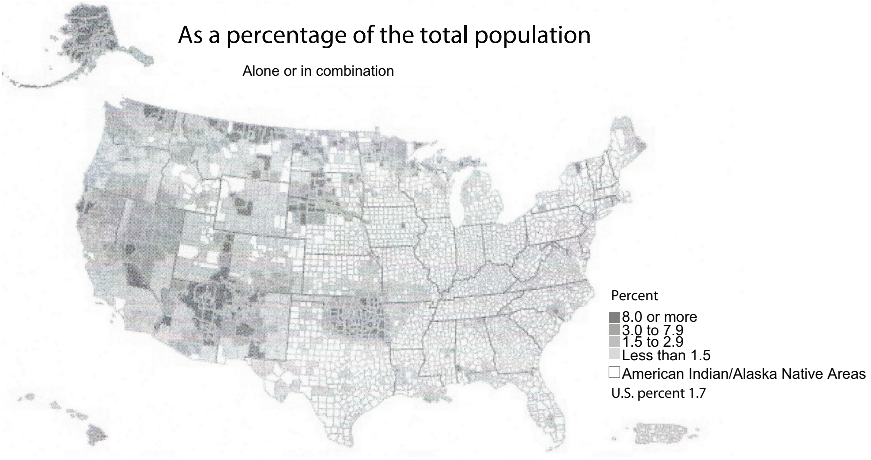

**FIGURE 2-1** The representation of American Indians and Alaska Natives in the U.S. population varies geographically.
SOURCE: U.S. Census Bureau, *2010 Census Redistricting Data (Public Law 94-171) Summary File,* Table P1.

Despite their variety, two values that are common among these groups are balance and respect, said Knibb-Lamouche. These attributes are not something inherent within each person. Rather, they are inherent within the systems of which individuals are a part, including communities, families, jobs, and societies. All of these systems need balance and respect to function properly and to provide individuals with the means to achieve good health.

Similarly, when systems are unbalanced, they can produce ill health. "It is a different angle to be taking when you are looking at the provision of health," said Knibb-Lamouche. Good health is not something "that is given to you or that you pay for or that you can get from somebody else. It is something that must be gained and fought for within and of yourself, with the assistance of others."

Patients cannot be treated in isolation. Their condition derives from the culture of which they are part and the culture of the institution from which they are seeking help. Thus, patient-centered care cannot be culturally neutral. The way the health care system provides services is based on cultural assumptions that have been passed down over the generations. "Just because you do not pass on the information by singing and songs and storytelling does not mean that you do not have a culture," Knibb-Lamouche explained.

If health care institutions are not attuned to the culture of their patients, outcomes for both patients and institutions can be negative. If patients are noncompliant or reluctant to visit health facilities, they can become alienated from the health care system, and health care providers can become demoralized. These feelings of alienation and powerlessness have a trickle-down effect throughout the entire system.

Knibb-Lamouche mentioned unpublished results from an Alberta physician who talked with the elders and healers from his community. Although the health care system in the Alberta community is completely up to Western standards, the physician reported that community members tend not to use it. They think of the hospital as a place where people go to die. "There is something seriously and significantly wrong with a system that can so completely fail one group of people in a society," said Knibb-Lamouche.

Colonialism destroyed parts of the culture of indigenous groups. Residential schools and missionization are examples of culturally destructive acts that in some cases were intended to be destructive. "The saying in Canada around residential schools was that they must kill the Indian in order to save the man," said Knibb-Lamouche.[1] In other cases, indigenous cultures were simply ignored because they were "different," leading to the condition of cultural incapacity. Sometimes, health care providers hid

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[1] The original quote, written by Richard H. Pratt in 1892, is "Kill the Indian in him, and save the man."

behind the idea that culture does not matter and that providing the same service to everyone will achieve a good result. But cultural blindness does not provide equal outcomes, Knibb-Lamouche said, as shown repeatedly in indigenous communities.

## CULTURAL COMPETENCE, CULTURAL SAFETY, AND CULTURAL HUMILITY

Knibb-Lamouche described cultural pre-competence and cross-cultural care as the recognition by a service provider that culture has an effect on health and does matter. This recognition enables the provision of services in ways that are not as damaging as in the past. Further along the spectrum, cultural competence describes a situation in which services are provided in ways that are as congruent as possible with the culture of the client being served.

The ultimate goal of the provision of health care services is cultural safety, said Knibb-Lamouche. In this situation, the services provided stem from and are based in the culture of the individuals seeking the services. Ideally, such care is delivered in the patient's language, in the patient's community, and in ways that respect the patient's traditional practices.

Cultural humility denotes recognition by service providers of the common disconnect between patients and providers and of the need to drive their care toward cultural safety. As Knibb-Lamouche described it, cultural humility could serve as a codicil on the Hippocratic Oath: "Instead of 'First, do no harm,' it would be 'First, stop being a jerk.'"

## CULTURAL CONTINUITY

The idea of cultural continuity does not entail a rejection of new things, insisted Knibb-Lamouche. It does not mean that Native peoples should go back to living on the prairies and hunting buffalo. Rather, it means that cultures have evolved over time and that the people living in those cultures have the agency and self-governing ability both to change and to adopt new practices. If a Native American community decides that it needs an MRI (magnetic resonance imaging) machine, that decision does not contravene its traditions. Rather, it means that the community has decided to use available resources to provide a new service to its people.

Cultural continuity also reinforces the idea of the broader determinants of health, Knibb-Lamouche said. For example, Native communities have highly disparate rates of suicide, from almost zero in some communities to calamitous rates in other communities. According to research by Chandler and Lalonde (1998), the communities with the lowest suicide rates had the most self-determination and the most control over the social and cultural institutions within their communities. "Even if they were poorer, they still had better outcomes with respect to suicide rates," he noted.

## THE RELATIONSHIP TO THE LAND

Native Americans have a fundamentally different relationship with their land and territories than do other minority groups in Canada and the United States, said Knibb-Lamouche. The dispossession of land and the expropriation of resources destroyed traditional economies and undermined identity, spirituality, language, and culture. The loss of land and self-determination through missionization, residential and industrial schools, and the destruction of indigenous forms of governance also resulted in the breakdown of traditional and healthy patterns of individual, family, and community life. These things may seem to have nothing to do with health, but to improve health they need to be confronted, Knibb-Lamouche argued.

## RESEARCH

Research plans should be developed in conjunction with the communities being researched. This seems "blindingly obvious," said Knibb-Lamouche, but researchers need to be constantly reminded. Researchers can have the best of intentions and promise many beneficial outcomes. But if the community does not see value in the research, it will not be helpful.

Furthermore, if research does not have an ethical framework of respect for its subjects or participants, it will be inherently damaging. Researchers may equate ethics with morality, but Nazi researchers followed a strict ethical code, yet were morally bankrupt, Knibb-Lamouche pointed out. "Ethics is not necessarily good," he said.

To improve the health of indigenous peoples, research should reflect community needs, priorities, and realities. Methodologies should be culturally appropriate. Research designs should be credible and of high quality. And the research process itself should be open and inclusive. Anonymity may not be an important goal for community members, and simply providing anonymity may not be protect research participants. If research does not meet these criteria, it can damage the relationship between the community and the researcher—as well as all researchers who follow.

## RECOMMENDATIONS IN THE COMMISSIONED PAPER

Knibb-Lamouche briefly mentioned several of the recommendations he made at greater length in his commissioned paper (see Appendix A). His recommendations are not comprehensive, he emphasized, but they provide basic ideas for how an acknowledgement of the broader determinants of health can improve health.

First, healing, which is a concept central to indigenous cultures, should be distinguished from treatment. For many indigenous peoples, healing includes the process of active recovery from colonization. Communities themselves need to heal from the things that have happened to them in the past. Healing requires traditional practices, spiritual values, indigenous knowledge, and culture and, importantly, depends on the idea that the health and well-being of individuals, families, communities, and nations require the restoration of balance.

Second, the training of health care providers should emphasize cultural competence in the short term. In the long term, all of the health care professionals currently working in Native American communities should be mentoring the young people living in those communities so that these youth can be recruited to become health care providers in the future.

Third, students who are considering careers working with Native American communities should recognize the historical context of those communities. "If you are going into Lakota territory, you need to know about the history of the Lakota and their battles with the American government and the current issues around the Black Hills.[2] Those things will impact on your delivery of the services to an individual," he said. First Nation colleges in Canada and tribal colleges in the United States have the capacity to provide this training and to develop active relationships and partnerships.

As an example of this third recommendation in action, Knibb-Lamouche mentioned a program led by the Indigenous Physicians Associations of Canada to develop a medical elective course on aboriginal health and healing. In the pilot of the program, second- to fourth-year medical students worked for 3 weeks in Native communities with elders and healers and participated in traditional cultural events. "It is not the solution, but it is the first step in building those relationships with various medical schools," he explained.

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[2] Although the Great Sioux Reservation created by the federal government in 1868 included the Black Hills, the discovery of gold in the Black Hills in the mid-1870s led the federal government to retake the land following the Battle of the Little Bighorn. The federal government offered to purchase the land from the Sioux, but the tribe refused because it is considered to be sacred ground. In spite of this refusal, Congress passed legislation in 1877 that created a new treaty allowing the purchase of the land for a fraction of its value. The Sioux have never accepted the validity of the purchase; this led to a number of court cases that eventually required the federal government to pay the 1877 estimated value of the Black Hills territory. The Sioux want the land returned to them. The issue is still unresolved; the federal settlement money remains in an interest-bearing account.

## DISCUSSION

In the discussion session following Knibb-Lamouche's talk, roundtable chair William Vega, director of the Edward R. Roybal Institute on Aging in the School of Social Work at the University of Southern California, asked about incorporating cultural competency into both health care delivery and research, despite the lack of research on how to do so or on the effects of doing so. The key to both delivering care and doing research, Knibb-Lamouche responded, is collaboration. The members of a particular group are experts on delivering care to that group, so they need to be part of the conversation. When researching cancer care in Native American communities, for example, Native Americans should be on the research board, part of policy development, and represented in the research engagement arm of an institution.

In response to a question from roundtable member Winston Wong, medical director for community benefit at Kaiser Permanente, about how technology can be used in a culturally appropriate way to extend the healing relationship to indigenous communities, Knibb-Lamouche observed that culture is not technology. Although the stereotype may be that older people are isolated from technology, some of the elders in his community are "text demons," he said. If the medical arena could build the proper relationships, technology could provide an excellent opportunity to improve things like compliance with medicine schedules or follow-up visits. Similarly, the use of Facebook could enable the medical community to engage with the young people in a community, which is especially important because Native American and First Nation communities are overwhelmingly young compared with the U.S. population as a whole; according to the Census Bureau, 30 percent of this population is younger than 18 years, as compared to 24 percent of the population as a whole.

Language is also important in preserving culture and using culture to improve health. Knibb-Lamouche's college is working on a medical dictionary in the Cree language to explain medical information to the elders, which "would increase their compliance with interventions exponentially."

Leilani Siaki, a cardiology nurse at Madigan Army Hospital, called attention to the difficulties of getting institutional review boards to approve research using methods appropriate for the Native American groups being studied. She had to bring a cultural broker in to talk with the institutional review board to get her research plan approved.

Linda Burhansstipanov, president and grants director of the Native American Cancer Research Corporation, who spoke later in the workshop, described a survey of technology use among Northern and Southern Plains American Indians that showed that the major reason elders use technology is to communicate with their children and grandchildren. Overall, she said, a large number of Native Americans are using technology.

In response to a question about cultural safety, Knibb-Lamouche pointed out that a system will never be able to match itself precisely to what a client is seeking. For example, a Native American hospital in Seattle will have different understandings of treatments or interactions among people than a Cree hospital. Culturally safe care would incorporate indigenous knowledge not by subsuming it into Western knowledge but by acknowledging that traditional methods are available in conjunction with Western medicine. Culturally safe care is “a moving target that we can always be striving toward.”

> Cultural humility could serve as a codicil on the Hippocratic Oath: “Instead of ‘First, do no harm,’ it would be ‘First, stop being a jerk.’” *—James Knibb-Lamouche*

# 3

# Why Culture Matters in Addressing Health Inequities

Following the keynote address, two speakers considered the broad issues involved in using culture to reduce health inequities. Bonnie Duran, associate professor in the department of health services at the University of Washington School of Public Health and director of the Center for Indigenous Health Research at the Indigenous Wellness Research Institute, described the historical forces that have shaped Native communities and the role of research in documenting and addressing problems in those communities. Michael Trujillo, associate dean for the Outreach and Multicultural Affairs Program and professor in the department of internal medicine at the University of Arizona College of Medicine in Phoenix, recounted some of the efforts he made as a federal policy maker to incorporate culture into health care systems and described the potential that remains.

## THE LEGACY OF COLONIALISM

Colonialism is a cultural event (Kelm, 1998), said Bonnie Duran, University of Washington School of Public Health. It involves control of not just people but also the context of their lives—control of the economy through land appropriation, labor exploitation, and extraction of natural resources; control of authority through government, normative social institutions, and the military; control of gender and sexuality through oversight of the family and education; and control of subjectivity and knowledge through imposition of an epistemology and the formation of subjectivity (Quijano, 2007).

Federal Indian policy has been dictated by a succession of colonial narratives (Shelton, 2004). A narrative of assimilation and allotment dominated from the 1870s through the early 20th century. Given this long historical emphasis on assimilation, in 1883, some forms of traditional medicine were outlawed, and in 1887 the Allotment Act abolished group title to Native land. Colonialism was not just an economic event but a cultural event. It sought to control gender, sexuality, subjectivity, and even knowledge. During this period, "expert knowledge" formed a close relationship with political power in determining perceptions of Native peoples. Duran has collected more than 100 19th-century articles from scientific and medical journals in which Native peoples are described in crude and stereotyped terms. For example, in an article entitled "Obstetric Procedures Among the Aborigines of North America," Eli McClellan wrote, "The Navajoes, a branch of the Apache tribe, live in the rudest huts and lead a drunken, worthless life. The women are debased and prostituted to the vilest purposes. Syphilitic diseases abound" (1873, p. 585). Colonial themes of the destruction of Native culture and Native Americans as a people imbue early social science, said Duran.

Colonialism has occurred not just in the United States but also throughout the world (Alexander et al., 2004), and it has generated an international response. The 1948 United Nations (UN) Universal Declaration of Human Rights stated, "The principle of universality of human rights is the cornerstone of international human rights law." The 2007 UN Declaration on the Rights of Indigenous Peoples affirmed that "indigenous peoples and individuals have the right not to be subjected to forced assimilation or destruction of their culture." It added that "states shall provide effective mechanisms for prevention of, and redress for any action which has the aim or effect of depriving them of their integrity as distinct peoples, or of their cultural values or ethnic identities."

The relationship between indigenous knowledge and Western science continues to be overshadowed by the history of colonialism, Duran said. Many indigenous people believe that evidence-based interventions are a form of forced acculturation. Many evidence-based interventions are extremely prescriptive. They target things like obesity or chronic disease that involve people's actions and behaviors, which are part of culture. Most of the evidence-based interventions developed through randomized controlled trials have not been tested in communities of color, and there is no evidence that they work in those communities.

Revitalization of culture through indigenous health promotion and treatment, as a hybrid approach, can be much more effective than relying purely on Western medicine, said Duran. Similarly, pragmatic trials and comparative-effectiveness research could have better success in determining what is effective in communities of color than randomized controlled trials. Why mandate a new heart disease drug that is only minimally more effective than low-dose aspirin?, she asked. In another example, ideas such as the contention that historical trauma has negative health effects, long derided as having no empirical basis, now are being verified through investigations into epigenetics and other fields.

Duran described two research projects being conducted through the Center for Indigenous Health Research that demonstrate how to leverage culture to reduce health disparities. With funding from the Native American Research Center for Health, the center is working with the National Congress of American Indians (NCAI) to look at the variability, across several dimensions, of community-based participatory research. The project is assessing and describing the impact of governance—and tribal sovereignty in particular—on community-based participatory research processes and outcomes across communities of color, including Native American communities. It is examining the associations among group dynamic processes and recording three major outcomes of this research: culturally responsive and culturally centered interventions; strengthened research infrastructure and other community capacities; and new health-enhancing policies and practices. Finally, the project is identifying promising practices, assessment tools, and future research needs for community-based participatory research, with NCAI bringing those practices and tools to tribal leaders and researchers.

Duran emphasized the importance of partnered research in particular, because it results in culturally centered measurements and interventions. The research group at the Center for Indigenous Health Research has been working with a health communications scholar who developed scale domains for cultural centeredness, which include factors such as the role of the community voice in identifying problems and solutions (Dutta, 2011). These scale domains contain elements of cultural safety, cultural humility, structural determinants of health, and communicative agency. As an example of cultural centeredness, Duran cited a billboard in Navajo country that reads, “Have you noticed a change in your harmony, breath, energy? It may be [tuberculosis].” “There is cultural centeredness right there,” she said.

The research project, which is surveying 164 projects, was still under way at the time of the workshop, so Duran was able to share only preliminary results. But the research has shown that cultural centeredness has positive effects on the personal benefits participants derive from research, including their personal agency in dealing with health issues.

Duran and the Center for Indigenous Health Research also are involved with a second study, in partnership with 34 tribal colleges and universities, to document alcohol and drug problems. The study is looking at what is known about problematic alcohol and other drug use; risk factors, protective factors, and outcomes of alcohol and other drug use; the extent of clinical-level problems; the best, most promising, and current practices for alcohol prevention, screening, treatment, and referral services; and the organizational capacity and readiness of tribal colleges and universities for student alcohol interventions. Tribal colleges are located for the most part in rural, economically depressed places. But the study has found that social capital is very strong in these institutions. According to surveys conducted for the study, 88 percent of faculty and staff strongly agree or somewhat agree that people associated with a tribal college demonstrate respect for the beliefs and values of other people's spiritual and religious traditions. More than three-quarters of faculty and staff believe that traditional activities bring people together regardless of conflicts on the campus. The percentages were even higher for student responses on those two questions: 94 percent and 87 percent. Students and faculty both believed that the tribal colleges were working in their best interests and that they were able to bring people together to solve problems. Solid majorities of students said that their institutions educate students to take responsibility for their own problems and give students an opportunity to voice their concerns to faculty and staff.

Public policy is not driven by data alone, Duran emphasized. Compelling stories often convince policy makers to go in one direction or another. Thus, examples of how culture impacts health status have to be circulated along with data on culture's impact on medicine. For example, one much-discussed hypothesis, said Duran, is that people are no longer citizens of a society; instead, they are clients of a system. "We have to go back [to] being citizens having control over a health care delivery system," she concluded.

> Revitalization of culture through indigenous health promotion and treatment, as a hybrid approach, can be much more effective than a reliance purely on Western medicine. —*Bonnie Duran*

## INCORPORATING TRADITIONAL VALUES AND PRACTICES INTO FEDERAL POLICIES

When Michael Trujillo, University of Arizona College of Medicine in Phoenix, was director of the Indian Health Service (IHS) during the Clinton administration, he released a memo "to affirm [his] commitment to protect and preserve the inherent right of all American Indians and Alaska Natives (AI/AN) to believe, express, and exercise their traditional religions." The memo went on to lay out the policy of the Traditional Cultural Advocacy Program, which it called "an important means of ensuring that traditional healing practices are respected by IHS employees in all our services and programs." This initiative was the product of months of meetings and deliberations not only within the IHS but within the Department of Health and Human Services and other agencies. The goal was to reflect traditional medicine and cultural advocacy not only for clients of the IHS but also for the employees, providers, and other staff who set policies and provided services. The initiative signaled that "the management, the participation, the inclusion, and the involvement really came from the tribal leaders and people that we served," said Trujillo.

A major challenge of the initiative was to define a traditional medicine provider. The definition used today, as specified by the IHS after consultation with tribal leaders, is "a person who is trained in a Native American community and applies culturally specific knowledge and skills in the diagnosis, treatment, or referral of patients to promote their well-being physically, mentally, and spiritually" (IHS, 2007). Definitions of providers can raise complicated issues of financing and reimbursement, Trujillo acknowledged, but definitions also can demonstrate that traditional medicine is part of the Indian health program.

As part of this initiative, the IHS, which had no allocated research funds of its own, partnered with the National Institutes of Health to direct research funding to tribes and to urban programs. This funding has enabled tribes and other programs to manage, administer, and oversee research while also partnering with universities, communities, and other institutions to do research "with the tribes, not on them," as Trujillo put it. In addition, this research funding has made it possible to train and mentor researchers of Indian background or heritage.

The development of research programs with Indian tribes has led to a number of other initiatives. An association for Native American researchers has been created. Tribes have become involved in collaborative processes to decide whether they want to be involved in research and to develop protocols. For example, Trujillo has been involved with the Translational Genomics Research Institute in Arizona, which developed a research protocol with one of the tribes in the valley. The tribe has had complete control of the process, including tissue banking and collection of tissue. It approves any papers generated by the research and is a collaborator on those papers. It also controls the data and statistical analysis. When the final agreement was signed by the CEO of the Translational Genomics Research Institute and the chairwoman of the tribe, the document was blessed, followed by a blessing from a traditional healer on the floor where the tissues were going to be held. The instruments and storage areas for the tissues were also blessed, as was a separate location where tissues were going to be banked. The individuals who handle the tissues were blessed over a period of time, and any new individuals who join the research are fully trained in the standards that need to be maintained. “It has become a model protocol in many areas,” said Trujillo.

After leaving the IHS, Trujillo was associated with the Department of Veterans Affairs (VA) program in New Mexico and worked on reimbursement for veterans or others who wished to use traditional medicine within the VA system. He helped work out a process by which an Indian individual who wanted to receive traditional healing could be reimbursed for that service, including travel and family costs, a policy that then was adopted by several other VA hospitals around the country.

Health care facilities and programs need to recognize that health is multi-factorial, Trujillo stated. Accreditation, cultural inclusion, and other aspects of the system need to reflect this recognition. “Unfortunately, many times it is a noontime lecture,” he said. “We as individuals who are part of programs, who care for individuals or communities, must make sure that that is not just a check mark, but rather it is an implementation of a process. . . . It is establishing trust not only with the communities and those individuals who walk through our doors, but also with our own staff and our peers.”

Trujillo concluded by quoting Black Elk, a holy man of the Oglala Sioux, from John G. Neihardt’s 1932 book *Black Elk Speaks*: “Of course, it was not I who cured. It was the power from the Outer World. The visions and the ceremonies had only made me like a hole through which the power could come to the two-leggeds. If I thought that I was doing it myself, the hole would close up and no power could come through. Then everything I could do would be foolish” (p. 163).

Researchers need to do to research “with the tribes, not on them.”
*—Michael Trujillo*

## DISCUSSION

During the discussion session following the panel presentations, Frank James, a physician and health officer for the Nooksack Tribe, noted that his tribe was the recipient of more than $2 million from the Substance Abuse and Mental Health Services Administration (SAMHSA) to address alcohol issues among youth, and many other tribes were funded as well. The people who control funding streams, like those at SAMHSA, are good people with good intentions, he said. But they want evidence-based interventions, and such an approach can create major conflict in Native communities. Culture is the most effective and highest order of prevention, he said. For example, he works with a canoe poling tradition, in which canoes are navigated with a pole rather than a paddle, that provides "amazing" health benefits. How can federal agencies be given the message that evidence-based practice is not sufficient and is not proven in Native communities?

Trujillo said that people in federal agencies and on Capitol Hill need to recognize continually the factors that matter for the recipients of health care or research. This requires constant work to reorient these individuals. With the Patient Protection and Affordable Care Act (ACA), for example, criteria will continue to be modified as the act is implemented. "Words are good," said Trujillo, but "one has to see the implementation, the policies, the rules, and regulations that flow out of that. . . . Hopefully it will be positive, but the effect, I think, is still going to be relatively unknown."

Jamila Rashid, Office of Minority Health, emphasized the importance of community engagement. Such engagement puts everyone on a level playing field, not just inviting people to meetings but enabling them to understand the language and the landscape. For example, local community members can come together with researchers to train each other on the language that will be used in their partnership.

Duran agreed that community engagement is the key: "We have to invest in community engagement. . . . We have to work together to ensure that culture is central." She expressed the hope that some of the provisions of community prevention in the ACA can be targeted toward the use of culture to improve health. "Some of our excellent local, regional, and national Native institutions are looking at culture and trying to spread that message," she stated.

Trujillo urged that individuals remain consistent in their values and beliefs. "If we are inconsistent, that flows out from the work that we do and into others. . . . If those values are not there, all your research, all your publications, all your TV ads, etc., are meaningless. . . . Being able to work with others in an open and trustful manner is . . . one of the mainstays that I think all of us operate on."

Finally, Mildred Thompson, PolicyLink Center for Health and Place, who moderated the session, said that she had been inspired by the session, but the challenge is to return home and do things differently. How can the ideas discussed at the workshop be converted into policies that are sustainable and make a difference? How can practitioners be engaged? What examples are there of integrating indigenous healing practices with Western medicine? "What I'm saying is that I'm having more questions emerge for me than I have answers," Thompson concluded.

# 4

# Cultural Sensitivity in Health Care Delivery and Research

The final morning session featured four speakers who examined in greater detail the influence of culture in determining health inequities. Roger Dale Walker, professor in the departments of psychiatry, public health, and preventive medicine at the Oregon Health and Science University (OHSU), described a mentoring program designed to recruit and retain Native Americans and Alaska Natives (ANs) in health care delivery and biomedical research. Terry Maresca, medical director for the Snoqualmie tribe and clinical associate professor in the department of family medicine at the University of Washington School of Medicine, listed a number of programs that can serve as models for increasing the number of culturally aware clinicians and researchers. Benjamin Young, former dean of students at the University of Hawaii School of Medicine, described his extremely successful efforts to increase the number of Native health care practitioners in Hawaii and the Pacific Islands. Finally, Arne Vainio, a family practice physician at the Min-No-Aya-Win Human Services Clinic on the Fond du Lac Ojibwe Reservation in Cloquet, Minnesota, discussed how important it can be for practitioners to share the culture of the communities they serve.

## A MENTORING PROGRAM FOR NATIVE STUDENTS

The One Sky Center is a national resource center for all American Indian (AI) communities in North America, said Roger Dale Walker, OHSU. It also is a resource center for policy makers in the federal government and elsewhere, because to make good decisions about Native Americans, policy makers need to know Native Americans. The center, which operates out of the office of the president at OHSU, does research, recruits Native Americans to medicine and research, works to retain Native Americans in medical training, provides training and technical assistance for clinicians and community workers, and conducts other programs aimed at the intersection of Native Americans with medicine and biomedical research. It also maintains a listing of more than 100 programs that are doing excellent work across Indian communities but often do not get the visibility they deserve.

Every site is different, said Walker. The One Sky Center works at more than 50 different sites in a year, which means that people working with the center need to absorb a history and a culture every time they go to a new community, whether it is inner-city, rural, or high-poverty.

Walker focused in his presentation on a national model for mentorship to attract and retain Native Americans and ANs in health care delivery and biomedical research. The model is complicated by the diversity of places where AIs live. Today, two-thirds of Indians live off a reservation, which means that their lives and health care are influenced not only by the federal government but also by states, counties, and cities. Mentorship also is complicated by the high rate of attrition among Native American students. Half of the Native Americans who enter college leave in the first year, according to the National Institute for Leadership in Higher Education. Only 3 of every 20 Native Americans who enter college graduate. “That is a hard place to find Ph.D. candidates,” he stated.

Having a critical mass of other Native American students and mentors is a major problem. Association of American Medical Colleges data from 2008 show that there is a total of only 14 Native American professors in the United States, said Walker, and “we need to do something about that” (see Figure 4-1).

The mentorship program at OHSU is designed to increase that number substantially. Among its goals are the following:

- Provide instruction on conducting research.
- Provide insight into Native identity, both at the personal and community levels.
- Improve trainees’ self-confidence.
- Critique and support trainees’ research.
- Assist in defining and achieving career goals.
- Socialize trainees into the profession.
- Assist in the development of collegial networks.
- Advise how to balance work and personal life.
- Assist in the development of future colleagues.

Native peoples have unique struggles in college, said Walker. They have to preserve their home lives while embracing a life of research. Trainees have to be socialized not just on Indian issues but also on institutional and

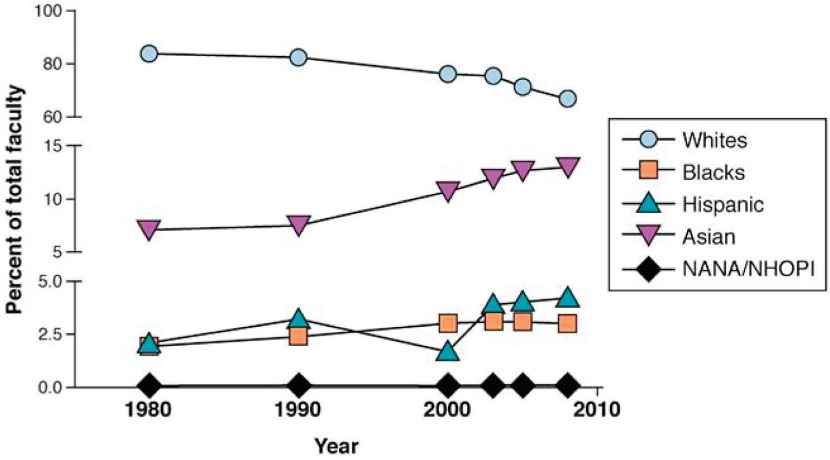

**FIGURE 4-1** The percentage of Native American and Native Alaskan faculty members in degree-granting institutions remains very low.
NOTE: NANA = Native American/Native Alaskan; NHOPI = Native Hawaiian/Other Pacific Islander.
SOURCE: National Center for Education Statistics, 2010.

research issues. Many Native Americans come back home after being in college and are told that they have changed. "There are some real conflicts that we need to think about," he explained.

The program currently has 17 Native mentors from across the United States, all at the associate professor level or higher. These mentors are serving 27 mentees, about half of whom are in premedical programs or in medical schools, with the other half in doctoral or postdoctoral programs. It is a tight-knit community that encourages multiple types of mentorship contact, including

### Face to Face

- Attend national and regional conferences as mentor/mentee teams.
- Discuss career objectives and strategies to accomplish those objectives.
- Co-present at conferences.
- Have lunch or share breaks at meetings.

### E-mail

- Alerts of programs and new information.
- Answers for mentees of quick questions.
- Reminders about programs and other activities.

### Phone

- Set up strategy meetings and touch base (especially when tone of voice is important and e-mail will not suffice).

### Internet

- Reference materials, data links, and news.
- Job search information and recruitment.
- Communication through Facebook.

Mentors and mentees discuss research methods, proposals, and grant management. They attend scientific conferences with Native researchers and go to meetings on Native or community themes and policies, along with workshops designed specifically for mentees. The program holds an annual conference and focused workshops and has prepared individuals for national leadership roles. The relationships formed through the program are ongoing and go on indefinitely, because American Indians will continue to face difficult issues throughout their careers. Recently, the program has begun working with high school students to increase the number of students entering the pipeline in college. Students can work with anyone in the network who has the expertise they need.

Walker emphasized the need to increase interactions between Native people and national leaders. "People who are leaders and non-Native need to know Natives," he said, and "people who are Native need to know who these leaders are and begin to make outreach happen."

The program has already had many successes, including new faculty members, admissions to graduate school, postdoctoral fellowships, grants in preparation, funded grants, and numerous publications and presentations. Furthermore, it has ambitious future plans, including

- Recruit new mentees each year.
- Further refine the mentor role and recruit new mentors.
- Recruit new senior non-Native researchers as associates.
- Continue to develop relationships with the Indian Health Service (IHS) and professional health organizations.
- Develop a National University Consortium for Native Health Research.
- Apply for a National Mentoring Network Grant.

"We are very excited about trying to make this a movement and to expand our richness as broadly as we can," Walker concluded.

> Many Native Americans come back home after being in college and are told that they have changed. “There are some real conflicts that we need to think about.” —*Roger Dale Walker*

## INCREASING THE NUMBER OF CULTURALLY AWARE CLINICIANS AND RESEARCHERS

Terry Maresca, University of Washington School of Medicine, discussed five broad approaches to increasing the number of culturally aware clinicians and researchers. The first is increasing cultural safety for patients and students. As models, Maresca cited several programs:

- A program on the Crow Reservation in Montana pairs tribal elders as teachers with new clinicians in reservation settings, allowing providers who are new to the community to have a safe person with whom to talk. In dealing with issues such as birth, serious illness, or impending death, the community becomes the expert rather than the medical or nursing director.
- In the Rural Human Services Program at the University of Alaska, Fairbanks, elders-in-residence conduct onsite and distance learning with health care professionals, including behavioral health aides, who are serving Native villages. Having elders involved is especially important when dealing with sensitive issues such as chemical dependency, violence, or suicide, said Maresca.
- The Snoqualmie tribe in Washington and the Southcentral Foundation in Alaska have planted Native herbal medicine gardens on clinic property. Such programs have the effect of reconnecting Native peoples with the land. In addition, a program at Northwest Indian College in Bellingham, Washington, promotes the use of traditional plants, particularly for diabetes prevention, with the community as the driving force behind the program. The program is now being expanded to address issues of access to indigenous foods, which has sparked interest among tribes that have not been able to access areas where they can gather, hunt, or fish.
- The University of Washington has held an annual summit that brings together the university president and top staff with 29 leaders of the tribes in the state to discuss the barriers to postsecondary recruitment and retention for Native students. In the future, said Maresca, university officials would be even better served by going into tribal communities to have these conversations.

The second area Maresca discussed is the need to learn respect for indigenous healing practices, again using several examples as models:

- The Association of American Indian Physicians, a small group with less than 400 members that has been in existence for more than four decades, holds a cross-cultural medicine workshop that brings in indigenous healers from around the country to conduct a dialogue about Native health practices with students, clinicians, and other interested community members.
- The IHS holds an annual conference titled Advances in Indian Health designed to enhance awareness of disparities, the role of historical trauma, and cultural healing practices. Such programs help to address the reluctance of some parts of the health system to understand the health benefits traditional practices can produce.
- The Puyallup Tribal Health Authority in Washington conducts cultural in-service training for all staff. Such programs should not just be "helicopter training," said Maresca, but fully developed programs that work with communities to understand how to address disparities with the resources that are available.
- The Seattle Indian Health Board Family Medicine Residency Program, which was established in 1994, has been collaborating with traditional healers to conduct clinical training embedded in Native communities. More than three-quarters of the graduates of the program remain in underserved communities.
- The University of Washington has established rural training sites with a connection to Native communities for 6-month immersion training of medical students.

The third set of programs Maresca described are aimed at modifying work to fit the available workforce:

- A program for dental health aide therapists in Alaska is designed to meet the needs of rural Native villages. Therapists receive 2 years of training and do not require a dental college degree, which has generated controversy with the American Dental Association.[1]
- A parallel program in California is taking the same approach with urban Native communities, which have equally high oral health disparities.

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[1] The American Dental Association opposes the dental health aide therapist (DHAT) program because the organization believes that the training received in the DHAT program is inadequate for performing the surgical procedures typically performed by licensed dentists.

- Jobs to Careers, a Robert Wood Johnson Foundation partnership with the IHS, Northern Arizona University, and the Winslow Indian Health Care Center, supports medical technologists as entry-level health care workers, with students receiving college credit for work.
- Southcentral Foundation in Alaska has an internship program starting in high school that pays students to work in all divisions of the health system, including traditional healing and administration, with cultural values training to serve "customer-owners."
- Through a partnership with the National Institute of Diabetes and Digestive and Kidney Diseases, high school students from Alaska are able to remain in the state and participate in a biomedical research summer program that centers on alcohol and health.

Increasing the number of Native clinicians and researchers requires wider and more welcoming pathways into health professions schools. Programs that have been making a difference include the following:

- Since 1973, the Indians into Medicine program at the University of South Dakota has supported a robust pipeline program in a five-state region with a large AI population. A holistic admissions program has contributed to the program's success, as has a cultural diversity tuition waver.
- For two decades the University of Washington and the University of Minnesota have sponsored programs called Indian Health Pathways that feature a specific curriculum, including a research requirement, a traditional Native medicine clerkship, and mentoring. Several participants at the Institute of Medicine (IOM) workshop had completed one of these programs.
- Another consortium, called Pathways to Health, has brought together more than 150 tribes, AI/AN organizations, tribal colleges, universities, the IHS, federal agencies, area health education centers, and state health departments. The initiative offers cultural attunement, interprofessional training, and distance learning.

Finally, in the area of promoting culturally aware faculty and research, Maresca highlighted the following programs:

- The University of Washington, the University of Minnesota, and other institutions serve as Native American Centers of Excellence to provide faculty development fellowships and seminars.

- The University of Colorado Native Investigator Development Program and Centers for American Indian and Alaska Native Health provide intensive mentoring for Native researchers and clinicians to transition to research on elder health disparities.
- The Mayo Clinic Spirit of Eagles program promotes Native researchers, scientists, and medical students who are involved in cancer control activities in Native communities.
- The National American Research Centers for Health supports partnerships between tribes or tribally based organizations for research on Native health issues and faculty development.
- The Center for Native Health Partnerships at Montana State University creates community-based participatory research links with all seven tribes in the state and supports the student pipeline.

Maresca concluded by showing a photograph of a Native University of Washington graduate who, after training in rural Oregon and spending time with the Native health system there, chose to return to her home in northern California to practice medicine. "That is success for me," she said.

> In-service sessions should not be "helicopter training," but fully developed programs that work with communities to understand how to address disparities with the resources that are available. —*Terry Maresca*

## INCREASING THE NUMBER OF NATIVE PRACTITIONERS IN HAWAII AND THE PACIFIC ISLANDS

In 1972, Benjamin Young, who had just finished his residency, received a note from Terence Rogers, the dean of the University of Hawaii School of Medicine. At that time, Young was the first Native Hawaiian to go into the field of psychiatry, and he was 1 of fewer than 10 Native Hawaiian physicians licensed in the state of Hawaii. Rogers told Young that he wanted him to recruit more Pacific Islanders into the field of medicine.

Working throughout the Pacific was a great challenge, Young said. The islands of the Pacific are separated by huge distances and have different languages, cultures, and educational systems. At the time, there were no Pacific Islander physicians in Micronesia, and there was just one Samoan doctor, a surgeon in American Samoa.

Young began by working to develop a 1-year intensive review of biology, chemistry, mathematics, and physics to bring the MCAT scores of

Native students up to acceptable levels. Starting such a program required curricula, classrooms, and students. Young recruited students by talking with teachers, appearing at schools, and going on talk shows. He got essential support from a number of people, including the late U.S. senator Daniel Inouye, who was "a key person to know, especially for Native Americans."

Since Young began working on the problem, more than 350 Native Hawaiian physicians have graduated from the University of Hawaii School of Medicine and are in practice throughout the islands. Key leadership positions in Hawaii, including director of health for the state of Hawaii, the chairs of several departments in the university, and directors of community health centers, are products of the program, Young stated. The program has also produced 6 physicians for the Northern Marianas, 17 for Guam, 4 for Palau, 1 for Yap, and 12 for American Samoa. All returned to their islands, and several are in leadership positions, further encouraging students to enter medicine.

During much of this period, Young was director of the Native Hawaiian Center of Excellence at the School of Medicine, which seeks to recruit and retain Native Hawaiians and Pacific Islanders in medicine and the health professions. He also was dean of students for almost 15 years and shared in both the triumphs and the struggles of the students he helped recruit.

"In 1972, the dean told me, 'Let's increase the numbers of Pacific Islanders, including Hawaiians, in medicine.' Today, in 2012, we can look back with no small amount of pride that we did what we said we were going to do," Young concluded.

"In 1972, the dean told me, 'Let's increase the numbers of Pacific Islanders, including Hawaiians, in medicine.' Today, in 2012, we can look back with no small amount of pride that we did what we said we were going to do." —*Benjamin Young*

## WEAVING CULTURE INTO THE CLINICAL SETTING

Providers who grew up in the same culture as the people they are helping can make a huge difference to individuals and to communities, said Arne Vainio, Min-No-Aya-Win Human Services Clinic. Vainio is in great demand as a physician in his communities because he understands what people go through. When he was a young doctor, he tried to maintain a professional distance, but maintaining that distance turned out to be impossible. "I am part of the community," he said.

Vainio also emphasized the importance of keeping Native languages and cultures alive to encourage more Native students to become health care providers. He explained that "there is an Ojibwa language table that we go to, my family and I . . . that is a really special thing."

Vainio writes a monthly column for *News from Indian Country*, in which he has written about diseases and about "the strength and the beauty that come with people." He tells people in his community that writing about them is the best way to pass on their teachings. "That is a sacred obligation," he said, as Native Americans historically have not had a written culture or historical documents that say who they are. Instead, stories are passed down through the elders from one generation to the next.

Vainio also has written about his own experiences with medicine, although, he said, "you can't find a worse patient than a middle-aged Native man, unless you make him a doctor." Recently, a filmmaker suggested making a documentary about Vainio's experiences and put him and his wife in touch with a graphic arts student from the University of Minnesota, Duluth. For 2 years Vainio worked and traveled accompanied by a film camera, he recalled, "in case I said something profound." The documentary that resulted is called *Walking into the Unknown*. At the workshop, Vainio ran a short segment from the film, in which he talked about suicide among his family members and among his people.

Vainio concluded by explaining that "this is dark stuff that people don't talk about. It is difficult to bring up these conversations. These are scary conversations, but it is important. . . . When you have those kinds of demons, you either hide them in the closet, so they haunt your dreams, or you open the doors and you let the sunlight get them. That is what I have chosen to do."

> "It is difficult to bring up these conversations. These are scary conversations, but it is important. . . . When you have those kinds of demons, you either hide them in the closet, so they haunt your dreams, or you open the doors and you let the sunlight get them. That is what I have chosen to do." —*Arne Vainio*

## DISCUSSION

Rosalina James, assistant professor in the department of bioethics and humanities at the University of Washington, asked about how to get Native Americans involved as researchers even when they do not have doctorates, because their knowledge of Native communities and health issues can be indispensable for research to succeed. Maresca said it was a powerful question and that she could immediately picture individuals without "initials after their names" who would make major contributions to research. Bridges need to be built to access the knowledge and skills of these individuals and others who could further research.

Models and examples could demonstrate the potential of tapping into a community's infrastructure, after which such initiatives could expand. As an example, Young described a $4.6 million endowment grant to the University of Hawaii to establish a research center to encourage young researchers to participate in projects on health conditions that are prominent in Native communities such as cancer, cardiovascular disease, and diabetes.

Walker pointed to the importance of grant writing in the funding process. Grants are awarded with the expectation of outcomes, and these outcomes need to be carefully defined around the needs of a community. Many people in Indian country have tremendous experience and continue to learn more all the time. "We need to find a mechanism to recognize that," he said, and some programs are beginning to succeed in finding ways to tap into this expertise.

Other ways to foster community-based research will be available through the Patient-Centered Outcomes Research Institute and the Agency for Healthcare Research and Quality, said Eve Higginbotham, Emory School of Medicine. Such research will be able to examine the economic drivers that are pushing health care to become more value-based and outcomes-driven.

Lisa Thomas, research scientist at the Alcohol and Drug Abuse Institute at the University of Washington, pointed to a project funded by the National Institute on Minority Health and Health Disparities, the Healing of the Canoe, which has community partners who are co-investigators on the project. In the eighth year of the partnership, the research skills of the community partners were "up to par" with those of the university researchers. However, longer grants may be needed for community partners to build the capacity to be fully prepared partners.

# 5

# Diabetes Prevention in Native Communities

Speakers from three different communities talked about the work they have been doing in their communities around diabetes prevention and management. Darlene Willis, coordinator of the Diabetes Prevention Program for the Mississippi Band of Choctaw Indians, described the wealth of programs she helps administer in the Mississippi Choctaw Health Department. Walleen Whitson, site coordinator with the Lifestyle Balance Program of the SouthEast Alaska Regional Health Consortium (SEARHC), detailed a pre-diabetes program she leads in southeastern Alaska. And Nia Aitaoto, University of Iowa College of Public Health, offered three different perspectives on a set of diabetes programs for Pacific Islanders.

## DIABETES PROGRAMS AMONG THE MISSISSIPPI BAND OF CHOCTAW INDIANS

The mission of the Choctaw Health Department in Mississippi, where Darlene Willis coordinates the Diabetes Prevention Program, is to raise the health status of the Choctaw people to the highest possible level. Diabetes is a serious obstacle to that mission, said Willis, and needs to be countered by an integrated set of programs, from the administrative and program levels to research and community involvement.

The Choctaw Health Department has had nationally recognized programs and initiatives in diabetes prevention and management for more than two decades. Today it has about 1,600 people in its diabetes registry—all but one with type 2 diabetes—from a population of about 10,600 people that it serves. The largest numbers of patients are in the 46- to 65-year age group, but almost as many diabetes patients are 19 to 45 years old. The diabetes education program run by the department has a certified diabetes educator, a nurse, a registered dietician, a diabetes education aide, and an administrative assistant. The Special Diabetes Program for Indians has additional staff, including fitness instructors, a podiatrist, and lifestyle coaches.

Willis outlined many of the activities run by the department's diabetes programs. Boot camp classes every morning draw community members, including many older members of the tribe. The department visits tribal schools and measures height, weight, body mass index, blood pressure, and blood sugar for all students, and enters the information into a resource and patient management system. The diabetes programs also sponsor activities in schools, such as walks, runs, and other kinds of exercise.

Education and prevention activities extend throughout the year. Willis provided just a partial list of activities that are common in Native communities:

- Health fairs
- Wellness seminars
- Choctaw Fair booth focusing on diabetes prevention
- Cooking demonstrations
- 10,000-step program
- Water aerobics
- Community walks
- Fitness Day
- Fishing rodeos
- Bike rodeos
- Pool parties
- Basketball tournaments
- World Diabetes Day
- Fitness education
- Diabetes education
- Home run derby
- Exercise classes
- Intensive fitness classes
- Bingo nights
- Annual Unity/Spring Walk

Willis also described the I Care Team, which was established in 2010 to provide integrated services for diabetes patients. The team includes expertise in dentistry, diabetes management, women's wellness, diabetes education, exercise, nutrition, and community health. One day each month it sponsors a Diabetes Wellness Day, in which patients can attend a "one-stop shop" for the services they need. Patients receive vision checks, foot exams, flu shots, exercise education, and any other services they might need.

The Choctaw Health Department has established a partnership with Vanderbilt University with funding from the Native American Research Center for Health and under the guidance of an advisory council drawn from tribal leaders. The goals of the partnership are to identify challenges in diabetes management and develop computer, cell phone, and Internet tools to improve diabetes care and management in Choctaw communities.

The Choctaw Tribal Government believes in unity, Willis concluded. Government departments work collaboratively on projects to provide better service to the Choctaw people. "Unity is our best practice," she said.

"Unity is our best practice." —*Darlene Willis*

## DIABETES PREVENTION IN ALASKA

The Lifestyle Balance Program of the SouthEast Alaska Regional Health Consortium serves the communities of Juneau, Sitka, and Kake, Alaska. Under a grant funded by the Special Diabetes Program for Indians since 2004, the consortium has been serving people with higher-than-normal blood glucose levels or with a diagnosis of pre-diabetes who are willing to participate voluntarily in 16 weeks of classes. Participants are free to withdraw from the program, but "we hope that they don't," said the program's Walleen Whitson. To encourage participation, program staff members "work on building those relationships, knowing their first name, their husband's name, their pet's names, what they do around town," Whitson said.

Two sessions of weekly classes are offered each year. The program staff is very flexible and will work around the schedules of people who choose to participate. Participants receive a healthy snack and recipe card for a healthy meal at each class, including recipes for healthier versions of traditional foods. They also receive incentives related to the lessons.

Recruitment to the program has come in part by building good working relationships with health care providers. The program keeps providers in the loop as it works with participants, and it stays involved in the community by partnering with community organizations. Funding is limited, but the program is fortunate to receive its lab and outpatient services directly from SEARHC.

Retention is critical, said Whitson. The program stays involved with patients by providing quarterly activities based on their ideas, offering coaching during and after completion of classes, and honoring their participation with rewards. "Hopefully they stay because they want to continue their journey of health and be around to play with their grandchildren and watch their daughter go down that aisle," she explained.

A focus group made up of program participants arrived at the mission statement "bringing back the way of life." The program brings traditional foods and activities, such as berry gathering and fishing, into the classroom whenever possible and accommodates seasonal subsistence activities. It helps to support healthy traditional lifestyles and tries to give participants part-ownership of the program so that they feel invested in it.

Whitson showed photographs of two participants, one who had lost more than 100 pounds and one who had lost more than 80. "Look at the smile," she said. "The smile tells the story."

> "Hopefully they stay because they want to continue their journey of health and be around to play with their grandchildren and watch their daughter go down that aisle." —*Walleen Whitson*

## DIABETES PREVENTION AND MANAGEMENT AMONG PACIFIC ISLANDERS

The islands of the Pacific Ocean cover an area three times the size of the continental United States, observed Nia Aitaoto, University of Iowa College of Public Health (see Figure 5-1). Providing services for these islands is like coaching a football team where the players do not all speak the same language, and under these less than desirable circumstances, is going to play in the Super Bowl, Aitaoto remarked.

The European countries that colonized the Pacific Islands introduced clinics and institutionalized medicine to the people already living there. But the islanders already had traditional ways of healing and seeking health. Today, indigenous languages refer to hospitals as "houses of illness." "You never say the hospital is for you to go and get well. When you get sick, you go over there," Aitaoto explained. In the process of establishing institutionalized medicine, colonization transferred responsibility for health from individuals to a place.

Today, chronic diseases are the greatest threat to Pacific Islanders, but hospitals are focused on acute illnesses. Although the prevalence of diabetes in the United States was 8 percent in 2007, it was 39 percent in Palau and 47 percent in American Samoa (Hosey et al., 2009). This rate represents a significant shift since the 1940s, when a U.S. government survey found that

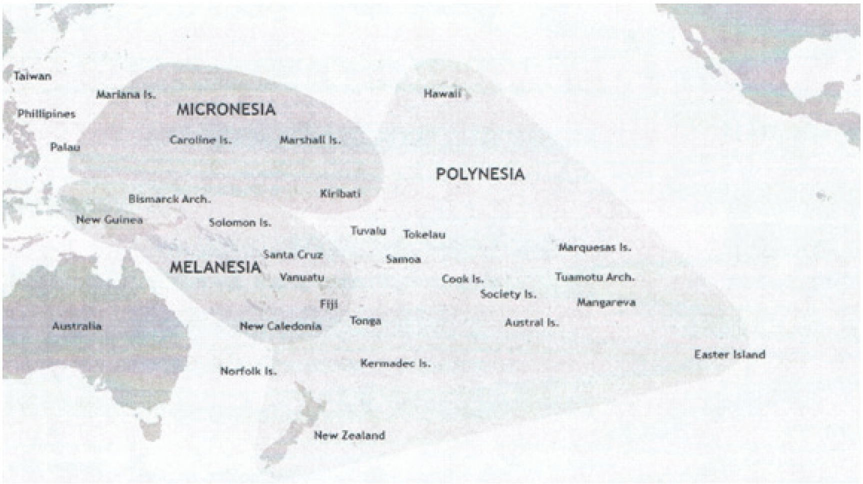

**FIGURE 5-1** The Pacific Islands cover an area three times the size of the continental United States.
SOURCE: Wikipedia (en.wikipedia.org/wiki/Pacific_Islands [accessed January 7, 2013]).

Pacific Islanders suffered from diseases such as tuberculosis and yaws but had no malnutrition, obesity, or diabetes.

Pacific Islanders face serious economic as well as health struggles. More than 60 percent of residents of Palau and American Samoa, and more than 90 percent of residents of the Federated States of Micronesia (FSM), are under the federal poverty line. In 2006, per capita spending for health care in the United States was $5,711, whereas in Palau it was $791, in the Marshall Islands it was $471, and in FSM it was $270. "What does $270 pay in health care for you? It is not a pretty picture, but if you want to come and see, it is about a $3,000 United Airlines round trip," Aitaoto said.

Pacific Islanders have always engaged in research, which Aitaoto described with the Samoan phrase *Tofa Sa'ili. Tofa* means wisdom, while *Sa'ili* means to search. *Tofa Sa'ili,* she said, "is man reaching out for wisdom, knowledge, prudence, insight, and judgment through reflection, meditation, prayer, dialogue, experiment, practice, performance, and observance." Patients seek new knowledge just as researchers do, but not in the pages of *JAMA*.

Aitaoto also described three forms of wisdom, which she referred to as *Tofa Loloto*, *Tofa Manino*, and *Tofa Mamao*. Using fishing as an analogy, she explained that *Tofa Loloto* is the fisherman's perspective from the boat, looking down into the water and figuring out how to catch a fish. *Tofa Manino* is the land crew on shore who buy fish and support the fisherman.

*Tofa Mamao* is the person on the mountaintop scanning the horizon for storms to warn the fisherman of danger. "Three different visions. We all need to go get the fish," she explained.

From a holistic health approach, the near-term perspective involves the mind, body, and spirit. Aitaoto has been involved in research that asked Pacific Islanders about the causes of diabetes, and she and her colleagues have identified four broad types of discourse. The first is that diabetes is caused by behaviors. This view generates shame and lack of support for change, which results in no action being taken. The second is that diabetes is caused by God's will and not by behavior, which also leads to no action being taken. The third is that it is a Pacific disease caused by a spirit, by wrong actions, or by magic. This belief can lead to action involving traditional healers. The fourth is that diabetes is the result of God's will but is also caused by disobedience or some other behavior. This belief can lead to repentance and, with proper support, action.

The challenge for health care providers is that diabetes beliefs contribute to two options that lead to inaction, another option that leads to largely traditional medicine, and only one option that leads to action and compliance. An additional complication is that fad medicines can be popular because they seem to be "natural," rather than based in Western medicine. Even when patients go to Western doctors, they are unlikely to keep going after their pain goes away. "And if they do not get healed, they stop going anyway. It is darned if you do and darned if you don't," Aitaoto said.

For many Pacific Islanders, health is not the ultimate goal, said Aitaoto. Health is a means to reach the goal that God gives a person. Also, a person's spirit has many parts, including shame, fear, forgiveness, and repentance, and Western medicine does not address these aspects of the spirit.

Motivating Pacific Islanders to adopt healthier lifestyles requires looking outside the medical paradigm. It requires support from the family and community. It requires *Tofa Manino* and *Tofa Mamao*, not just *Tofa Loloto*.

In a project in Chuuk State in FSM called the Pacific Diabetes Education Program, participants identified their own needs and concerns. Program organizers took this information and organized educational materials and specific initiatives. For example, the program engaged with women in villages and churches to promote better foot care to reduce levels of lower-extremity amputations, which are more than three times higher in Chuuk State than in the United States. Over the course of the program, amputations decreased by 56 percent.

An important lesson Aitaoto derived from this experience was to make educational materials more local. Materials should use photographs of local people and use the local language. Brochures should be culturally sensitive and relevant to the culture. They should include local foods that are healthy (such as fish and poi), show physical activities that attract local people (such as hula, surfing, and paddling), and engage the emotions. They should be pretested before use and evaluated after use to ensure their appropriateness at the local level.

From the perspective of *Tofa Mamao*, policies, systems, and environments affect the communities in which programs operate. A comprehensive survey of chronic disease prevention and control in the Pacific Islands revealed administrative, service, data, and support systems that all affect outcomes (see Figure 5-2). Systems themselves have cultures, said Aitaoto. For example, if one person in a Pacific Islander team does not absorb a necessary lesson, the entire team is often retrained to avoid shaming the person who did not keep up. Similarly, some people will do the opposite of what a government-led program urges, just to spite the program. In the Pacific, people often engage in feasts that involve huge meals. They are not likely to follow government admonitions not to overeat, but religious leaders have had some success in changing traditional feasting patterns. "When you look at policy, look at culture *and* policy," urged Aitaoto.

The Pacific Diabetes Today program started in 1998 with 11 community assessments, followed by planning and implementation. Even after the initial funding for the program ended, 9 of the 11 communities continued doing diabetes coalition work.

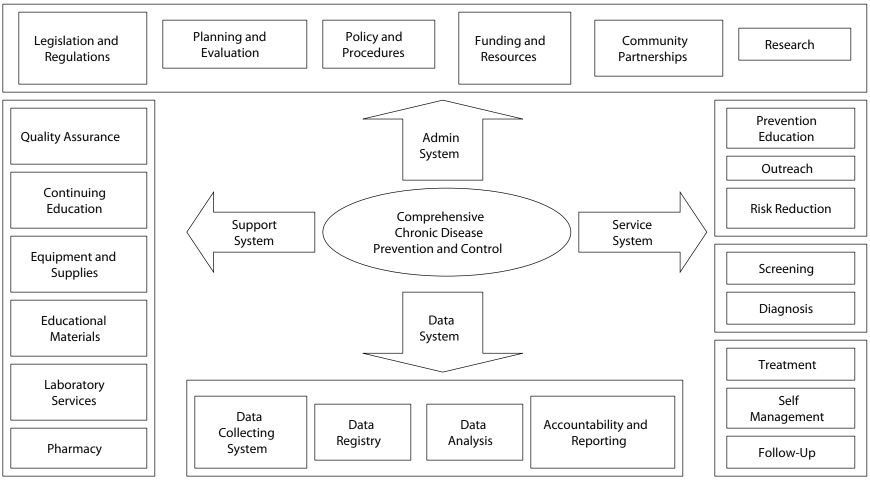

**FIGURE 5-2** A comprehensive system for chronic disease prevention and control encompasses administration, support, service, and data components.
SOURCE: Aitaoto presentation.

Aitaoto closed her presentation with the words *Tofa Soifua*, which is a blessing for wisdom and health.

> "When you look at policy, look at culture *and* policy." —*Nia Aitaoto*

## DISCUSSION

In response to a question from Newell McElwee, executive director of U.S. outcomes research for Merck & Co., Inc., about whether community based programs such as the programs described by the speakers are scalable and sustainable, Aitaoto pointed to the Pacific Diabetes Today programs that continued to operate after funding ended. The reason these programs were sustainable is that the community worked hard and got buy-in, she said, adding that "if you get your community's backing . . . and stand together with one voice, you can go a long way."

Whitson said that the Lifestyle Balance Program of the Special Diabetes Program for Indians has been developing a dissemination toolkit to be ready for use when funding ends. The toolkit is designed to enable a community to open the kit and get a program up and running quickly.

Jennie Joe, University of Arizona College of Medicine, observed that one of the most significant steps in diabetes prevention and management in recent years is Congress's decision to provide special funding to address diabetes because of the magnitude of the problem. Most communities were able to develop the types of interventions that worked in those communities. However, "food and culture are so intertwined that you cannot talk about changing lifestyle or the kind of food that people eat without putting a knife into that sacred spot called culture," she noted. Hard thinking is needed to devise a program that is workable.

With type 2 diabetes appearing in children as young as 8, Joe is running a camp for children to teach them about diabetes and to get to know other kids who have similar problems. "Some of them become very angry. Some of them are even suicidal . . . because they feel like they are so different," she explained. The problem is so pervasive that solutions need to start with the very young.

Maresca said that in urban areas like Seattle, Native people do not live in close proximity, so communities need to be created. People come from multiple counties and have affiliations with different tribes. Community events, such as prevention pow wows, can bring people together to build trust, relationships, and cultural connections while also educating the community.

Ralph Forquera, Seattle Indian Public Health Board, said that the medical model for diabetes intervention and treatment works relatively well, but collective approaches to health intervention remain difficult. Many prevention programs are geared around the idea of using the community to provide support. People who see each other every day can create reinforcing mechanisms to support an idea. But this sense of community is not as easy to create in an urban environment. Forquera's organization serves 4,000 to 5,000 Indian people per year, but 44,000 Indians live in King County alone. Because his program has no contact with the rest of the Native population, there is no way to know about their health status or to advocate for more resources. In general, the IHS is funded at less than half of need. But only about 1.9 million of the 5.1 million (just over one-third) of the Indian people in the country are served. "It is the community piece that is the biggest struggle for us to try to resolve," Forquera said.

Willis suggested that individuals from different communities are needed who have the emotional commitment to find Native peoples and teach them. Members from different tribes need to teach people how to live in a healthy way.

Ira SenGupta, executive director of the Cross Cultural Health Care Program, spoke about work her program did with a small grant from the vitamin settlement[1] on diabetes and chronic disease prevention in local Seattle area Asian-Pacific Islander communities. One program emphasized hula, not just as a form of exercise but also because members of the community enjoyed that activity. The program also taught children in after-school programs about good nutrition and exercise; the children then were able to take this information back to their parents and grandparents.

Kerri Lopez, Northwest Portland Area Indian Health Board, said that part of her job is to examine the standards of care that tribes submit annually,[2] and "we are not doing very good." Accountability has been increasing, but not all achievements can be measured in quantitative terms or according to best practices. With funding about to run out, said Lopez, "I encourage you all to go call your congressman and your legislatures and say support the Special Diabetes Program for Indians, because our funding runs out in exactly 1 year. If we lose all these programs, it will be devastating to our communities."

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[1] In 2000, six vitamin companies were fined for illegally conspiring to raise the price of vitamins. The settlement funding in Washington state was used to fund grants for programs benefitting and improving the health and nutrition of Washington consumers.

[2] Indian Health Service Standards of Care for Patients with Type 2 Diabetes.

# 6

# Cancer Prevention and Treatment in Native Communities

Cancer has been a silent disease for Native communities, said Jennie Joe, director of Native American research and training and professor in the department of family and community medicine at the University of Arizona College of Medicine, who moderated the panel on cancer prevention at the workshop. Many Native communities did not even have a name for the disease, and indigenous cultures did not have experience diagnosing or treating it. This situation is starting to change, she said, partly because cancer has become a critical problem in Native communities. In particular, community-level groups are implementing innovative approaches to prevention, early diagnosis, and effective treatment that are useful and effective.

Three speakers covered programs in cancer prevention and treatment. JoAnn Tsark, project director at ‘Imi Hale Native Hawaiian Cancer Network, described a program to train both clinical cancer patient navigators and community cancer patient navigators in the Hawaiian Islands. A comprehensive cancer control program was the subject of the talk by Kerri Lopez, director of Northwest Tribal Cancer and Western Tribal Diabetes Projects with the Northwest Portland Area Indian Health Board. Linda Burhansstipanov, president and grants director of the Native American Cancer Research Corporation, shared some of the lessons she has learned in tailoring cancer prevention and survivorship programs for local communities.

## A CANCER PATIENT NAVIGATION TRAINING PROGRAM IN HAWAII

Although Native Hawaiians make up about 20 percent of the population in Hawaii, cancer is a cause of death for Native Hawaiians at a rate 50 percent higher than for the state as a whole. In response to this disparity, the ʻImi Hale Native Hawaiian Cancer Network was established to increase cancer prevention and control in Native Hawaiian communities, cancer prevention and control research, and the number of Native Hawaiian researchers.

JoAnn Tsark described the Ho'okele i ke Ola Navigating to Health program within the ʻImi Hale network. The program is a community-driven effort to address cancer health disparities in Hawaii by training cancer patient navigators. The health care system is fractured and disjointed in Hawaii, said Tsark, as in the rest of the country. In addition, rates of mammograms and colonoscopies are lower for Native Hawaiians than for other groups, which means the cancers are detected later, are more complicated, and have worse outcomes. Although some islands have sophisticated medical care delivery systems, other islands have fewer oncologists and services. For example, the island of Molokai has no oncologists or radiologists.

The Navigating to Health program involved communities from the start and sought to build on community strengths and values. It promoted co-learning and capacity building and sought to provide tangible benefits, including an increase in the number of people who could access cancer services when needed. It conducted an extensive review of navigator programs elsewhere, held focus groups with cancer survivors and their families on five islands, and consulted with mentors from the National Cancer Institute.

In the process, the program discovered three truths about cancer care, according to Tsark. First, cancer care is complicated and fractured. Even within Hawaii, what Maui patients want is not necessarily what Kauai patients want. Second, regardless of regional preferences, all people need information, access to services, emotional and cultural support, and confidence and assistance to manage their care. Third, all patients face barriers both in the community and in the health care setting. As access barriers, Tsark listed

- high costs,
- no insurance,
- few providers and services,
- long travel distance to care,
- patients too busy to seek care, and
- stressed support systems.

In addition, systems barriers include

- running between different providers for different services,
- lost referrals and paperwork,
- not knowing who is in charge,
- not knowing what to ask,
- feeling intimidated, and
- providers' lack of sensitivity, time to answer questions, or knowledge of resources.

The 'Imi Hale patient navigator model is designed to provide navigation through the cancer care continuum. It is training both clinical cancer patient navigators and community cancer patient navigators, because the two categories of navigators need expertise in their different domains. The program identified 14 core competencies:

1. Describe the role of a cancer patient navigator.
2. Explain the importance of maintaining the confidentiality of the people you help.
3. Describe barriers to cancer care and ways to overcome them.
4. Identify unique risk factors, tests, and treatments of cancer.
5. Identify related physical, psychological, and social issues likely to face people with cancer and their families.
6. Demonstrate the ability to gather data and create a "Patient Record."
7. Demonstrate ability to find reliable cancer information from agencies and on the Web.
8. Describe cancer-related services available in your community.
9. Describe the advantages of participating in clinical trials and barriers to participation.
10. Define palliative care and hospice care.
11. Assist patients in completing an advance directive.
12. Demonstrate the ability to work through "mock" cancer cases.
13. Demonstrate ability to organize a resource binder.
14. Describe ways to care for yourself.

The findings of the review process also shaped the format of the training. Future navigators receive 48 hours of training spread over 2 days per week for 3 weeks. The training was instituted as a three-credit community college class, because college credits were more valuable to the trainees than a certificate. Training incorporated multiple methodologies, including lectures, class activities, onsite tours, role playing, networking, writing, and developing resource binders, with an emphasis on communications, roles and boundaries, and relationships.

The curriculum and materials were developed from scratch to support the navigators, and funding came from a variety of sources, including an initial grant in 2005 from the Office of Hawaiian Affairs. "I'm a believer that if you ask for what you want and you know where you're going to go, you're going to get the funds to do it," said Tsark. Many of the physicians, radiologists, nurses, social workers, and others who were consulted in setting up the program agreed to volunteer for each 6-day session, which helped build relationships among navigators and health care providers. Cancer survivors and previously trained navigators also served as trainers. "It's not a very expensive program, but it is very much labor-intensive," she explained.

By 2012 the program had conducted 11 48-hour trainings on four islands and 30 continuing education sessions. It had produced 146 navigators, held 5 annual conferences, and made multiple national presentations. It also had started to expand into screening navigation to enhance prevention. The program established 13 paid positions for community patient navigators and received a grant to put navigators in three rural hospitals. And the majority of graduates had reported using their patient navigation skills in their jobs as community outreach workers and health care providers.

Future goals of the program are to develop navigation programs in more clinical settings, strengthen navigation at both the screening and survivor ends of the cancer spectrum, receive third-party payor support for navigation services, and report and publish outcomes data for the state of Hawaii. "Did we increase the number of navigators? Yes. Did we increase the number of hospitals offering this service? Yes. Did we reduce financial and geographical cultural barriers? Yes. Did we establish it as a reimbursable service? Not yet. But we're on there," Tsark concluded.

> "I'm a believer that if you ask for what you want and you know where you're going to go, you're going to get the funds to do it."
> —*JoAnn Tsark*

## A COMPREHENSIVE CANCER CONTROL PROGRAM IN THE NORTHWEST

The Northwest Portland Area Indian Health Board was founded in 1973 to serve the 43 federally recognized tribes in Oregon, Washington, and Idaho. Its mission is "to assist Northwest tribes to improve the health status and quality of life of members' tribes and Indian people in their delivery of culturally appropriate and holistic health care." Kerri Lopez started working for the board in 1992 and has been involved in tobacco control, women's health programs, elders' programs, and seatbelt safety. "I've been a part of it for 20 years, so I've seen a lot happen," she said.

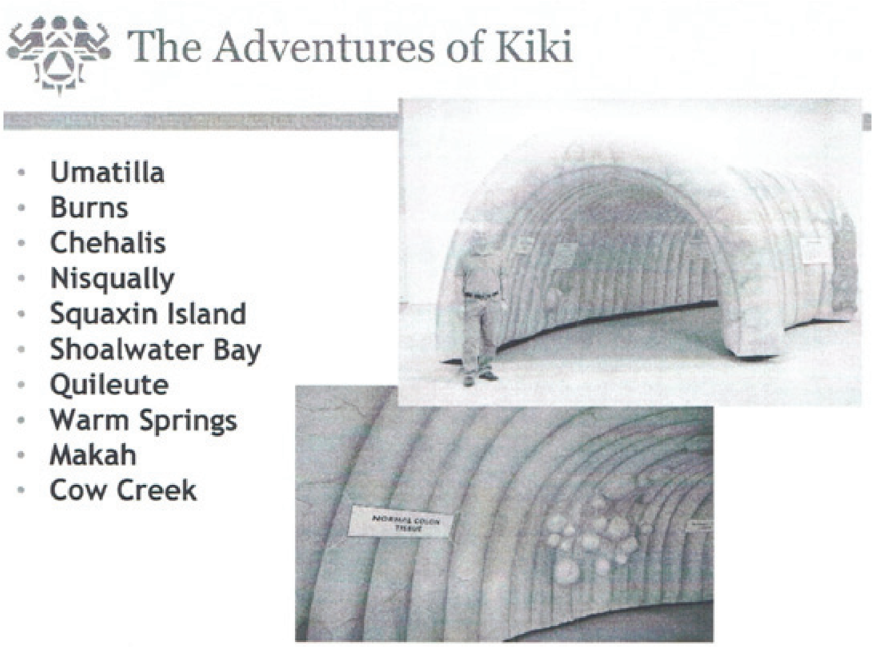
In 2002 the Yakama tribe hosted a major meeting on cancer control, which led to funding of the first tribal comprehensive cancer program. A navigator project involving six tribes also began in 2002, along with a survey of behavioral risk factors through the Indian Health Board, which was repeated starting in 2012.

Since 1998 the Northwest Tribal Cancer Coalition has held meetings involving many Northwest tribes and has achieved several important benchmarks, according to Lopez. It performs trainings and has distributed tribal mini-grants for a variety of cancer control activities. It also provides cancer updates for clinicians covering such issues as cancer screening, Native American/Alaska Native cancer policy, cancer patient education, and the use of electronic health records. "For a comprehensive cancer program to actually get primary care providers to a training is a minor miracle, [but] we manage to get about 35 to 40 people at our trainings every year," she explained.

During tribal site visits, the cancer program conducts a Cancer 101 training, helps to develop tribal action plans, and engages in grant writing that has led to the reception of several mini-grants, with follow-up phone and e-mail technical assistance. It also sponsors visits from Kiki, a large, inflatable, walk-through section of a colon that demonstrates the progression from healthy cells to polyps to cancer (see Figure 6-1). "When folks start talking about that to me I was like, eww, that is so not going to go over in Indian country," said Lopez. But "Kiki's been a hit. She's been to all these tribes. She's gotten folks talking about colorectal cancer screening. There's education going on." Furthermore, as Lopez said in response to a question during the discussion session, colon cancer screening numbers have been going up at the Indian Health Service (IHS) clinics.

The Northwest Tribal Comprehensive Control Program has developed a variety of tools and resources, including a Northwest Tribal Cancer Resource Guide, a text for its Cancer 101 training, cancer fact sheets, an appointment companion, and tribal cancer action plans. It also has developed a 20-year Northwest Tribal comprehensive cancer control plan. The program has developed partnerships among the tribes, with state health programs in the Northwest, with foundations and nonprofit organizations, and with the Centers for Disease Control and Prevention. As just one example, the program has partnered with the Fred Hutchinson Institute in Seattle to interview cancer survivors.

Cancer control and epidemiology in Indian country still need better clinical data and cancer data capacity for electronic health records, Lopez said. Prevention also will remain critical, including youth activities, better



The Adventures of Kiki

- Umatilla
- Burns
- Chehalis
- Nisqually
- Squaxin Island
- Shoalwater Bay
- Quileute
- Warm Springs
- Makah
- Cow Creek

**FIGURE 6-1** Kiki, an inflatable walk-through colon, has helped increase colon cancer screening in Native American communities.
SOURCE: Northwest Portland Area Indian Health Board.

nutrition, physical activity, tobacco cessation, and wellness in the workplace. And cancer survivors who come back to their tribes need better care, because the clinics offer only ambulatory health care, not cancer care.

The best ideas come from the tribes themselves, Lopez added, providing a partial list of the kinds of activities going on at the tribal level:

- Pap-a-Thon (free pap test and health education for women)
- Pink Paddle Project (canoe trip for female cancer survivors to raise awareness of cancer)
- Aerobics video
- Pink Shawl Project (multigenerational breast health awareness project)
- Mother-daughter tea/lunch
- Golf tournaments
- Cancer awareness day
- Cancer 101
- Great American Smoke-Out

- Men's health day
- Relay on the Rez (cancer fundraising event)
- Cooking classes/healthy eating
- Just Move It (campaign to promote physical activity)
- Tribal Cancer Coalition
- Women and Wellness
- Lifestyle intervention classes
- Breast cancer awareness bingo
- Colorectal cancer poker walk (a walking event where participants draw a card at each of several stations. The best poker hand at the end of the walk is eligible for prizes)

> "I want to give credit to my tribes," she said, "but we could do a lot more with more funding." —*Kerri Lopez*

## CULTURAL ISSUES IN CANCER PREVENTION AND SURVIVORSHIP

Native communities are well known for their sharing traditions, said Linda Burhansstipanov, Native American Research Corporation. All of the programs and approaches described at the workshop by the workshop speakers are free for others to use. "We don't believe in hoarding," she said. "You shouldn't have to start from scratch on anything."

But every program needs to be tailored to the local community, because every community is different. In particular, different parts of the United States have statistically significant differences in cancer incidence and mortality. Lung and bronchus cancer incidence rates do not differ much among non-Hispanic white men, but they differ greatly for Native Americans and Alaska Natives, from well above the national average (in Alaska and the Great Plains) to well below (in the East, the Pacific Coast, and especially the Southwest). Using a single number for the cancer rate among Native peoples masks the uniqueness of different regions. "It's lifestyle. It's behavioral variation. It's cultural practices of what you can and cannot eat or what you can and cannot do," said Burhansstipanov.

Understanding these differences and lowering cancer rates require addressing the barriers to prevention and care in culturally respectful manners, Burhansstipanov continued. Community-driven and community-based participatory research programs are essential. Programs are not necessarily evidence-based unless they are based on evidence from the community in which they will be applied; a program designed for and by one community will not necessarily translate to another community. And community-based means that budgets should be split equally, instead of the typical structure in which most of the money goes to the researchers and a small portion goes to the community.

No community program is now or ever will be perfect. Community programs evolve, and interventions that work for a while need to change as the community changes. Interventions need to go beyond collecting survey data to have some sort of benefit for the community. "We have been surveyed to death," said Burhansstipanov. Strategies that work for non-Native communities frequently lack the inherent characteristics that need to be included in Native programs. Also, interventions need to be informed by the community, and particularly by the guidance of elders. "We stand on the shoulders of our ancestors," said Burhansstipanov.

To be successful, surveys need to integrate traditional, healthy American Indian culture and behaviors, she said. They need to result in improved and culturally acceptable services and programs that survive beyond the length of a grant. Examples of successful interventions include Native patient navigators, stories and vignettes captured from Native peoples, and interactive patient activities.

Everything needs to be evaluated. For example, workshops that involve interactive activities show a 25 percent greater retention rate 3 months later than workshops that lack interactive activity, "so we do not do a community workshop without having an interactive activity," Burhansstipanov explained. Local leadership and partnerships are essential if an intervention is to be sustainable.

In particular, supplying Native patient navigators "is the most beneficial, interactive, proactive, strategic intervention that we have ever done," Burhansstipanov said. The best qualification for being a navigator is not education but passion for a community and respect from the community. The navigators even have made it possible to talk openly about cancer, whereas before Native people tended to avoid the subject.

Burhansstipanov's work on cancer prevention and survivorship has yielded several lessons that she shared at the workshop. Prevention is needed for all people, including cancer survivors. One-third of the survivors in the network are overweight. One-third go back to smoking cigarettes after they have been diagnosed with cancer. Thirty-eight percent of survivors have concurrent diabetes. Also, inequities due to living in poverty are exacerbated in rural areas. And a willingness to undergo screening does not help unless people have access to health care.

The Patient Protection and Affordable Care Act (ACA) seeks to address these issues in three ways. First, it enrolls people into some sort of insurance. The IHS never has served as insurance, Burhansstipanov observed. It is not funded at a high-enough level. In the network's database of about

820 survivors, only 12 percent use the IHS for their cancer care. However, the ACA will need Native navigators who can translate policies into action and get people into the appropriate programs.

Second, the ACA will coordinate services in a system that is extremely fragmented today. This will ease the current problem of establishing residency and qualifying for programs, which can be extremely complex, costly, and time-consuming. In local programs today, funding for health care can run out at certain points in the funding cycle, and delays in enrollment and referrals can delay treatment, even for people with advancing cancers.

Third, the ACA emphasizes behavioral interventions. In this regard, it overlaps with responsibilities traditionally allotted to public health.

Burhansstipanov concluded by noting several essential components of community-based participatory research. First, local leadership is essential. Second, the budget must truly be split equally between the researchers and the tribes. Finally, it is critical that researchers spend some time in the communities they are studying.

> "We stand on the shoulders of our ancestors." —*Linda Burhansstipanov*

# 7

# Reflections on the Workshop

During the final session of the workshop, Michael Painter, senior program officer at the Robert Wood Johnson Foundation, invited participants to sum up the lessons they had drawn from the day's presentations and discussions. This chapter summarizes those observations, with the name of the participant who made the comment in parentheses.

## THE IMPORTANCE OF CULTURE

- Healing is different than treatment. (Mildred Thompson, PolicyLink Center for Health and Place)
- Wellness is more than the absence of disease. It has spiritual, emotional, and cultural dimensions that extend beyond health care into the community. (Thompson)
- Cultural humility is a critical dimension of delivering culturally safe care. (Thompson)
- Good health involves harmony, balance, and rhythm, not just the absence of disease. (Jack Lewin, JCL Health Innovation Strategies)
- Health care by itself does not guarantee good health. Many other factors are involved. (Jennie R. Joe, University of Arizona)
- More important than the newest technologies are transportation, nutrition, sanitation, and other basic services. (Lewin)
- Given the rates of re-admission and nosocomial infections that occur in hospitals, the perspective common in Native communities that hospitals are a place where people go to die is not surprising. (Lewin)

- Equity is important because everyone does better when everyone is doing well. (Thompson)
- Medicine is a compassionate and caring field, and the people who choose that profession are people who appreciate the importance of culture and can incorporate it into practice. (Arne Vainio, Fond du Lac Ojibwe Reservation)
- Humor is an important part of wellness, and humor was a prominent feature of the Workshop on Leveraging Culture to Address Health Inequalities: Examples from Native Communities. (Thompson)

## A FOCUS ON PREVENTION

- Under the Patient Protection and Affordable Care Act (ACA), medical facilities are going to be doing much more early screening, prevention, and reaching out to communities, activities traditionally associated with public health. Yet, public health schools and medical schools are largely siloed from each other and have so far failed to engage in dialogue. (William Vega, University of Southern California)
- Effort devoted to prevention will reduce the amount of effort devoted today to treating diabetes, cancer, and other diseases. (Thompson)
- Prevention requires a holistic perspective that encompasses a person's circumstances and multiple health-related conditions, rather than a piecemeal perspective. (Joe)

## THE POWER OF COMMUNITY

- Native peoples have much to offer in the refashioning of health care. (Lewin)
- Cultural traditions should reshape health care, not the other way around. (Lewin)
- The power of Native communities resides partly in their ability to convene as communities and identify what needs to be done. (Ralph Forquera, Seattle Indian Health Board)
- The power of community that is well known among Native peoples is being realized technologically through such means as Facebook. (Lewin)
- The people being served by the health care system need to be involved in developing new payment and delivery models and otherwise shaping the future of health care. (Lewin)

- Most scientific studies of U.S. populations still list American Indians and Alaska Natives as "other." Native peoples need to make their voices heard if they are to be treated fairly in research. (Roger Dale Walker, Oregon Health and Science University)
- Seven out of 10 Indians now live off reservations, and better health for Native Americans has to encompass all members of these communities, not just the Native people who live on reservations. (Forquera)

## INSTITUTIONS AND TRAINING

- Institutions, professions, and groups of people all have their own cultures, which in turn have an effect on health. (Joe)
- Native people need to think about how to get their message across at the highest levels, and health care reform offers an opportunity to do that. (Walker)
- Health care training generally does not reflect cultural differences. A new emphasis on relationships and two-way exchanges is essential to accommodate the effects of culture on health. (Joe)
- Health care providers need to be trained to deliver care in a respectful way to patients, yet health care training itself can be inherently disrespectful to trainees. (Eve J. Higginbotham, Emory School of Medicine)

## THE NEED FOR CHANGE

- Paradoxically, during a time of radical change in science, health care, and government, people will need to change to preserve and protect the cultural traditions that contribute to good health. (Michael Painter, Robert Wood Johnson Foundation)
- In an era of big data, improving the quality and outcomes of health care will be a major theme. (Lewin)
- Technical changes, such as adopting technologies and instituting quality improvements, are straightforward compared with cultural changes. (Painter)
- Given constrained federal funding for health care, creativity will be needed to improve equity in the U.S. health care system. (Lewin)
- One reason it is important to preserve culture is that culture is a tool that can be leveraged to create change. (Painter)
- Self-determination equals power, and power contributes substantially to health. (Thompson)

- As the novelist and poet Alice Walker has written, the most common way that people lose power is by not realizing that they had any in the first place. (Painter)

"This has been a great meeting," said Painter in summing up the workshop. "There was a lot of knowledge and creativity and innovation and wisdom here, and that's a good thing, because our country and our nation face some incredibly complex and huge problems."

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# A

# Culture as a Social Determinant of Health

Commissioned paper prepared for the
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Elimination of Health Disparities
by James Knibb-Lamouche
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## ABSTRACT

Native American populations in the United States are subject to the longstanding effects of historical subjugation. The consequences of colonization, forced migration from their land, and oppression include poor health conditions, high mortality rates when compared with the majority white population, and disproportionately high rates of diseases such as diabetes, alcoholism, and tuberculosis. The extreme levels of poverty among Native American populations mean lower education attainment, economic adversity, social dysfunction, and little or no access to high-quality health care.

Additionally, because the traditional biomedical approach focuses primarily on disease progression and treatment, traditional Indigenous healing practices and other cultural complexities often have not been taken into account in the design of programs to change health behaviors and improve health outcomes in Indigenous communities. The purpose of this paper, then, is to describe the role of culture in health promotion and disease prevention for Native American communities.

## CULTURE AS A SOCIAL DETERMINANT OF HEALTH

For a majority of the history of modern medical science, health was viewed primarily as the absence of disease or defect. It was a state of being in which all of the systems that make up the individual were operating "normally." A continuous battle was begun with ill health, and the weapons in this battle were better understanding of the mechanisms of disease and better understanding of the structures and processes of the human body. While this viewpoint achieved many victories and some spectacular successes, its weaknesses have become more and more apparent.

Chief among these limitations is that although there have been staggering developments in medicines and technologies currently available, there has been an equally staggering cost for their use. Prescription drugs are the primary cost driver in the modern health system, and these costs have been growing exponentially in the past few decades, with no expectation that this trend will slow in the future. The development of increasingly complex and specialized treatment and diagnostic technologies results in the allocation of significant resources to technological marvels that will only affect a comparatively small portion of the population. With the development of each new wonder drug or miracle machine, the system reinforces the idea that for complete health, society needs the newest, the best, and the most advanced treatments. The belief that diseases must be eradicated at all costs results in a system that misallocates resources.

A second limitation of the medical materialist approach is also, paradoxically, one of its greatest strengths. In dealing with individuals in a mechanistic way—that is, as a collection of parts working as a very complex machine—science and medicine have made great strides in our understanding of human biology and the biology of disease. In practice, however, this viewpoint results in a piecemeal and symptomatic approach to disease and ill health. Symptoms are "fixed" with a specific treatment or cure without, in many cases, dealing with the individual as a whole or with the underlying causes for those symptoms.

Another limitation is the reliance on, and belief in, the scientific method as the sole source of information and the directing force for innovation. By focusing only on those aspects or facets of individuals and diseases that can be measured, observed, or reproduced in a laboratory, a large blind spot emerges in which the medical model has nothing, or little, to contribute when considering the individual as anything other than a collection of parts. Treating individuals as human beings with minds, emotions, and spirits is not something this approach does well, and this has resulted in the denigration of systems or viewpoints that attempt to address these facets. This can be seen in the manner in which the medical and scientific establishments have looked down upon treatments and technologies not developed by their methods. For example, in both Canada and the United States, traditional Healers and Elders have been prevented from providing ceremonies and other healing interventions—in some cases through punitive and legislative methods—and as a result, medicines and treatments developed over the centuries were denigrated as superstition and quackery.

Recently, however, there is a growing recognition of what has been called a "population health" or a "health determinants" approach in which health is viewed as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[1] In this view, nonmedical determinants of health are considered when analyzing the health of individuals and populations. In these models, other forces and factors in the lives and environments of individuals may have as much or more impact on their health than access to, or the provision of, medical services. These include determinants such as socioeconomic status, education level, geography, cultural identity, social inclusion and integration, community, and infrastructure. A significant number of correlations can be made between this approach and what is considered a more Indigenous or Native American viewpoint on health. In attempting to be more holistic and comprehensive in dealing with more aspects of an individual or community's life, there are many ways in which this viewpoint intersects with and complements Indigenous worldviews and value systems.

## SOCIAL DETERMINANTS

> *"Every disease has two causes. The first is pathophysiological; the second, political."*
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> *—Ramon Cajal, 1899*[2]

The recognition and further refinement of the idea that while biology is obviously important, there are also nonmedical and nonphysiological aspects to the health of individuals, communities, and populations has come to be called the "social determinants approach." This approach recognizes that there are a great number of inputs to both individuals' health and the systems (environments, families, communities, nations, etc.) to which they belong. Some of the factors that have come to be recognized as having a direct impact on health at the individual level are as follows:

- income,
- social support networks,
- education,
- employment,
- social environments,

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[1] World Health Organization, *Preamble to the Constitution of the World Health Organization* (1948).

[2] Brant, C., Suicide in Canadian Aboriginal Peoples: Causes and Prevention. *The Path to Healing: Report of the National Round Table on Aboriginal Health and Social Issues.* 1993:55.

- physical environments,
- coping skills and resilience,
- childhood development,
- biology,
- health services, and
- gender.

This list is far from exhaustive, but it gives us a glimpse of the complexities that arise when considering the deceptively simple question of why particular individuals or groups of individuals (i.e., minorities, immigrants, Native American communities, etc.) are less likely to be healthy than others in society. In considering these issues, the World Health Organization stated:

> Social justice is a matter of life and death. It affects the way people live, their consequent chance of illness, and their risk of premature death. Within countries there are dramatic differences in health that are closely linked with degrees of social disadvantage. Differences of this magnitude, within and between countries, simply should never happen.[3]

## BROADER DETERMINANTS OF HEALTH

Along with the above individually-based determinants, there are more broad based determinants that act at the community, population, and national levels. These broader determinants of health have only recently begun to be examined for their impacts on the health of specific groups within societies. The following are of particular importance when considering the health of Native American individuals, communities, and populations:

- culture and cultural continuity,
- access to services and supports,
- colonization,
- globalization,
- migration,
- poverty,
- self-determination, and
- territory.[4]

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[3] Brascoupé, S., and Waters, C., Cultural Safety: Exploring the Applicability of the Concept of Cultural Safety to Aboriginal Health and Community Wellness. *Journal of Aboriginal Health*. Vol 5, No. 2, 2009:6-41.

[4] Brascoupé and Waters, Cultural Safety.

In this paper, I will further examine the role of culture as a determinant of health, particularly with respect to the health of Native American populations.

## WHY CULTURE MATTERS IN ADDRESSING HEALTH INEQUALITIES

Two fundamental values that are shared by many Indigenous peoples are balance and respect. These values form the cornerstones of worldviews in which the individual is not the raison d'être for the universe. Instead, the individual is a vital and valued part of the dynamic systems that make up our world, and, as a part of these systems, must respect them enough to ensure that their balance is neither upset nor destroyed. Promoting or protecting the balance found in these systems does not mean keeping them stagnant or unchanged. Dynamic systems are under constant change, but if they are balanced, this change will be incorporated without detriment to the system or the individual. In viewing health from this vantage point, I will focus on the different aspects of a health delivery system that provides the services, programs, and organization necessary to promote healthy lives.

Under the social determinants approach, health, like all other aspects of an individual's life, is not seen as a separate and distinct entity. Health is interconnected with, and interdependent on, larger systems such as the individual, the family, the community, and the environment. Ailments, diseases, and conditions are seen as the result of imbalances in these systems. Treatments and interventions attempt to restore an individual's health through analysis of the disturbances in these systems and the restoration of the balance inherent to them. This analysis also takes into account the fact that a person is not only comprised of his or her physical being alone. Individuals also have emotional, mental, and spiritual aspects that need to be considered. The methods used to perform this analysis, and the treatments required, will vary according to the healer, community, or culture under consideration. These methods may include nonmedical interventions such as healing circles, storytelling, prayer, song, and ceremony, as well as more medically-based traditional medicines and practices.

This approach is not to be offered in a manner that rejects biomedical interventions altogether in an either/or proposition. Both systems have their strengths and both have their weaknesses. This approach is offered in the hope that by recognizing the strengths and limitations of each system, a better path can be discovered that will lead to the improvement of health for many of the most underserved participants of current services and systems. Culturally competent and culturally safe care will need to recognize that one of the main causes of ill health in Indigenous communities and nations has been the almost complete disregard for and denigration of cultural conceptions of health and healing not found in the biomedical or medical materialist model of health.

In order for any intervention, treatment, or healing to take effect, however, the principle of respect must be fostered. For changes to take place in an individual's health, the individual must have respect for him- or herself and his or her position in all of the systems mentioned above. This respect will form the foundation of all interactions and will direct or guide efforts to improve health.

> The native concept of health . . . is said to be holistic because it integrates and gives equal emphasis to the physical, spiritual, mental, and emotional aspects of the person. The circle is used to represent the inseparability of the individual, family, community and world. . . . The circle (or wheel) embodies the notion of health as harmony or balance in all aspects of one's life.[5]

From this brief comparison of views on health, it is clear why culture matters in addressing health inequalities. Culture dictates the language used to define issues, the identification of problems, the framing of those problems, the manner in which solutions are sought, and the methods for defining and measuring success.

## THE IMPORTANCE OF CULTURE IN PATIENT-CENTERED CARE

There is growing recognition of the need for culturally safe, patient-centered care in improving the health outcomes of minority populations, particularly Native American populations. The health status of Indigenous populations is well below the national average both in Canada and the United States.[6] The experience of many Indigenous populations with the mainstream health care system has been negative, often due to cultural differences. Frequently, cultural differences and the inability of health care providers to appropriately address these differences have contributed to high rates of noncompliance, reluctance to visit mainstream health facilities, and feelings of fear, disrespect, and alienation.[7]

Cultural misunderstandings can affect the ability of health professionals to assist their clients or patients in achieving optimal health. For example, health professionals may view clients or patients who are culturally different from themselves as unintelligent or of differing intelligence,

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[5] Government of Canada, *Royal Commission on Aboriginal Peoples*. 1996: 203.

[6] Shah, C. P., Svoboda, T., and Goel, S., The Visiting Lectureship on Aboriginal Health: An Educational Initiative at the University of Toronto. *Canadian Journal of Public Health*. Vol. 87, No. 4, 1996:272-274.

[7] National Aboriginal Health Organization, *Analysis of Aboriginal Health Careers Education and Training Opportunities*. 2003.

irresponsible, or disinterested in their health.[8] This can result in poor health status, marginalization within the health care system, increased risk, and experiences of racism for the Native American patient. In turn, the health care system may operate inefficiently, staff morale may be affected, health care costs may rise as patients return with progressed illnesses, wait times may increase, health centers may be overburdened, and the overall ethical standard of care may be diminished.[9]

For many indigenous people, the almost complete lack of recognition of culture as a determinant of health and the lack of access to culturally competent care results in an alienating and disheartening experience.

Commonly, people from a *nehiyawak* (People of the Four Direction; Plains Cree) community in northeastern Alberta would recall their experiences of accessing health care in the area by saying, "They only go there [a hospital] to die, not to get better."[10]

Adopting a culturally safe approach to patient-centered care can benefit individuals, providers, institutions, and health care systems. When culturally appropriate care is provided, patients' response to care is improved, compliance increases, and engagement with the health system is more likely at earlier and potentially less-complicated and less-expensive points in disease progression.

A commitment to acquiring the skills needed to provide culturally safe care will also benefit health care providers. It can lead to increased confidence on the job through the ability to address the needs of various groups within their clientele and society at large. The resulting increase in job satisfaction may help to increase retention rates in high-turnover facilities and communities (e.g., inner-city, rural, or remote communities). Currently, the dominant discourse on cultural awareness, cultural sensitivity, cultural competence, and cultural safety can be viewed as a continuum that measures the congruence of a person's culture and his or her experience in the health system. This concept largely focuses on increasing health providers' knowledge of various cultural beliefs or trends.[11] While cultural awareness is an important part of cultural safety, it should be emphasized that awareness is only the starting point of the learning continuum and that cultural

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[8] Dowling, J., Transversing the Cultural Gap—Cultural Awareness on Deployments. *First Annual ADF Nurses Forum*. 2002.

[9] Fortier, J., *Bringing Cultural Competence into the Mainstream: Engaging Policymakers, Providers, and Communities to Increase Access and Improve Quality. Resources for Cross Cultural Health Care*. PowerPoint presentation. http://www.diversityRx.org. 2002.

[10] Makokis, J., and Steinhauer, D., *They Only Go There to Die: Experiences of Nehiyawak Seeking Out Health-Care in Rural Alberta; Results of a Talking Circle*, unpublished manuscript, currently submitted to *Canadian Family Physician Journal*.

[11] Papps, E., Cultural Safety: Daring to Be Different. *Cultural Safety in Aotearoa New Zealand*. Dianne Wepa, ed., 2005.

safety is near the endpoint of this continuum. It is therefore important to note the distinctions between cultural awareness, cultural sensitivity, cultural competence, and cultural safety. The provision of culturally safe care involves lifelong learning and continuous development and refinement of competence based on awareness of the cultures of their clients and sensitivity to how culture mediates determinants of health, as well as their clients' experience with and beliefs about the health care system. Cultural safety is the outcome of culturally competent care.

Arriving at an understanding of the concept of cultural safety is a journey of self-awareness on this continuum. According to Irihapeti Ramsden, the Maori nurse and educator who developed the concept in her doctoral thesis in 2002, cultural safety is the ultimate goal in a learning process, starting with cultural awareness of a patient's ethnicity and, in culturally safe practice, growing concerns with "social justice . . . and nurses' power, prejudice and attitude." In other words, Ramsden turns the focus of cultural safety away from the cultural understanding and knowledge of the health care worker and onto the power inherent in their professional position. She seeks to redefine cultural safety from a transformative point of view of the Aboriginal person receiving care; the determination of success is by the recipient, who defines the care received as culturally safe, or not.[12]

**Cultural Competence Continuum**
**(Adopted from the National Center for Cultural Competence)**

- Cultural destructiveness: The imposition of foreign and damaging systems, actions, and policies (e.g., reservations, industrial schools, etc.) with the intended outcome of disruption or destruction of existing cultures and structures.
- Cultural incapacity: The ongoing withholding of recognition and respect for the cultural structures of the client or the client's community or population.
- Cultural blindness: The deliberate act of development and delivery of programs and services in a manner that pretends that "culture does not matter" or that seeks to treat all clients "equally."
- Cultural pre-competence/cross-cultural care: The recognition that culture does matter and that the culture of a particular client or community may be different from that of the service provider.
- Cultural competence: Awareness of one's own culture and the culture of clients and communities, and how these will impact the health and healing relationship being developed. Culturally com-

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[12] Brascoupé and Waters, Cultural Safety.

petent care will be as congruent as possible with the culture of the client under consideration.

- Cultural safety: Complete congruency between the culture of the person seeking services and the services provided. This would be seen as a goal for all health systems and all clients but, for the most part, would be a continuous and iterative process to be striven toward and not necessarily an end result in and of itself.

An overarching concept necessary for the creation of cultural safety in health services and systems is the willingness of health care professionals to develop, implement, and internalize the idea of cultural humility, which can be defined as follows:

> Cultural Humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations.[13]

Cultural humility can be seen as the driving force in moving health and health care services further toward culturally safe care, and is based on a specific and ongoing commitment of service providers, administrators, policy developers, and decision makers. It relies on recognition of the fundamental inequalities that permeate the "traditional" patient-professional relationship and that these inequalities have a significant impact on the health outcomes of clients and communities.

The increasing cultural, racial, and ethnic diversity of the United States compels medical educators to train physicians who will skillfully and respectfully negotiate the implications of this diversity in their clinical practice. Simultaneously, increasing attention is being paid to nonfinancial barriers that operate at the level of the physician/patient dynamic. This dynamic is often compromised by various sociocultural mismatches between patients and providers, including providers' lack of knowledge regarding patients' health beliefs and life experiences, and providers' unintentional and intentional processes of racism, classism, homophobia, and sexism.[14]

Cultural humility is, at its heart, recognition of the failures of past, and many present, service models and relationships in the field of health (i.e., relationships that are external or expert-based searches for diagnoses, treatments, and cures driven by the idea that one person or professional

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[13] Tervalon, M., and Murray-Garcia, J., Cultural Humility Versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved*. Vol. 9, No. 2, 1998:117-125.

[14] Tervalon and Murray-Garcia, Cultural Humility Versus Cultural Competence.

will have the answer and that the trick is to find that individual). Cultural humility is a commitment to improving the health of diverse and disparate clients through true partnership at the community level as well as true patient-centered care models.

It is a process that requires humility in how physicians bring into check the power imbalances that exist in the dynamics of physician-patient communication by using patient-focused interviewing and care. And it is a process that requires humility to develop and maintain mutually respectful and dynamic partnerships with communities on behalf of individual patients and communities in the context of community-based clinical and advocacy training models.[15]

## THE ROLE OF COMMUNITY-BASED EFFORTS TO PROMOTE BETTER HEALTH OUTCOMES

Cultural continuity in a community context is at the heart of promoting better health outcomes in Native American communities. Cultural continuity should not be confused with “authentic,” “traditional,” or similar labels. Cultures are dynamic systems under continuous internal and external pressure to respond, change, and adapt. The key to continuity is that the persons involved have the ability for self-determination with respect to the systems and structures through which they choose to engage the world. Ideally, the health system that serves them would be located within these systems and structures and not imposed externally. The responses of communities would then be more likely to be culturally-based—and therefore more likely to be culturally competent and culturally safe—even in instances where these responses include or utilize external service providers or structures. It is important to note that Native American populations differ significantly from other minority groups in their conceptions, relationships, and interactions with lands and territories as well as with the State or States currently occupying their lands or territories. Even for individuals who reside in urban environments, connection to the land is a fundamental aspect of the expression of cultural experience, whether through seasonal or regular migrations, ongoing connections and relationships with “home,” or individual expressions of this connection.

Community-based efforts are the best hope for promoting better health outcomes, whether that community is at the Nation or Tribe (i.e., Lakota, Tulalip, Haudenosaunee, etc.), reservation, municipal, or virtual (i.e., groups within an urban milieu) level. Culturally competent and safe health systems and services have never, and will never, exist at the national level. No single system could provide for all the variations in culture, geography,

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[15] Tervalon and Murray-Garcia, Cultural Humility Versus Cultural Competence.

demography, and economics found in Native American communities across the country. A single "one-size-fits-all" design for systems and services has not been successful in the past and will not be successful in the future.

Over the past decade, the United States has spent an average of 16 percent of gross domestic product (GDP) on health expenditures (federal, state, and individual). This is the highest amount spent by any Organisation for Economic Co-operation and Development (OECD) country. Health expenditures in many other OECD countries (Australia, Canada, Germany, Japan, and Sweden, for example) represent approximately 10 percent or less of GDP. However, by many measures of health outcomes (infant mortality, life expectancy at birth, disease-specific mortality, etc.) the United States achieves significantly lower scores than most.

Another dimension of the problem involves the variation of health care costs across the United States. A recent analysis by the Medicare Payment Advisory Commission found that spending in higher-cost areas of the United States (that is, those in the 90th percentile ranked by cost), even after controlling for various factors, was 30 percent higher than in lower-cost areas (those in the 10th percentile). This substantial variation is undesirable both because the high cost areas unnecessarily drive up total costs and the results are often haphazard for patients. Indeed, higher costs typically do not equal better care—and sometimes they mean the opposite.[16]

Through shared colonial histories, Australia, Canada, New Zealand, and the United States share relatively similar levels of development, economic philosophies, and legislative regimes. Each of these countries also has similar experiences with respect to relations with Indigenous populations. In each of these cases, it can be seen that these populations are overrepresented at the higher-cost end of the spectrum with respect to health care. This is not a result of intrinsic poorer health among these populations, but is more likely a measure of the disengagement from the health care system until emergent (i.e., the most expensive) services are required.

For culturally competent care to be effectively developed and delivered, it must be designed, managed, and administered by the community. This requires a level of flexibility and responsiveness not easily attained with current delivery models and paradigms. This also requires a fundamental shift in how health is viewed and defined. As stated previously, a rough definition of health under the biomedical model would be the absence of disease or defect. With this definition, it is easy to see how systems would be developed and reinforced that solely dealt with the treatment and eradication of diseases or conditions. Under a community-developed or culturally safe model, however, health can be defined as a life lived in balance with

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[16] Orszag, P., How Health Care Can Save or Sink America: The Case for Reform and Fiscal Sustainability. *Foreign Affairs*. Vol. 90, No. 4, 2011:42-56.

all the other systems of which an individual is a part. These include systems such as environment, community, and family. In this definition, a health care system and health services developed to provide or promote health would need to be holistic, flexible, and responsive not just to the disease or condition but to the individual and restoring the balance necessary for health. From this perspective, many of the interventions or developments necessary for the improvement of health outcomes would take place outside of what would be considered "health areas" in a biomedical, policy, or bureaucratic sense.

A landmark study conducted by Chandler and Lalonde (1998)[17] revealed that among First Nations people in British Columbia, rates of suicide (which are strongly linked to proximal determinants) varied dramatically and were associated with a constellation of characteristics referred to as "cultural continuity." Cultural continuity might best be described as the degree of social or cultural cohesion within a community. According to Chandler and Lalonde, low rates or a lack of suicide in a community appear to be related to land title, self-government (particularly involvement of women), control of education, security and cultural facilities, as well as control of the policies and practice of health and social programs. Cultural continuity also involves traditional intergenerational connectedness, which is maintained through intact families and the engagement of elders, who pass traditions to subsequent generations.[18]

## LAND AND SELF-DETERMINATION

It is important to note that Native American populations differ significantly from other minority groups in their conceptions, relationships, and interactions with lands and territories. There are also distinct and politically charged divergences between the relationships of Native American populations with the land and those of majority populations. In order to understand these divergences and how they impact the development and delivery of care, it is imperative to take into account the connections between land, spirituality, and politics, and to recognize that the Native American relationship with the American state is anchored in land politics. This historical reality has resulted in a number of determinants of ill health that are unique to this group, including

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[17] Chandler, M. J., and Lalonde, C. E., Cultural Continuity as a Hedge Against Suicide in Canada's First Nations. *Transcultural Psychiatry*. 1998 (35[2]:191-219).

[18] Loppie-Reading, C., and Wien, F., National Collaborating Centre for Aboriginal Health. *Health Inequalities and Social Determinants of Aboriginal Peoples' Health*. 2009:18.

- the destruction of traditional economies through the expropriation of traditional lands and resources;
- the undermining of traditional identity, spirituality, language, and culture through missionization and residential or industrial schools;
- the destruction of indigenous forms of governance, community organization, and community cohesion through the imposition of European governmental forms; and
- the breakdown of traditional and healthy patterns of individual, family, and community life.

These attributes of the relationships between Indigenous populations and colonial states such as Australia, Canada, New Zealand, and the United States result in the need for the recognition, integration, and support for the revitalization of culture through the restoration of connections to land and territories and the recognition of self-determined forms of governance and decision making at all levels (individual, community, and tribal/national).

## THE ROLE OF CULTURE IN HEALTH RESEARCH AND PRACTICE

Indigenous peoples have explored, researched, refined, and perfected healing traditions for millennia. These traditions continue to provide guidance for the protection and promotion of individual and community health throughout their territories and communities. Unfortunately, the process of colonization has resulted in these traditions being devalued, denigrated, and alienated by the mainstream society and health system. Colonization and marginalization have resulted in some of the worst health outcomes in the world for Indigenous communities in Canada and the United States. Elders and Healers continue to practice and develop Indigenous healing traditions to this day, and continue to call for support for these traditions as part of any response to the dismal determinants of health and poor health outcomes in many Indigenous communities and nations.

Scientists ignore Indian myths and traditions because they have been trained to do so. It is simple racism to believe that people have been on the planet for 100,000 years or so and not have known or observed anything.[19]

Indigenous peoples have always had health knowledge, although many traditional teachings have been lost, underused, or intentionally hidden. However, these communities are experiencing a rebirth of cultural and traditional knowledge as what was almost lost is being reclaimed and applied to meet the needs of contemporary people. Many communities are combining traditional healing and wellness approaches with the best of Western technology and ideas.

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[19] Deloria, V., *Custer Died for Your Sins: An Indian Manifesto*. 1969.

The need for knowledge has never been greater. Indigenous communities are facing rapid change and daunting symptoms of ill health, such as community and family violence, suicide, high levels of infectious and chronic diseases, and tragic levels of childhood deaths, youth injuries, and adult disabilities. However, there is great opportunity for change as Indigenous communities gain more control over their present and their future. Knowledge is essential to positive change.

Conducting and using research are integral to the worldview of Indigenous peoples. Research, in its purest sense, is about both gathering and sharing knowledge. Indigenous peoples have been in this business for thousands of years and have developed extensive and diverse systems for both the collection and dissemination of knowledge. Therefore, in order to have an effective discussion with respect to an Indigenous definition and understanding of research, Indigenous epistemological and pedagogical methods and systems need to be given the same weight as biomedical methods and systems. This needs to be more than just lip service to "ethical" treatment within what for all intents and purposes is a foreign system. A system used for guidance or direction in activities (ethics) that is not respectful of Indigenous worldviews or perspectives will be inherently unethical and likely damaging regardless of the character or the intent of that system or the professionals and researchers within that system. The fundamental assumptions of biomedical research, i.e., that the research is inherently good, for the greater good, and necessary for the expansion of knowledge, have all in one form or another been used to direct or justify some particularly odious ethical practices. The ideas and assumptions that drive research in its current form must be examined and reframed to be more inclusive of Indigenous insights and perspectives if that research truly seeks to be reflective of, or useful to, Indigenous peoples, communities, and individuals.

With respect to Indigenous definitions or understanding of research, it is important to note that Indigenous communities are not, for the most part, against the acquisition of knowledge or information that results from research. The issues that are repeatedly raised are not, as some assume, a romanticization of the past or a fear of the new. They are a reaction to what has been, for the most part, a severely unbalanced and unhealthy relationship with the health system for Indigenous individuals, communities, and peoples. For this relationship to become more balanced and, hopefully, more healthy, the value and usefulness of Indigenous knowledge must be fully recognized, not in the sense of what it brings to "scientific" thought or how it can be subsumed into that body of knowledge, but as a source of knowledge in and of itself.

A body of knowledge differs when it is viewed from different perspectives. Interpretations of Indigenous knowledge depend on researchers' attitudes, capabilities, and experiences, and on their understanding of Indigenous consciousness, language, and order.[20]

Research is a systematic way of building knowledge that can be as simple as observing the world, drawing conclusions from what is seen, testing those conclusions, and confirming what is learned. More sophisticated research involves developing a sound method, collecting accurate information in a variety of ways, analyzing what is collected (often using elaborate theories and technologies), interpreting the results (understanding what the information means), and communicating the results to others.

Unfortunately, many Indigenous communities have been the victims of research that was badly designed, failed to collect accurate information or understand information in context, and did not communicate its findings well. Indigenous peoples and communities have cooperated with—and sometimes have been forced to engage with—research they had little say in or control over and that was used to further misinformation and negative stereotypes. Much needs to be done to restore Indigenous peoples' trust in academic and scientific research. Some critical issues to address include the need to embrace "different ways of knowing" based on traditional and cultural knowledge; the development of true partnerships among researchers and those researched; greater ownership and control by Indigenous people over research; and research ethics, priorities, and principles that reflect the values and beliefs of participants and participating communities and institutions. For research to be relevant to the needs of Indigenous people, it is important that Indigenous people develop and promote culture-based principles to guide this research.

Just as research continues to evolve with every scientific advance, research principles are intended to be dynamic and adaptable to change as we learn better ways of working toward meaningful research agendas and outcomes. Below are some key guiding principles to inform the development of research activities.

- Research is focused on community priorities, needs, and realities.
- Methodologies are culturally appropriate and respectful.
- The research process is open and inclusive.
- Research designs are credible and of high quality.
- Due consideration is given to ownership, control, access, and possession of data and research outcomes.

Just as the concept of cultural humility is useful in guiding the development of culturally safe health care, it can be utilized by researchers in

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[20] Batiste, M., and Youngblood-Henderson, S., *Protecting Indigenous Knowledge and Heritage: A Global Challenge*. 2000.

understanding the historical and cultural contexts of research, and it can help guide them in making conscious commitments to the development of research that is a joint activity in conjunction with, and for the betterment of, Indigenous peoples, communities, and individuals. The goal is to move the locus of control and efficacy from something that is done to Indigenous communities and institutions to something that is done with Indigenous communities and institutions.

## RECOMMENDATIONS AND CONSIDERATIONS

The following are a number of recommendations and concepts for the consideration of health professionals, administrators, policy decision makers, community members, and researchers. They are offered in the hope that they can assist in guiding discussion and thought around the recognition of culture as a determinant of health as well as in working toward culturally safe care and services for Native American nations, communities, and individuals.

- Healing is a central concept for many Indigenous cultures and should be distinguished from treatment or curative processes in a biomedical context. For many Indigenous peoples and communities, healing includes an active process of recovery from the social impacts of colonization that have had adverse affects on the lives and health of Indigenous peoples for generations.[21]
- Wellness refers to the maintenance and enhancement of health and well-being for individuals, families, communities, and nations through the restoration of balance at each of these levels. This restoration, sought by many Indigenous peoples, is based on a return to traditional spiritual values, Indigenous knowledge, and culture.
- The focus should be on training current health care providers to be culturally competent in the short term while working toward the goal that all service providers share the cultural background of the clients they serve. Within Native American communities and institutions that serve a large Native American population, the demographic makeup of service providers should at the very least match the demographic makeup of the community and clientele. On an individual or personal level, professionals should continuously be vigilant for opportunities to be role models and mentors for promising youth, in the hope of being succeeded by them.

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[21] Brascoupé, S., *Cultural Safety: Exploring How the Concept of Cultural Safety Applies to Aboriginal Health and Wellness*. Presentation to the NAHO National Conference. http://www.naho.ca. 2009.

- Educational programming in the health sciences for those likely to work in or with Native American communities must include Native American history, culture, conceptions of health, and principles of self-determination and management. This programming would likely be of benefit to all professional programs at some point and should be undertaken in conjunction with Native American institutions and educational structures (i.e., not anthropological study of Native Americans, but educational engagement and opportunities for cross-cultural exchange).
- Pursuit of equity in access to culturally competent health care and healing services must be an overarching goal of any strategy for the amelioration of negative health outcomes. Proximity to services is not equity of access. In order for best results to be attained, services need to be accessible physically, emotionally, mentally, and spiritually. The concept of equity also needs to be reframed as equity of opportunity or equity of outcome rather than a focus on equity of investment or equity of service. Equal services do not necessarily deliver equal outcomes.
- The pursuit of holism is important in approaches to problems, their treatment, and their prevention. Multifactoral analysis of dynamic systems is the essence of consideration of broader determinants of health. Health care providers, administrators, and policy decision makers need to open their minds to factors that are not "traditionally" considered health-related in the bureaucratic or service sense. For example, it is a widely held belief in many Indigenous communities that youth interventions that focus on language and culture will enhance the health of communities. Unfortunately, these interventions are often "unfundable" through most health program jurisdictions.
- Indigenous and community authority over health systems, facilities, and services need to be fostered and supported where they currently exist, and mechanisms to support this authority need to be developed in those areas where they do not currently exist.
- Diversity in the design of systems and services should accommodate diversity in communities, cultural groups, and nations or tribes. There are fundamental differences between Indigenous and biomedical approaches to health and healing. There are also differences among and within Indigenous cultures and communities themselves. Any approach or system that fails to recognize this diversity cannot hope to be fully effective. Culturally appropriate program design and delivery are not frills to be tacked on to health care services or programs; they must be at the heart of generating health and healing in any community. When this is the case, cul-

turally competent care will flow directly from the service delivery model and not exist as a separate goal in and of itself.

- For research to be useful, it needs to be practical and directly applicable to the needs of Indigenous communities. Research conducted solely to benefit a clinical or biomedical approach will contribute little to the creation of knowledge that can be used to improve health status. As a guiding principle, it is important that health research priorities be based on population and community needs. Good research involving Indigenous peoples
    - considers the root causes of ill health and the requirements for optimal health that are particular to the experiences and histories of Indigenous peoples;
    - respects the worldviews of Indigenous peoples on connectedness, respect, balance, and the equal importance of physical, emotional, social, mental, and spiritual health;
    - provides insight into key health issues, and offers the potential to improve promotion, prevention, treatment, rehabilitation, and family and community support; and
    - addresses particular issues within the context of the long-term aspirations of Indigenous communities to be self-sustaining, healthy, and prosperous.
- The importance of the relationship of Native Americans to their lands and territories cannot be overstated. Indigenous cultures are the manifestation of a deep and spiritual connection to the land. One of the primary determinants of poor health outcomes in Indigenous communities is their dispossession and disconnection from the land. The best hope for improvement on these outcomes is the reestablishment of this connection through culturally competent care.

# B

# Agenda

**Leveraging Culture to Address Health Inequalities:**
**Examples from Native Communities**
**Roundtable on the Promotion of Health Equity**
**and the Elimination of Health Disparities**

**November 14, 2012**
**Sheraton Seattle Hotel**
**Seattle, WA**

8:30-8:45 am **Welcome, Blessing, and Overview**

**Ralph Forquera, M.P.H.**
Executive Director, Seattle Indian Health Board

**Howard Hansen**
Quileute Tribe (Blessing/Song)

**William Vega, Ph.D.**
Roundtable Chair
Director, Edward R. Roybal Institute on Aging
School of Social Work, University of Southern California

8:45-9:30 am **Presentation of Commissioned Paper**

**James Knibb-Lamouche**
Director of Research and Indigenous Health Sciences Coordinator
Blue Quills First Nations College

9:30-10:30 am **Why Culture Matters in Addressing Health Inequities**
**Moderator: Mildred Thompson, M.S.W.**
Director, PolicyLink Center for Health and Place

**Bonnie Duran, D.P.H.**
Professor, Director
Center for Indigenous Health Research
University of Washington

**Michael H. Trujillo, M.D., M.P.H., M.S.**
Associate Dean, Office of Outreach & Multicultural Affairs
Professor, Department of Internal Medicine,
University of Arizona College of Medicine–Phoenix
Assistant Surgeon General/U.S. Public Health Service (Retired)

10:30-10:45 am **BREAK**

10:45-11:45 am Panel #1:
**Training in Cultural Competence: Increasing the Number of Culturally Competent Researchers and Clinicians**
**Moderator: Eve J. Higginbotham, M.D.**
Emory School of Medicine

**Terry Maresca, M.D.**
University of Washington

**Roger Dale Walker, M.D.**
Oregon Health and Science University

**Benjamin Young, M.D.**
University of Hawaii

11:45 am-12:45 pm **Panel #2**
**Weaving Culture into the Clinical Setting**
**Moderator: Terri D. Wright, M.P.H.**
Director, Center for School, Health and Education
Division of Public Health Policy and Practice
American Public Health Association

**Ursula Knoki-Wilson, C.N.M., M.P.H.**[1]
Chinle Comprehensive Health Care Facility Office of Native Medicine
Chinle, AZ

**Arne Vainio, M.D.**
Fond du Lac Ojibwe Reservation
Cloquet, MN

12:45-1:30 pm **WORKING LUNCH**

1:30-2:45 pm **Panel #3**
**Action in Diabetes Prevention in the Communities**
**Moderator: Newell McElwee, Pharm.D., M.S.P.H.**
Executive Director
U.S. Outcomes Research, Merck & Co., Inc.

**Darlene Willis**
Diabetes Prevention Program
Mississippi Band of Choctaw

**Walleen Whitson**
SouthEast Alaska Regional Health Consortium, Sitka Site Coordinator

**Nia Aitaoto, M.P.H.**
University of Iowa

2:45-3:00 pm **BREAK**

3:00-4:00 pm **Panel #4**
**Action in Cancer Prevention in the Communities**
**Moderator: Jennie R. Joe, Ph.D., M.P.H.**
Director, Native American Research and Training Center
Professor, Department of Family and Community Medicine
College of Medicine, University of Arizona

**JoAnn Tsark, M.P.H.**
‘Imi Hale Native Hawaiian Cancer Network

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[1] Did not attend workshop.

**Kerri Lopez**
Tolowa Tribe
Director, Northwest Tribal Cancer and Western Tribal Diabetes Projects
Northwest Portland Indian Health Board

**Linda Burhansstipanov, Dr.P.H., M.S.P.H.**
Cherokee Nation of Oklahoma
Native American Cancer Initiatives, Incorporated

4:00-4:45 pm **Open Discussion and Closing Comments**

**Jack Lewin, M.D.**
Principal
Lewin and Associates
Health Innovation Strategies

**Mildred Thompson, M.S.W.**
Roundtable Co-Chair
Director, PolicyLink Center for Health and Place

**Jennie R. Joe, Ph.D., M.P.H.**
Director, Native American Research and Training Center
Professor, Department of Family and Community Medicine
University of Arizona College of Medicine

4:45 pm **WORKSHOP ADJOURNS**

# C

# Speaker Biographies (in order of appearance)

**Ralph Forquera, M.P.H.,** is executive director for the Seattle Indian Health Board, one of the largest and most comprehensive urban Indian community health centers in the nation. He is a member of the Juaneno (pronounced Juan-n-yo) Band of Mission Indians, Acjachmen (pronounced Uh-Hosh-Men) Nation, a state-recognized Indian tribe from the San Juan Capistrano region of Southern California.

Mr. Forquera holds a faculty appointment as a clinical assistant professor with the School of Public Health, Department of Health Sciences, at the University of Washington. He is president of the Community Health Council of Seattle/King County, and immediate past-chair of the American Indian, Alaska Native, and Native Hawaiian Caucus of the American Public Health Association. He is the urban representative to the American Indian Health Commission for Washington State, and recently joined the Board of Directors for PRO-West, a private health quality review organization for the Northwest. He is active with the Washington Association of Community and Migrant Health Centers, the National Association of Community Health Centers, and other national health care advocacy groups for better health care for low-income/uninsured Americans. Mr. Forquera has an M.P.H. degree from California State University, Northridge, and a B.S. degree in health science and safety from San Diego State College.

Prior to moving to Seattle in 1990, Mr. Forquera was executive director for the San Diego American Indian Health Center in California. In 1985, he was appointed and later elected to the board of trustees for Palomar College, a large community college in the northeastern section of San Diego County, where he served as president of the board in 1987. He lectured in the Department of American Indian Studies and in the School of Public Health at San Diego State University and California State University, San Marcos. In 1994, Mr. Forquera was a co-author of the first and only population-based study on the health status of urban American Indians and Alaskan Natives, which was published in the *Journal of the American Medical Association*. He co-authored an article titled "A Political History of the Indian Health Service," which appeared in the December 1999 issue of the *Milbank Quarterly*.

In July 2000, Mr. Forquera launched a new enterprise by creating the Urban Indian Health Institute as a division of the Seattle Indian Health Board. The institute was created to provide leadership and support for national information on the health of urban Indians and the social factors, health policies, and systems of care that effect urban Indians and their health. Mr. Forquera has spent much of his professional career working to improve the health and well-being of urban American Indians and Alaska Natives, an often misunderstood, overlooked, and gravely underserved population.

**James Knibb-Lamouche** is Cree/Métis and grew up in northern Alberta, Canada, near Kpawe'no (Grouard) on the shores of the Lesser Slave Lake.

Mr. Knibb-Lamouche has experience working as an educator developing science and health curricula that respects Indigenous knowledge and attempts to engage Indigenous students more fully. His research experience includes the Pulmonary Research Institute at the University of Alberta as well as the Dana Farber Cancer Institute in Boston, Massachusetts. Mr. Knibb-Lamouche has also served as both a participant and coordinator for the Four Directions Summer Research Program, as well as a research fellow at Harvard Medical School.

His most recent position with the National Aboriginal Health Organization provided him with the opportunity to work with elders and healers from many different nations and traditions toward the goal of protection and promotion of Indigenous knowledge and traditional medicines. He also has extensive experience working internationally in the areas of traditional medicines, Indigenous rights, multilateral environmental agreements, and intellectual property rights. Mr. Knibb-Lamouche currently holds the positions of director of research and Indigenous health sciences coordinator at Blue Quills First Nations College.

## WHY CULTURE MATTERS IN ADDRESSING HEALTH INEQUITIES

**Bonnie Duran, Dr.P.H.,** is an associate professor in the department of health services, University of Washington School of Public Health, and director of the Center for Indigenous Health Research at the Indigenous Wellness

Research Institute (www.iwri.org). She received her Dr.P.H. from the University of California, Berkeley, School of Public Health in 1997. Dr. Duran teaches graduate courses in community-based participatory research, health promotion/disease prevention, and critical theory. She has worked in public health research, evaluation, and education among Native Americans and other communities of color for 27 years.

Dr. Duran is currently the principal investigator of two National Institutes of Health–funded research projects in Indian country. Working with the National Congress of American Indians Policy Research Center and the University of New Mexico, she is studying the promoters, barriers, and mechanisms of change in community-based participatory research. With the Northwest Indian College and the American Indian Higher Education Consortium, she is conducting a needs and capacity study of behavioral health at 34 tribal colleges (http://www.iwri.org/health). Dr. Duran is also co–principal investigator of a National Institute of Mental Health–funded HIV and mental health research training program. Her past work includes partnering with the Navajo Nation, Indian Health Service, and Indigenous community-based organizations on frontier rural projects aimed at improving health services, and developing culture-centered health promotion. Using indigenous theories to guide her work, Dr. Duran's research includes studies of the prevalence and correlates of mental disorders, violence, and child abuse; and treatment-seeking patterns and barriers to care among Native peoples.

The overall aims of her research are to work with communities to design public health treatment and prevention efforts that are empowering, culture-centered, assessable, and sustainable and that have maximum public health impact. She is the author of more than 50 publications, including articles in peer-reviewed journals, book chapters, and books.

Dr. Duran is on the editorial boards of the *American Journal of Public Health* and *Progress in Community Health Partnerships* and is on the Centers for Disease Control and Prevention Health Disparities Advisory Board. In her free time, Dr. Duran teaches "Indigenous Presence" (mindfulness) meditation to Indigenous and other communities of color.

**Michael H. Trujillo, M.D., M.S., M.P.H.,** is presently the associate dean for the Outreach & Multicultural Affairs program and professor in the department of internal medicine at the University of Arizona College of Medicine–Phoenix. The program office serves to increase the ethnic and cultural diversity of the college's student body. Dr. Trujillo is a part-time consultant for the Translational Genomics Research Institute (TGen) in Phoenix. He assists TGen to engage Indian communities in the development of applied community-based participatory research partnerships that will not only increase scientific understanding of the genetic basis of disease, but also lead to improvements in clinical care and treatment. In this effort, new partnerships and new alliances have developed that affect research strategies to improve health outcomes for Arizona American Indian (AI) tribes. Dr. Trujillo was TGen's executive director for Program Development & Community Outreach from 2006 to 2008. He also continues with TGen's clinical outreach to AI patients for cancer clinical trials.

From November 2008 until June 2010, Dr. Trujillo was the health research director for the Inter-Tribal Council of Arizona, Inc. (ITCA) in Phoenix, Arizona. There, he assisted the executive office of ITCA in managing, coordinating the various health care initiatives, projects and grants, and extended collaboration with federal, non-federal, state, community, and AI tribal organizations and programs, especially dealing with National Cancer Institute/National Institutes of Health cancer initiatives.

Dr. Trujillo served as the national director of the Indian Health Service (IHS), Department of Health and Human Services (HHS), in Rockville, Maryland. In March 1994, he was the first president-appointed director of the IHS with Senate confirmation. As director, he was an Assistant Surgeon General/Rear Admiral (08) in the U.S. Public Health Service (USPHS). He served two confirmed 4-year terms as the IHS director. In June 2002, he was appointed to the Office of the Surgeon General, HHS, where he was involved in nationwide initiatives to improve the health status and disparities in health care of minority and underserved populations. In May 2003, he retired after serving 29 years as a USPHS Commissioned Corps Officer and having served in several agencies of the HHS and in the Bureau of Prisons of the Department of Justice.

As the director of the IHS, Dr. Trujillo led the effort that resulted in unprecedented tribal participation and collaboration in the IHS and within the HHS. He headed an IHS budget expansion of more than $1 billion to tribes and urban Indian programs that exceeded $5 billion and more than 15,000 employees. He directed the IHS in developing the expansion for tribes to manage their own health care programs through the new self-governance compacting process. He led the agency's headquarters reorganization with participation of tribal and urban Indian program leadership, and he directed the development of the first business plan for the agency.

In 2003, Dr. Trujillo retired back to his roots and served as an associate professor in the department of family and community medicine, and as the associate director for minority and community programs and outreach for the Regional Cancer Research & Treatment Center at the School of Medicine, University of New Mexico (UNM), in Albuquerque, New Mexico. Concurrently, he was the tribal liaison officer for the Office of the Director at the Albuquerque VA Regional Medical Center, and served as an outpatient clinician evaluating veterans for disabilities and compensation.

Dr. Trujillo, a member of the Laguna Pueblo tribe in New Mexico, was the first AI to graduate from the UNM School of Medicine after he earned several undergraduate and graduate degrees from the UNM. He completed his family practice internship and an internal medicine residency at the UNM School of Medicine. Later, he earned an M.P.H. degree in public health administration and policy from the University of Minnesota School of Public Health, and completed a fellowship in preventive medicine, department of internal medicine at the Mayo Clinic, Rochester, Minnesota.

## PANEL 1: TRAINING IN CULTURAL COMPETENCE: INCREASING THE NUMBER OF CULTURALLY COMPETENT PHYSICIANS AND CLINICIANS

**Terry Maresca, M.D.** (Mohawk Tribe, Kahnawake Band), is a board-certified family physician and the medical director for the Snoqualmie Tribe of western Washington. She is a graduate of Vassar College and the Albert Einstein College of Medicine. She has spent the past 25 years working in reservation, tribal, and urban American Indian communities. She is a clinical associate professor at University of Washington School of Medicine, department of family Medicine, where she serves on the admissions committee. A faculty member with Seattle Indian Health Board's family medicine residency training program since 1997, Dr. Maresca served as the program director on grants to promote cultural competency. Her training and clinical practice has blended both Native plant medicine work and Western approaches to health. A former president of the Association of American Indian Physicians (AAIP), Dr. Maresca has worked with a number of AAIP programs during the past 30 years to mentor and increase the pool of Native people serving Native communities.

**Roger Dale Walker, M.D.,** is professor of psychiatry, public health, and preventive medicine and director of the Center for American Indian Education and Research at Oregon Health and Science University. His current work draws attention to best practices for the prevention and treatment of addiction and mental health disorders with American Indian populations.

Prior to arriving at the Oregon Health and Science University 7 years ago, Dr. Walker led the development of the first National Center of Excellence for Treatment of Alcohol and Drug Problems within the national VA Medical Center system. This work and focus began at the Seattle VA Medical Center and the University of Washington School of Medicine.

Nationally, Dr. Walker has participated in numerous consultations and provided testimony on promoting access to care, best practices, and effective research integration into community settings, especially focusing on American Indian populations. He has presented testimony in both houses of Congress in regard to these issues, and provided leadership, direction, and advocacy for the American Psychiatric Association's efforts for mental health and addictions parity for all citizens.

Throughout his career, Dr. Walker has served nationally and locally as an advocate and activist for access to health care and the elimination of the stigma of mental illness and substance use disorders. A major focus of his research has been on addictions and mental health issues of American Indians. Over the past 25 years, the American Indian Research Group has studied the prevalence and natural history of addiction disorders, risk and protective factors relating to addiction disorders, the relationship between mental and addictive disorders, and treatment strategies. He and his colleagues have consulted and lectured throughout North America on American Indian issues.

**Benjamin Young, M.D.**, was born and raised in Hawaii. He graduated from Milligan College, Tennessee, with a degree in English literature, and received his M.D. from Howard University College of Medicine, Washington, DC. He trained in psychiatry at the University of Hawaii and is the first Native Hawaiian to enter the field of psychiatry.

He served as dean of students at the University of Hawaii, John A. Burns School of Medicine, and was also vice president of student affairs systemwide. His last position was executive director of the Native Hawaiian Center of Excellence.

In 1973, he was one of only seven Native Hawaiian physicians in Hawaii. At that time, he was asked to start a program to increase the numbers of Hawaiians in medicine. Today, there are more than 350 practicing Native Hawaiian physicians.

Dr. Young was awarded the prestigious title Living Treasure of Hawaii, and was named a Distinguished Medical Historian by the Hawaiian Historical Society. In addition, the American Academy of Child and Adolescent Psychiatry named him the Joseph Noshpitz Lecturer at their recent convention. The National Library of Medicine/Medical Library Association also awarded him the title Joseph Leiter Distinguished Lecturer.

Dr. Young is currently immersed in writing a book on Hawaii's medical history.

## PANEL 2: WEAVING CULTURE INTO THE CLINICAL SETTING

**Arne Vainio, M.D.,** was born in Chisholm, Minnesota, to a full-blood Ojibwe mother and a Finnish father. He is an enrolled member of the Mille Lacs Band of Ojibwe.

He completed his undergraduate studies in 1990 at the University of Minnesota–Duluth, entered the University of Minnesota Medical School–Duluth, and graduated in 1994. He completed his family practice residency program at the Seattle Indian Health Board and Providence Hospital in Seattle, Washington, in 1997.

He has been employed as a family practice physician at the Min-No-Aya-Win Human Services Clinic on the Fond du Lac Ojibwe Reservation in Cloquet, Minnesota, since September 1997. His hospital affiliations include St. Mary's Medical Center, St. Luke's Hospital & Regional Trauma Center, Miller-Dwan Medical Center (all located in Duluth, Minnesota), and Cloquet Memorial Hospital in Cloquet, Minnesota. He is also employed as a preceptor at the Duluth Family Practice Center in Duluth, Minnesota, and volunteers as a preceptor for the University of Minnesota Medical School–Duluth campus.

He is a member of the Association of American Family Physicians and the Association of American Indian Physicians. Dr. Vainio is the recent recipient of the following awards: National IHS (Indian Health Service) Director's Award, National Diabetes Physician's Recognition Award, and the Minnesota Medical Foundation's Early Distinguished Career Award. Dr. Vainio is featured in the 2009 Emmy-nominated American Indian health documentary film *Walking into the Unknown*, currently showing on more than 200 public television stations, and writes a monthly column for News from Indian Country (www.indiancountrynews.com). His column is picked up by multiple tribal newspapers across the country.

## PANEL 3: ACTION IN DIABETES PREVENTION IN THE COMMUNITIES

**Darlene Willis** is a member of the Mississippi Band of Choctaw Indians. She resides in Choctaw, Mississippi, with her husband and three children. Ms. Willis has been employed with the Mississippi Band of Choctaw Indians for 29 years. Nineteen of those years have been with the health department. She has been the Diabetes Prevention Program Coordinator since the establishment of the Special Diabetes Program for Indians in 1998.

Ms. Willis received her bachelor's degree in social work in 1996 from Mississippi State University. In 2011 she received a Special Initiative Award from the Indian Health Service. She is actively involved in the Native American Research Center for Health project with representatives from Vanderbilt University and United South and Eastern Tribes. She serves as a board member for the several entities of her tribe and is an active member of the Spirit of Life Christian Center. Her goal in life is to make a difference in peoples' lives bringing awareness in the area of health and finances. In her spare time she enjoys teaching at her church and community on basic finances. Ms. Willis is also a retired veteran from the Mississippi Air National Guard.

**Walleen Whitson:** "My Tlingit name is Shaun' Nuth Du' Joon, from the Raven moiety, Seapigeon clan. My parents were Harvey and Marietta Williams and I am the proud mother of three. My husband and I will be celebrating our 25th anniversary next month. I was born and raised in Sitka, Alaska, with a population of approximately 7,500, of which one-third are American Indian/Alaska Native. My employer is the SouthEast Alaska Regional Health Consortium (SEARHC) located in Sitka, Alaska. I have been working in the health prevention field for 8 years. Presently I am a Health Educator II within the Lifestyle Balance Program (LBP), which is a part of the SEARHC Health Promotion Programs. The SEARHC LBP is 1 of 37 grant programs funded by the Special Diabetes Program for Indians (SDPI) Diabetes Prevention Project established by Congress in 1997. The SDPI funds are targeted toward diabetes prevention and treatment services in the Indian Health Service, tribal, and urban Indian health programs.

While working full time, I am pursuing a bachelor of science degree to become a registered dietitian. My goal is to be a diabetes educator and work with my Native people in the fight against diabetes. Thank you for allowing me an opportunity to share with you how our program in Sitka, Alaska, is working in the fight against diabetes in Indian country."

**Nia Aitaoto, M.P.H.,** is a Ph.D. candidate and fellow at the University of Iowa College of Public Health. She is currently the principal investigator of the Faith In Action Research Alliance, a National Institutes of Health–funded (R21) research project that utilizes constructs such as culture, religion, and family to design diabetes prevention and control interventions. She is also the advisor of two regional coalitions, the Pacific Chronic Disease Coalition and the Pacific Partnership for Tobacco-free Islands. Prior to this, she was the coordinator for the Pacific Diabetes Education Program at Papa Ola Lōkahi, where she provided health education, community mobilization training, and technical assistance in American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Hawaii, Republic of the Marshall Islands, and Republic of Palau. She was also a program coordinator for the Cancer Council of the Pacific Island and a principal investigator of a National Cancer Institute–funded research project to investigate health-seeking behaviors of American Samoans in Hawaii.

## PANEL 4: ACTION IN CANCER PREVENTION IN THE COMMUNITIES

**JoAnn Tsark, M.P.H.,** is the research director for Papa Ola Lōkahi and project director of 'Imi Hale Native Hawaiian Cancer Network (U01CA114630; U54CA153459), 1 of 23 National Cancer Institute–funded Community

Network Program Centers. ʻImi Hale is a community-placed, community-driven initiative that provides a robust infrastructure to support increasing the number of Native Hawaiians in cancer prevention and control research and building capacity through training and education in Hawaiian health agencies and communities to address cancer health disparities. As a founding member and project director of ʻImi Hale Native Hawaiian Cancer Network, she and her team have mentored and supported more than 50 Native Hawaiians to win and lead (as principal investigators [PIs] and co-PIs) cancer research grant awards, developed the largest body of culturally tailored cancer education materials for Hawaiian and Pacific audiences, established the Hoʻokele i ke Ola Cancer Patient Navigation Training Program in Hawaii and trained 130 navigators, and assisted the Queen's Medical Center in attaining their designation as one of 30 National Cancer Institute (NCI) Community Cancer Center Program. ʻImi Hale programs and research incorporate community-based participatory principles community leadership, capacity building, and community participation (www.imihale.org).

She received a master's degree in public health from the University of Hawaii at Mānoa in 1984 and focused her tenure in public health on Native Hawaiian community health and wellness. Prior to joining Papa Ola Lōkahi, she served as director of research education and training at the Rehabilitation Hospital of the Pacific and director of the Governor's Pacific Health Promotion and Development Center, which focused on health disparities in Hawaii and the U.S. Affiliated Pacific. At Papa Ola Lōkahi, since 1999, she has spearheaded federally funded programs from the NCI, the Health Resources and Services Administration, and the Centers for Disease Control and Prevention to support programs for cancer prevention and control research and education, and diabetes prevention and control in Hawaiian and Pacific Islander communities. Additionally, she has supported efforts in cardiovascular risk factor research with Dr. Emmett Aluli and Na Puʻuwai, Inc. and worked with the Molokaʻi community as a grants writer and program developer to launch their Native Hawaiian Health Care System.

**Kerri Lopez (Tolowa)** is the project director for Northwest Tribal Comprehensive Cancer Western Tribal Diabetes Projects and has worked in tribal public health for the past 15 years. Ms. Lopez has more than 10 years' experience in program management for tobacco, diabetes, and breast and cervical cancer prevention, and has provided training and technical assistance in diabetes, tobacco education and cessation, breast and cervical cancer, cultural competency, as well as the history of Indian health. Ms. Lopez serves on the Oregon State Diabetes and Comprehensive Cancer Coalitions, the Oregon Nutrition Council, and the Washington State Diabetes and

Cancer Coalitions, is a current board member for the Oregon Public Health Association, and served on the workgroup for OR HB 3486 to make guiding principle and policy recommendations impacting obesity and diabetes.

She has served on the Tobacco Free Coalition of Oregon and Washington, the Board of the County Multicultural Breast and Cervical Cancer Coalition, and Oregon's Multi-Cultural Advisory Committee. Her work was instrumental in setting the agenda for negotiation for tribal allocations for tobacco prevention funds from the tobacco tax initiative in Oregon. Ms. Lopez was the director for the Diabetes Program, American Legacy Foundation Cessation Project, the State of Oregon American Indian Tobacco Prevention Project, and the National Breast and Cervical Cancer Screening Program for the Portland Urban Indian Health Clinic.

**Linda Burhansstipanov, Dr.P.H., M.S.P.H.,** is Cherokee Nation of Oklahoma and is the founder of the Native American Cancer Research Corporation (NACR). Her work has emphasized Native American cancer patients since 1987. The NACR has been involved with navigator and survivorship programs that are local, regional, national, and international since 1994. She is a nationally recognized cancer survivorship researcher for the implementation and assessment of culturally appropriate interventions for American Indians and Alaska Natives. Her personal interest in cancer started in 1979 when her stepfather, whose name she carries, was diagnosed with lung cancer. He passed in 1983 of lung and bladder cancer. In collaboration with Linda U. Krebs, the original Native American Cancer Education for Survivors intervention was developed. She is the original designer for NACR's online evaluation program. She is the originator for NACR's outreach, recruitment, and screening programs beginning with the Native American Wellness through Awareness cancer screening and outreach intervention in1994. She has been the lead educator for the Centers for Disease Control and Prevention (CDC) National Breast and Cervical Cancer Early Detection Board annual training for tribal and urban recruitment and outreach strategies for breast and cervix screening since 1996. She has been the principal investigator for a community-based participatory research R01 research application through the National Institutes of Health (NIH) since 1989 (cervix cancer among urban American Indian women). She has conducted community-based participatory research since 1988. She was recruited to the National Cancer Institute to develop the National Native American Cancer Research Program within the Special Population Studies Branch from 1989 to 1993 (first in an intergovernmental personnel act position and then "expert" position within NIH).

She has served on several federal advisory boards, including, but not limited to, the National Heart, Lung, and Blood Institute's Women's Health Initiative Working Group (May 1996 to 2002), the CDC National Breast and Cervical Cancer Early Detection Board (July 1996 through 2002), the Diversity Advisory Group for the National Institute of General Medical Sciences on "Pharmacogenetics" (spring 1999 to 2003), and most recently the CDC's Promising Practices Assessment of the National Breast and Cervical Cancer Early Detection Program Expert Panel (start date January 2011).