Eliminating Health Disparities

Conversations with American Indians and Alaska Natives

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ETR Associates
Santa Cruz, California

ETR Associates (Education, Training and Research) is a nonprofit organization committed to fostering the health, well-being and cultural diversity of individuals, families, schools and communities. The publishing program of ETR Associates provides books and materials that seek to empower young people and adults with the skills to make positive health choices. We invite health professionals to learn more about our high-quality publishing, training and research programs by contacting us at 1-800-321-4407 or visiting our website at www.etr.org.

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Guest Editor: Michael E. Bird, MSW, MPH
Series Editor: William M. Kane, PhD, CHES
Editor: Marcia Quackenbush, MS, MFT, CHES
Designer: Philip Shima

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Health Disparities Among American Indians and Alaska Natives

An estimated 3 to 5 million Native people were living in the region that is today the United States when European explorers reached the shores more than 500 years ago. In the first 400 years of contact with Europeans, vast numbers died or were exterminated. Around 2 million American Indians and Alaska Natives are living in this region today.

There are more than 330 Indian Tribes and Nations recognized by the federal government in the 48 contiguous states. There are seven distinct Native cultures, dozens of subcultures and more than 220 Native communities recognized by the federal government in Alaska. These tribes, nations and communities have been acknowledged through a federal process to have immunities and privileges available to them by virtue of their government-to-government relationships with the United States.

In recent years, the longevity of Native people has increased substantially. Between 1940 and 2000, life expectancy increased from 51 years to more than 70 years. Yet, despite these increases, great health disparities still exist.

Leading Causes of Death

The leading causes of death among Native people in the United States differ considerably from those of other groups. Table 1 compares the leading causes of death among American Indian and Alaska Native men to those of white, non-Hispanic men in 1996. Unintentional injuries were the second leading cause of death among American Indian and Alaska Native men, but the fourth leading cause among white,

Table 1

Leading Causes of Death: American Indian and Alaska Native Men Compared to White, Non-Hispanic Men in the United States (1996)

American Indian/Alaska Native	White, Non-Hispanic
1. Diseases of the heart	1. Diseases of the heart
2. Unintentional injuries	2. Malignant neoplasms
3. Malignant neoplasms	3. Cerebrovascular disease
4. Diabetes mellitus	4. Unintentional injuries
5. Chronic liver disease and cirrhosis	5. Chronic obstructive pulmonary disease
6. Suicide	6. Pneumonia and influenza
7. Cerebrovascular diseases	7. Diabetes mellitus
8. Pneumonia and influenza	8. Suicide
9. Homicide and legal intervention	9. HIV/AIDS
10. Chronic obstructive pulmonary disease	10. Chronic liver disease and cirrhosis

Table 2

Leading Causes of Death: American Indian and Alaska Native Women Compared to White, Non-Hispanic Women in the United States (1996)

American Indian/Alaska Native	White, Non-Hispanic
1. Diseases of the heart	1. Diseases of the heart
2. Malignant neoplasms	2. Malignant neoplasms
3. Unintentional injuries	3. Cerebrovascular diseases
4. Diabetes mellitus	4. Chronic obstructive pulmonary disease
5. Cerebrovascular diseases	5. Pneumonia and influenza
6. Chronic liver disease and cirrhosis	6. Unintentional injuries
7. Pneumonia and influenza	7. Diabetes mellitus
8. Chronic obstructive pulmonary disease	8. Alzheimer's disease
9. Nephritis, nephritic syndrome and nephrosis	9. Nephritis, nephritic syndrome and nephrosis
10. Suicide	10. Septicemia

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. 1996. *Deaths: Final data.*

non-Hispanic men. Diabetes mellitus, chronic liver disease and cirrhosis, and suicide were all in the top six leading causes of death for American Indian and Alaska Native men. None of these were in the top six causes for white, non-Hispanic men.

Similar differences are found when American Indian and Alaska Native women are compared to white, non-Hispanic women (see Table 2). Unintentional injuries are the third leading cause of death for the former, and the sixth for the latter. Diabetes mellitus is the fourth leading cause of death among American Indian and Alaska Native women, but drops to seventh among white, non-Hispanic women. Chronic liver disease and cirrhosis and suicide, the sixth and tenth leading causes of death for American Indian and Alaska Native women, are not among the top ten leading causes of death for white, non-Hispanic women.

Among both American Indian and Alaska Native men and women, there is an observable trend toward causes of death that occur earlier in the life cycle, which pushes causes that are normally associated with old age lower in the ranking.

Years of potential life lost (YPLL), a measurement that calculates the devastating effects of premature death within a population, is another format for identifying health disparities. When years of potential life lost is used as the measure, health disparities among American Indians and Alaska Natives are obvious in several areas, including unintended injuries, diabetes mellitus, suicide, homicide, chronic liver disease and cirrhosis, and pneumonia and influenza. Overall, YPLL before age 75 for American Indian and Alaska Native people, as compared to white, non-Hispanics, is 33% greater for men and 39% greater for women (CDC, 1996). White, non-Hispanics experience greater YPLL from diseases of the heart, cerebrovascular disease, cancers and pulmonary obstructive disease. A possible explanation is that many American Indians and Alaska Natives die prematurely from other causes before reaching the age where certain diseases routinely cause death.

Table 3 provides an overview of death rates from all causes, and compares those rates by gender among American Indians/Alaska Natives and white, non-Hispanics in

Table 3

Death Rates from All Causes
(deaths per 100,000 resident population, 1994–1996)

	Men		Women	
	American Indian/ Alaska Native	White Non-Hispanic	American Indian/ Alaska Native	White Non-Hispanic
All ages, adjusted	573.7	602.8	362.3	356.5
All ages, crude	498.2	986.4	386.0	995.4
Under 1 year	837.7	689.9	762.0	556.7
1–4 years	78.5	37.5	64.9	29.7
5–14 years	33.0	23.3	23.8	16.2
15–24 years	188.5	109.7	63.6	43.5
25–34 years	278.9	160.9	116.4	62.1
35–44 years	391.6	267.4	186.3	121.7
45–54 years	635.5	520.9	392.6	295.2
55–64 years	1,346.3	1,339.4	889.5	795.5
65–74 years	2,685.4	3,225.0	1,841.3	1,940.8
75–84 years	4,713.7	7,354.7	3,542.1	4,863.5
85+ years	7,789.3	18,152.5	6,464.8	14,665.2

Source: Centers for Disease Control and Prevention, National Center for Health Statistics. 1996. *Deaths: Final data.*

the United States. Again, the disparities are obvious, with greater proportions of native people dying in childhood, adolescence, early adulthood and mid-life.

Accepting the Challenge

Healthy People 2000, the U.S. Public Health Service plan for the nation, identified *reducing* disparities as one of three overall goals. With President Clinton's announcement in February 1998 of a new initiative that established a national goal of *eliminating* longstanding disparities in health status by the year 2010, the rhetoric has changed. The president condemned the fact that racial and ethnic minority groups suffer from greater disease, disability and death, and announced the end of a historical practice of setting lower health goals for minority Americans. At least in rhetorical terms, health disparities among Americans will no longer be tolerated. But the question remains: does this nation have the scientific knowledge, understanding, expertise, personnel and political will to eliminate these disparities?

The five-step plan to eliminate health disparities by the year 2010 focuses on:

- Infant mortality
- Cancer screening and management
- Cardiovascular disease
- Diabetes
- HIV/AIDS
- Child and adult immunizations

The plan calls for:

- Local communities, churches, nurses, physicians, community-based programs, and experts in minority health to send critical treatment and prevention messages with a special focus on reaching racial and ethnic minorities.
- Allocation of $400 million to develop new approaches and build on existing successes to eliminate racial and ethnic health disparities.

- Public and private sector collaboration to help coordinate research, demonstration and evaluation efforts to eliminate disparities.
- A taskforce to bring together disease prevention, health promotion and minority community experts to develop a comprehensive plan to eliminate racial and ethnic health disparities.
- Communities, foundations, advocacy groups and businesses to develop ways to focus on eliminating racial and ethnic health disparities.

The Board of Directors of ETR Associates, a not-for-profit health education organization established in 1981, has accepted the challenge to do its part in eliminating racial and ethnic health disparities. *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives* is the first in a series of publications that will examine the disparities experienced by racial and ethnic populations, highlight the contributions of leaders working to prevent disease and promote health within the population, and identify issues that must be solved and barriers that must be overcome to eliminate health disparities.

The intention of the Board of ETR Associates in producing the *Eliminating Health Disparities* monograph series is to honor those individuals who are working on these issues and capture their collective wisdom, to provide role models for students in professional preparation programs in public health, and to articulate future strategies that providers and policy makers can apply to help eliminate health disparities.

A Note on Terminology

It is difficult to find acceptable terms when talking about the first inhabitants of the Americas and their modern-day descendants. In the fifteenth century, Christopher Columbus mistakenly called the people he encountered here "Indian" because he thought he had reached India. This error stands as a symbol of the myriad misunderstandings Europeans have had over the centuries about the first peoples of America.

Today, some people use the term *Native American*, wanting to avoid the misidentification implied by *Indian*. But this term may be confusing. Might it mean native-born? Aren't most Americans "native"? Some feel it panders too heavily to political correctness, while others think it simply replaces one inaccurate and insufficient term with another.

Most Indian people prefer to go by their tribal identification. However, the tribe names that are most familiar were usually chosen by European explorers or by a tribe's enemies, and are often quite pejorative. The name that members of a tribe use for themselves is the ideal choice, but this is not always practical when talking in broad terms or making general statements about the entire nations of first peoples. Most of these names are still unfamiliar to general readers (e.g., Hotinonshonni for "Iroquois").

In this publication, we have let contributors choose for themselves the terms that they prefer. In our overviews, we have generally used the terms *Indian* and *Alaska Native* because these are currently the most widely accepted terms among first peoples themselves.

Confidence & Possibility

Michele Suina

Michele Suina, bs, *from the Cochiti Pueblo in New Mexico, has a degree in health education from the University of New Mexico. Affiliated with UNM's Research Opportunity Program, her research has examined the efficacy of theories used in health program planning for Indian communities, with an emphasis on health promotion and disease prevention. She has also pursued qualitative research on tobacco use among Indians, bringing particular attention to the interplay between appropriate use of tobacco for ritual purposes and prevention of addiction. In 2001, she served a research internship at the Centers for Disease Control and Prevention. She looks forward to a rich and rewarding career in public health.*

I didn't start out wanting to be a community health educator. My first stint in college was in the field of music education. I learned scales and technique, and music history and theory. It seemed right when I started. But as I was finishing up my music studies, I had no real idea of what I wanted to do with any of it.

The desire to be a health educator came more quietly and took time to develop. I had begun to learn more about the history of Indian people. I found out about the things that had been left out of the books we read in elementary and high school. I talked to the people in my tribe, and to people in other tribes. I began to understand how burdensome it was for Indians to deal with the erosion of their sovereignty or the loss of their language.

I wanted to do something that would make a true difference.

Health Is Important

I began to realize that health is an important part of the big picture. If a community is physically sick, how can it effectively tackle the other issues chipping away at its foundations? Maintaining language and traditions requires a lot of work and energy. How can we effectively do this if we are struggling with diabetes, alcoholism or heart disease? How can an elder share the old stories with children if she is too ill to visit with them?

After learning about the health disparities that face Indian people, I was convinced I had chosen the right direction. Four years ago, I returned to college to devote myself to the field of public health.

Mentors Are Key

I was lucky enough to find a good mentoring program at the University of New Mexico. Through the program, I was connected with a health education professor who opened the door to many possibilities. I cannot overemphasize how important this kind of connection has been for my professional development. There are so many aspects of public health that are not covered in university classes. Through my mentor, I have been able to learn about many of them.

At his urging, I attended the annual meeting of the American Public Health Association (APHA) in Boston. He told me that I would be able to find some people to interview to complete the research I had started in the summer. He didn't tell me—although I think he knew—that I would also find I was part of a rich and diverse community of professionals making a difference in tribal health affairs.

Learning About Leadership

The APHA meetings regularly draw over 10,000 attendees and offer more than 1,000 scientific sessions. Knowing this, I was expecting my contacts to be positive but essentially impersonal. This notion was quickly dispelled when I attended the business meeting of the American Indian, Alaska Native and Native Hawaiian Caucus (AIANNH). I was given a chance to speak to the group about my research and enlist candidates for the project interviews.

Instead of speaking to a group of intimidating professionals, I spoke to people who were very welcoming and eager to help me. I was able to line up interviews that first morning at the business meeting. I was surprised, and also very gratified. The caucus members believed my work was worthy and important.

I was also able to get to know many members of the AIANNH Caucus between sessions. I discovered that for these professionals, the power of leadership lay in their ability to help one another and bring others into the circle. They seemed to believe they were stronger as leaders when they helped me see myself as a leader, too.

My experience was not unique. I met two other Indian students and spent much of my time in Boston with them. They had also come with the support of mentors. They also felt they were learning about entirely new possibilities in public health. I could see that there was a great desire, and much encouragement, for Indian students to succeed.

It's Like Home

Professional support is one thing, but I was also surprised by the *personal* support I received. Caucus members looked out for me. I was taken care of. One shared a sandwich with me between sessions so I didn't have to go and buy one. Several were concerned for my safety at night getting back to my hotel. Over and over again, people reached out to show that they cared about me personally.

One evening, I attended dinner with a group from the Caucus. Most of us were women. I felt as if I were back at home among my aunts, sitting around the table sharing the latest news and happenings in the village. My new "aunts" shared stories and inside jokes from previous Caucus gatherings. I felt embraced and accepted. Even though I was a newcomer, I truly felt like part of the group.

Connecting with National Organizations

There is great power in joining with a national organization like APHA. The caucus was wonderful, and I made many other important connections as well. I found a world of information at the Exhibit Hall; I talked to recruiters from universities across the country; I learned about fellowships and internships with various government agencies, including the Centers for Disease Control and Prevention. The meeting gave me a chance to make personal contact with organizations I had only read about or visited through the Internet.

Connecting in this way helped me realize how many opportunities there are for students in health education. The field is very broad. Many things I had thought were out of reach are really quite attainable. Things I once felt were impossible seem entirely achievable now. As a result, I've decided to pursue several fellowship and internship opportunities.

I plan to attend the next APHA meeting. I will reconnect with my new aunts and friends from the caucus. I hope to bring along a few of my friends from the University

of New Mexico so they can benefit from the meeting, too. The example set by my mentor is rubbing off on me. Like him, I am excited about sharing what I have experienced and learned.

I hope to encourage other students, especially Indian students, and show them that anything is possible, and that there are many good and helpful people who want to see them succeed.

Toward Wisdom

Michael E. Bird

Michael E. Bird, MSW, MPH, *from the Santo Domingo and San Juan Pueblos in New Mexico, served as president of the American Public Health Association (APHA) for 2000–2001. APHA is the oldest and largest organization of public health professionals in the world, representing more than 50,000 members from over 50 occupations of public health. The association and its members have been influencing policies and setting priorities in public health since 1872.*

Mr. Bird is the first American Indian to head the APHA in its history. He has more than 20 years experience in social work, substance abuse prevention, health promotion and health administration. A tireless advocate for public health programs serving Native people, he has also served as president of the New Mexico Public Health Association.

Mr. Bird has a Masters of Social Work degree from the University of Utah and a Masters of Public Health degree from the University of California, Berkeley.

Who has inspired your work?

That's a good question. I guess that a big part of why I'm in health care, and why I did social work and public health, was because I grew up with a father who was an alcoholic. At a very early age, this caused me to look at things and wrestle with some issues. It gave me a sense of the difficulties many people face.

At that time, my focus was specific to Indian people, because that's what I was and what I knew. I grew up knowing how difficult it was for me personally to sort out what all of that—what's called "dysfunction" now—was all about. It was a hard issue for me. Then I became aware that it could be a major issue for a lot of folks, and I wanted to do something that would make a difference in a positive way.

In terms of children who are resilient—and I consider myself one of these—it often boils down to having people around you who inspire you, support you and encourage you.

There have been many people who have inspired me along the way. I have a fantastic mother. She grew up without having a mother, and she had a father who was even less present than mine was. She never graduated from high school. She got married and had me when she was about 17. Yet she raised two children on her own. She provided for us, worked for the Bureau of Indian Affairs (BIA) for 30 years. Even though I didn't have much of a father in many ways, I had a mother who was always there for me. There was always love.

And I had an incredible grandmother. My grandfather had had his own problems earlier in his life, but he always encouraged me. He was very supportive of my going to school. In terms of children who are resilient—and I consider myself one of these—it often boils down to having people around you who inspire you, support you and encourage you, even when you're getting messages from other people that you'll never succeed, that you're not good enough. I've been very fortunate because I've had a whole host of people who did that for me. Some of them were Indian, and some of them weren't. There have been many people who have made a difference in my life.

There are all kinds of heroes out there. There are the ones I think are overlooked: the fathers and mothers who get up every day, go to work, come home, nourish and provide a safe, sound environment for their children to grow up in. They don't give them everything—they aren't perfect. But they're there for their children in the ways families are supposed to be. And, of course, there are incredible people who get acknowledged for standing up and inspiring people—Mohammed Ali, Malcolm X, Martin Luther King. There are Indian people, too—Crazy Horse, Geronimo.

Can you say something about the ways these people inspired you?

I guess the quality I admire is that they were committed to something bigger than themselves and their own needs and egos. They all could have chosen an easier path. But they were courageous. They stood up for what they believed in even when it was extremely unpopular, even when people misunderstood and misconstrued who and what they were.

They were people who had integrity. They were their own people; they chose their own path. There were instances where they paid a heavy price for doing that. But it wasn't about taking care of themselves. They were people who loved humanity. They were motivated by that and acted on that. They had a greater vision that was based on a higher level of leadership—the kind of leadership that comes from a place of love, not fear.

Are there any American Indians today or in your lifetime who come to mind as providing inspiration for you?

Wilma Mankiller, who was principal chief of the Cherokee Nation until quite recently. Interestingly enough, she's a social worker by training. And there are a lot of other people out there doing great work, but we don't hear much about them.

What lessons do you have to share with others?

I'd like to think I'm wiser than I used to be. Somewhere along the line you begin to appreciate wisdom, to value it. Because I think there's a difference between intelligence or knowledge, and wisdom. Wisdom is the ability to see things clearly, understand, and do what is morally and spiritually correct. Intelligence and knowledge are fine, but when you run into people who are wise, they're operating at a whole different level. They're not operating from a place of ego. They're operating from that place of love, not fear.

Intelligence and knowledge are fine, but when you run into people who are wise they're operating at a whole different level.

So I've begun to appreciate wisdom and love. And to appreciate and recognize people who have that quality, who come from that place. Because it's not easy. A lot of people don't come from that place. Wisdom is like a gift that's been shared with me. And people have shared it in a variety of ways—even people who aren't kind. Sometimes you learn a lot from them, too.

I've been thinking about this recently. There are very real limitations operating in the world in terms of racism and bigotry. This is an issue for people in this country who are culturally and ethnically different, and a barrier that has to be dealt with.

On the other hand, I think there are also self-imposed limitations that sometimes operate within the populations and cultures we come from. Some of the messages we get within our cultural groups are mixed and can be limiting as well. Not to mention that the greater society gives you messages about who you are, what you can be, and what you can't be. If we allow people to define who we are, what we are, and what we are and are not capable of, and if we take that message to heart, we limit ourselves. If someone tells you something enough times, you may start to believe it. So it's important to challenge the validity of some of those assumptions. And to be courageous enough to try to do things differently if you can and to want something different.

You know, you hear that the definition of insanity is doing the same thing over and over and expecting things to turn out differently. If you want something to be different, you have to decide to do something different. And if you do that, people external to you are going to see you in a different way. Some of them will see you positively for being different, and some of them might see you negatively.

I guess I've had to struggle with some of that. I'm clearly not the only one—all people have their struggles. But I think that for people in this particular country who come from ethnic populations—African Americans, Asians, American Indians, Native Hawaiians—because of our history and experience there are other sorts of issues one has to deal with. Issues that are internal to your community, but also external. I'm still sorting it out.

The issues that tend to perpetuate disparity are primarily based on economics and race. But when I talk with friends who come from a variety of ethnic backgrounds, more often than not some of the issues we face are very similar in terms of trying to find who you are and not have people define you. Because in any definition, there are both positive *and* negative things. I think the most important thing is to come to your own acceptance and understanding of who you are and what you are, and be comfortable with that.

Then it really doesn't matter how other people want to define you or see you, or if they like you or don't like you. That becomes irrelevant. Not that you don't hear it—you have to be open to hearing it. But the fact of the matter is that you have to be your own person and live your own life. Other people can tell you what to do or what not to do, but that's not really where it's at. Becoming who and what you are, and being comfortable with that and accepting yourself, is what it's really about. It reflects an evolution, or a greater consciousness and awareness. The people I know who are at that place are pretty happy with who they are. They're not struggling to be something they're not comfortable with.

The fact of the matter is that you have to be your own person and live your own life.

It's a lot easier being 48 than it was being 18. I was at a school reunion recently that really brought this forth. At 18, you're so insecure in terms of trying to figure out who you are and what you are and where you belong and what you should be. And I'm glad to say that at 48 I'm so much happier because, hey, what you see is what you get. This is Michael Bird. And you either like him or you don't. And if you don't, that's OK too. I'm not going to lose any sleep over it. It's not my problem. People who know who they are and what they are can accept other people in the same way.

What have your experiences allowed you to accomplish in being involved in health care and the health of American Indians?

I feel very lucky to have had the opportunities I've had. Margo Kerrigan was the first American Indian ever to serve on the board of the American Public Health Association (APHA), and she also founded the American Indian, Alaska Native and Native Hawaiian Caucus. She raised the bar. And I feel fortunate because I then had the opportunity to become involved in APHA, and be the second American Indian ever to serve on the board, and be elected Chairman of the Board. To be the first American Indian to be president of this association was such a wonderful opportunity. It's a real statement on where APHA is in terms of being consistent with its values and its commitment to diversity and social justice.

In my own mind, the direction that native people need to move is out into the broader arena.

In my own mind, the direction that Native people—American Indians, Alaska Natives, Native Hawaiians—need to move is out into the broader arena. I give credit to those people who have worked in BIA and IHS all these years and have made a difference in the lives of Indian people. But I think the next step is to move beyond that into arenas we have not historically or traditionally been involved in. We are part of this greater society. And, unfortunately for Indian people, because of our small numbers—about 2 to 2.5 million—and the relative poverty of tribes, we're just not there in the public eye. We're not seen as part of this country.

An example I would use to make the point was a press conference at APHA with Dr. David Satcher when we announced the collaborative between APHA, HHS and the Surgeon General's office on the issue of disparities. Dr. Satcher and Dr. Archer spoke and made specific reference to a number of different groups, including American Indians' rates of diabetes. But when it was reported in the paper, the headline said, "Surgeon General Announces New Collaborative," and then the text of the story said, "African Americans, Hispanics and others." Well, guess who the others are? The American Indians, Alaska Natives, Native Hawaiians and Asians, and, of course, other groups as well.

What happens is that Indians are not even on the screen. In this country, because it's about the number of votes you can generate or the amount of money you can contribute to a party, clearly those populations that can contribute get more attention and more support in terms of programs. The American Indians, Alaska Natives and Native Hawaiians are kind of an afterthought. What I'd like to see happen is for people's level of awareness to be raised. Let people know, "Hey, we're still here. We still have needs." If you want to start talking about disparities, well, "Disparities-R-Us."

But beyond that, it's important to recognize that the populations we consider to be suffering disparities, well, we do have those disparities, but we are much more than that. So it's not a matter of just looking at all the negatives, but of recognizing the positives as well.

As communities of color, populations who've been excluded—be they Hispanic, American Indian, Alaska Native—gain power and assume leadership, one of the things we have to ask is, what sort of model are we operating on? Is it the dominant model of "I've got mine, so now you go get yours, because it's not my problem," "He who has the gold rules," or "He who has the dominant numbers makes the rules"? Or is it "Hey, we know what it's like to be excluded, so we're going to do something different and not just buy into that dominant model."

If this country is going to demonstrate a real commitment to inclusiveness and diversity and social justice, we have to question the models that have been in place.

If this country is going to be better and different, and demonstrate a real commitment to inclusiveness and diversity and social justice, we have to question the models that have been in place. We're going to have to do things differently. You can't fall into thinking, "OK, here's my network. I'll pull in all the people I know whom I'm comfortable with because they all look like me, and they all think like me, and they all want to be like me or be like each other." It's got to be something better than that.

You said that looking at disparities only focuses on the problems that exist. To overcome problems, we have to build on the strengths communities have. So what do you see as the strengths of Indian communities and people?

I think the strength of Indian communities, what has allowed them to survive and continue and thrive, is based on several things: the culture, the traditions, and the spiritual base on which they operate and see the world.

When you look at what Indian people on this continent experienced, in both North and South America, it's a miracle they even survived. If you look at the history, in the 1920s or 1930s they actually thought Indian people would cease to exist in this country. In fact, there are tribes and peoples who no longer exist. Some did *not* survive.

Those who did continue survived because they've always been strong people. It goes back to their spiritual perspective on who and what they are, the strength of the family, and the strength of tribal communities—the importance, even under great pressure, of perpetuating culture and tradition. We've had the Assistant Secretary of Indian Affairs apologizing—I'm not sure why it was him, it should have been the President and Congress—but he said what all Indian people know: which is that not only was a military war waged against Indian people by the government, but there was

an effort to wipe out Indian traditions, beliefs and culture. And in *spite* of that, Indians have survived. And that is no easy task.

Some of these people have lost a great deal. But the fact remains that there are still some 300 recognized tribes, and additional populations that want to be recognized. The numbers continue to increase. And however people may see it, gambling is allowing Indian people to achieve some economic opportunity to ensure the continuation of their communities and tribes. For the small percentage involved, it's a means that's allowing them to ensure their survival.

But the strengths are mainly culture, tradition and religion—and all of those go back to family and community.

If you were trying to build a national program to reduce disparities among American Indians, do you envision a program that could be built on their tradition, culture and spirituality?

I think so. Given the diversity in Indian communities, it could be challenging, but in general I'd say yes.

The problems that exist in many Indian communities didn't start overnight. Longstanding experiences created a negative environment that did not promote people's health, so it's something that would take time and real work. But I see it happening.

There are a lot of positive things going on in Indian communities now that you didn't used to see—in substance abuse programs, for example. When I started in the Indian Health Service (IHS) years ago, a lot of the communities wouldn't acknowledge that they even had problems. It was always somebody down the road—that *other* community—that had the problem. Now people are much more cognizant that substance abuse is an issue.

And you have young Indian professionals and nonprofessionals working together to define and solve the problem in their own terms. Whereas before it was somebody else defining the problem and bringing in the solutions, now you see efforts to address these issues coming from the Indian community itself. The community is defining the problem, grappling with it in the context of their community and coming up with their own solutions. This is a real change. There are still problems, but communities are developing their own capability to address the issues.

The Indian community is defining the problem, grappling with it in the context of their community and coming up with their own solutions.

What are the most important issues related to health disparities for American Indians, especially for other providers to know about?

Despite the fact that we're the first people on this continent and we have the longest standing here, not enough people understand what Indian people's experience has been—and not only historically. You have to have a basic understanding of the historical context of what happened, *and* combine that with the reality Indian people today have to deal with. I would say a big part of that reality is still a lack of opportunity.

There's a fair amount of ignorance, bigotry and racism. I guess there are also a lot of people who are *saying* the right things, but you have to do more than just say things. You have to get out there among "those people," Indians or whatever population you're talking about. You have to start talking directly to them and developing relationships with them. Most people want to do the right thing, and most people want to be fair. But I think a lot of them are afraid. They don't know where to start. Often the response you get is, "It's not my problem. The IHS or BIA will take care of them. Somebody will take care of them." Well, maybe that somebody is supposed to be you.

People will talk about the health disparities among Indians, and my response is, "Well, if you want to reduce disparities, maybe you should hire some Indian people." It's as though this never comes to mind—hiring Indian people and providing them with economic opportunity. In New Mexico, for example, there are a lot of places where you just don't see Indian people employed. Folks say, "We can't find them, or they don't apply, or they don't have the credentials." Well, I think that doesn't hold water in this day and age. People are either going to make an effort to really get out to recruit and retain people of diverse backgrounds or not. Often there's not a real commitment to doing that. It's just easier to talk than to do things that are really going to make a difference.

You also need to provide educational opportunities. I think of myself and a whole bunch of folks in the sixties who managed to qualify for scholarships and take advantage of those opportunities. I'm not saying we wouldn't have done it if the opportunities hadn't been there, but it would have been a lot harder. And even at that, when you look at the drop-out rates for Indian students in New Mexico, they're very high.

The country needs to invest in its most important resource—people. We need to be investing in the growing ethnic population in terms of education and employment. These are the people who are going to generate the taxes for the aging white population who are soon going to be the minority. If you don't have people who have gainful employment and are paying the taxes to keep everything going, where are we headed? It goes back to doing the wise thing, not the selfish thing.

It goes back to doing the wise thing, not the selfish thing.

I wouldn't be paying taxes today if someone hadn't said, "We're going to make sure you can go to school. We'll get you a scholarship. Here's the opportunity." Clearly then it fell on me to either do something or not. I did, and I'm glad I did, although there were times I wasn't sure why I was doing it. When people argue about what to do about this big budget surplus nationally right now, I say, "If you really want to address health

disparities among American Indians, fulfill the treaties and use the money to pay them off."

I'm frustrated because when you look at what this country holds itself up to be, versus what the reality is, there's so much more that needs to be done. I see so much selfishness and lack of vision—people concerned about their own economic well-being. This serves some people well in the short term, but it doesn't serve the country in the long term. It's like that story about two people in a boat on a lake. The boat springs a leak, and one guy says to the other, "Well, I'm sure glad that's on your end of the boat." But they're in the same boat.

What is your vision, your hope for the future? What is the one thing you would most like to see happen that would address the issue of health disparities?

I'm optimistic, which kind of surprises me. Although you *have* to be optimistic, to believe things can be improved. Otherwise, it's all down hill.

I see Indian and Native people moving more and more toward becoming more self-assured, more confident, and defining themselves on their own terms.

It's a long, slow process, but what I'm beginning to see in Indian communities is leadership that is visionary. Leadership that demonstrates wisdom. Leadership that comes from a place of love. Leadership that comes from a commitment to something bigger than oneself. Leadership based not on ego, insecurity or fear, but on vision, love and commitment to a community or a people's well-being.

There's a whole history of Indian people having things done to them, of course, but it comes back to what you do to yourself. People can define you and name you, and that gives them power, but only if you accept it. Only if you accept that definition, that name, that role, do they really have any ability to affect you. I see Indian and Native people moving more and more toward becoming more self-assured, more confident, and defining themselves on their own terms.

Would you have suggestions for how a health provider might help Indian patients or clients define themselves on their own terms?

That's a good question. I'd like people to have the opportunity to meet Indian people whom they respect and see as leaders, and be able to sit down and talk about what their experience has been. In Hawaii they use the term "talking story." I like it. It's about sitting down together and talking about who you are, what you are, and what your experience has been—just sharing. That's how I learn from other people's experiences. I can contrast and compare what their experience has been, what their reality is, how they've handled different situations and circumstances.

I'd like people to have the opportunity to meet Indian people whom they respect and see as leaders, and be able to sit down and talk about what their experience has been.

For example, I'm very open about the substance abuse issues in my family. More and more people are becoming open to discussing these things. When I talk with other people who have worked through some of the stuff you've got to work through around this issue, there's an instant connection. You know a lot about what they've felt, what their experience has been, how painful it's been. It's an instant bond—almost like family. It's comfortable and reaffirming in a lot of different ways. You can talk about the good; you can talk about the bad. But you are sharing a common experience you've both been through. What did you learn from that? What was the lesson? What was important about that experience?

You still feel the sadness, but you can also appreciate the fact that this person is doing good things, is helping people, is working with and advocating on behalf of their community. They took an experience that was so painful, so difficult and so negative, and turned it into something positive.

The older I get the more clearly I can see where someone's coming from. Are they coming from a place of love, or are they coming from a place of fear? Because the

behavior is very different. If they're coming from a loving place, a place of compassion, they relate to people in general, and to their clients or patients, in a different way.

The older I get, the less willing I am to be around people who are negative and fearful. Life is shorter. I don't have time to be playing games.

Leaders & Survivors

Linda Burhansstipanov

Linda Burhansstipanov, MSPH, DrPH, CHES, *a tribal member of the Western Cherokee Nation (Tahlequah, Oklahoma), is the executive director and president of Native American Cancer Initiatives, Inc., in Pine, Colorado. She implemented the Native American Cancer Control Program at the National Cancer Institute (NCI) from 1989 to 1993, and has served as principal investigator on numerous cancer research projects. She is the author of multiple publications on cancer control in Native populations.*

Dr. Burhansstipanov has more than 25 years experience as a teacher, researcher and administrator in public health. Her work in health promotion has been acknowledged with several awards, including the prestigious Award for Excellence in 1997 from the American Public Health Association. This award recognizes exceptionally meritorious contributions to the improvement of the health of the people.

A leader, advocate and spokesperson for efforts to establish comprehensive programs for care and treatment of Native Americans with cancer, she serves on numerous public health advisory boards and actively mentors younger colleagues.

Who has inspired your work?

Native American cancer patients. They've dealt with cancer with little or no support in the local community, yet they continue to find ways to make contributions to their communities. They're unbelievable in terms of how strong and how devoted they are to really making a difference, to not letting other people in the community go through what they've gone through.

Most of them didn't get quality of care. And yet they remain very positive, very full of life, energy, the whole works. You work with someone like that, and you have a little hurt back or something, and you think, "Wuss *(laughs)*, get focused, get doing what you should be doing."

How has this experience changed the way you work?

In our community, we use storytelling as a way to learn. The stories these survivors tell are powerful. And, typically, within their stories, there are directions about what needs to be done in the field to improve things. I take that as my mission.

One of the stories that really changed the direction I was going was that of a breast cancer survivor, a Cheyenne woman. She'd gone to her provider and was told she couldn't have cancer because she was an Indian and Indians don't get cancer. This was in 1990. But she knew there was something wrong, so she went to a different Indian Health Service (IHS) clinic.

In our community, we use storytelling as a way to learn.

At that first clinic, she was ranked number ten on the priority list, and would never have been referred for a mammogram. There were no mammograms available in that community anyway, which was 150 miles from her reservation. So she drove to another clinic, and saw a different doctor there. They also didn't have access to mammography screening, but he said, "No, this doesn't feel right" and put her as top priority. When money was available from contracted health services, she was sent for help.

She was sent a thousand miles away, by herself, going through cancer treatment all alone. No one there understood anything about Indian people—for example, her need to have her artifacts present in her room. She had an eagle feather that someone threw in the trash. When something like that happens, it has to be blessed before it's picked up again. This is just one example of what happened to her during this experience.

When she returned to the reservation, she went back to the first doctor, the one who told her she couldn't have cancer, and said, "Look, I'm full-blood, and I have cancer. You need to quit telling people they can't have cancer." He said, "Well, you're the first." And she said, "I don't think so. I want to know who else on the reservation has had cancer." He didn't know of anyone at all. So she went door to door, trying to find people who had experienced cancer. She found ten other people who were cancer patients. All had gone through the experience completely alone.

She went back to the doctor and demanded an office. She said, "We need a cancer support group." So they cleaned out the broom closet for her, put a little tiny desk and a little chair in it. Then she went to them and said, "Well, I need a phone." She's really quite amazing.

Her story made me hear future stories differently. This woman really affected what I did. I started thinking about what needed to be changed in the health care system for cancer patients in Indian country. That led to efforts to develop the National Clearinghouse that now exists at the Mayo Clinic, called the Native C.I.R.C.L.E. There also was no place for this woman to find information or connect with other survivors. Knowing her story really influenced the way we set up a survivor support network. It has taken eight years of aggressive efforts, but we now have a National Native American Cancer Survivor Support Network.

I started thinking about what needed to be changed in the health care system for cancer patients in Indian country.

There are still a lot of things about the Network that aren't quite what they need to be, but I think we're on the right

track. People do not have to go through this experience alone. We give them a long distance calling card and connect them with a Native cancer survivor—they can be matched on certain characteristics—and they get support. Sometimes they pray over the phone together. Sometimes they sing. Sometimes they talk about crafts, or about artwork as a form of spirituality, as part of the healing process. Sometimes they cry. Sometimes they talk to someone who's going through the same type of therapy they are, and they get a chance to help one another. Sometimes they talk about what type of traditional Indian healing needs to take place. A lot of this has evolved from meeting that woman and hearing her story.

Another phenomenal survivor is Alisa Gilbert (Tiwa Pueblo and Iñupiaq), the director of the Survivor Network. She was diagnosed with breast cancer at age 31. Again, she was told she couldn't possibly have cancer because she was Indian. She turned out to have a very aggressive form of cancer and was given six months to live. She channeled much of her distress, anger and frustration through poetry, artwork and photography. It's now been years, and she has two young children. She constantly has new ideas. She's like the E. F. Hutton commercial: when she speaks, I listen—100%. When she says, "You know, I think what we need in the community is…," I start taking notes.

When [a survivor] says, "You know, I think what we need in the community is...," I start taking notes.

Where else do you look for inspiration?

In terms of inspiration, I think the Creator always provides experiences in your life to help you go in a particular direction. I originally had zero interest in cancer. It was the worst area for me to even have to teach. I had started out in women's issues, working with women and children who had been victims of abuse. These were multi-racial groups, but of course there always seems to be a lot more of that in Indian country because of the alcohol abuse.

Then my stepfather was diagnosed with lung cancer. I think that was one of the experiences the Creator needed to give me to put me on this path. I carry my stepfather's name to honor him. He became my stepfather after I was an adult, but he was such a blessing in my life. He was wonderful in terms of helping me trust and respect men, because I had grown up in a very violent and physically abusive home. When he passed in 1985, his experience was definitely an inspiration for change.

Then one of the students I had been working with had cancer. We actually thought she was dying of a form of Hodgkin's lymphoma. It ended up not being that, but it made me look more into the area to find ways to get her help and to support her.

About the same time, I had some interactions with people from the Centers for Disease Control and Prevention (CDC). I was sent to some areas where they were having a lot of controversy—they thought I could keep things calm—plus there were some Indian people there, and since I was Native it was logical that I should go there to address the cultural issues.

The fellow from the CDC then talked to me about working with a local Indian clinic in Los Angeles to help them get a grant project rolling. I met with them, and immediately became a member of the board. The project they wanted to do was on cervical cancer. All of this stuff started funneling together to push me into working with cancer. I wrote a grant to the National Cancer Institute (NCI) on cervical cancer, and it was funded. Within two months of it being funded, I was contacted by the National Cancer Institute and asked to develop the national Native American Cancer Control Program.

I see all of those steps—my father's disease, my student with what we thought was lymphoma, the experience of making closer contact with the CDC, and then of being recruited to NCI—as inspirational things, all part of the path. I look back now on everything I did in my professional career, and I cannot see anything that did not help me get to where I am now, even though at the time I would never have thought I was going to go into the area of working in cancer in my own community.

Is there a way people can look for these signs along the way that lead you to the path you're supposed to be on?

Different cultures do it differently. Even within your own culture there's a lot of variability. There always is. But for many of the Native cultures, we are supposed to greet the sun every morning, and thank the Creator for the blessing of the new day. And you pray first for the people of all colors, from all around the world—for peace, for health. Sometimes there are certain catastrophic events occurring that you want to pray extra for.

And then you pray about things that are closer to your family and loved ones. Your family doesn't mean just your relatives; it means people you consider a brother, an uncle, or whatever.

And then you pray for yourself.

That helps me get geared up in the morning. When I was at NCI, I'd show up very early and burn sage. Some of the people in the building didn't appreciate my making what they called an "odor," but to me the sage is a spiritual cleansing. You burn it when you pray. It helps me get focused on today. If I'm angry, annoyed, worried or upset, or anything else, when I pray and when the sage burns, I give that up to the Creator.

When I start off the day burning sage, it helps [me] to stay spiritually focused.

And as part of my prayers—what helps me go forward—I try to think about what can help me work for the benefit of the community today. "Help me find the best way to express what I need to do. Help me be patient. Help me keep my ego on hold and make certain I'm doing what's best for the project, rather than what's easiest for me." Those are the types of things I've incorporated into my daily prayer. I really find that when I start off the day burning sage, it helps to clean things up in my mind, and to stay spiritually focused. Because it's hard to do. When I worked for the government, there were times I burned sage five times a day.

What lessons do you have to share with others?

There are a lot of things. I think one that's more cynical is that there are times in your career when a colleague or somebody you really trust does something inappropriate. I don't know any professional it hasn't happened to—that someone may have sabotaged or betrayed you—but the best thing you can do is to stay on your own path and succeed. I think a lot of people, particularly young professionals, get so upset and angry that they set out to get even. I think that when you do that you're no longer on your own path.

Don't get on the road of revenge and anger, of gossip and everything else or you sabotage yourself. It's just a way to not do what you're supposed to be doing. Instead, I think you really need to focus on a leadership path. How do you stay on it? What do you need to put in place to get where you need to go? That's one of the biggest lessons.

I think you really need to focus on a leadership path. What do you need to put in place to get where you need to go?

Publication is another lesson. Not publishing is one of the mistakes I made early in my own career. I think it's something young professionals who work in the community are also guilty of, and it's a mistake.

Back in the early 1970s, through a small grant in the community, I had a program that worked with children who had been abuse victims, and their mothers. What I needed to do was take what we were doing—because there was almost nothing going on in these areas at that point—and publish it. But I looked at publications as ego-boosting, as just something for people to get themselves all pumped up over. You only have so many hours in a day. Was I going to spend my hours working with the children and the teens and the women, or was I going to write an article that was just ego-boosting?

I chose working in the community. The result was that the funder felt nothing ever came out of the program. If I had published, even if it had been writing some articles

for the local newspaper, we would have still been funded. They stopped the program after about a year.

What have your life experiences allowed you to accomplish?

I'm the first one in my family ever to have finished college, much less earn two graduate degrees. A lot has happened that's been very good for me—things that weren't likely to happen. I have some unique experiences.

I started teaching at UCLA when I was 22. I finished my doctorate when I was 24. Then I was able to be in a position to teach as quickly as I did. I was involved in professional groups, and had the chance to interact with other people around the world because of some of those groups. Of course this was long before the Internet age, which now opens these opportunities to many people.

I've had the opportunity to publish. For the first 15 years of my career, I hardly published anything. You can't when you're spread too thin. What finally helped me take that step was seeing how few things were available to help other people working in Native communities.

For example, when I'd do a literature search, very rarely would I find a Native perspective on different health issues. Articles are primarily written by people outside the community. Some of them are eloquent; some are absolutely excellent. But I think that some young professionals think they can't do these things because there are so few articles written by Native people, that in some way we're just not fit to do that.

That's wrong. You need to publish so people can see that Native people *can* write about their own issues, and that they can be in peer-reviewed journals. People call to say, "I can't find this anywhere," and I say, "Well, this community knows it, and that community knows it," and what happens is that we start to get a very informal body of literature. I know about most of what goes on at the community level throughout the United States in cancer because one person or another will call me up and say, "You

know, this little tribe has done this. It's all in a notebook. They've written it out on lined paper." And I say, "Well, I'd like to see it." I find a way to talk with the people about what they're doing, and encourage them to publish it so other Native programs can benefit.

You need to publish so people can see that Native people can write about their own issues.

This started an informal network between people who thought they were on their own. That's how we were able to get some of those people into our national clearinghouse—from contact, from all these little things that come together. I consider it a major accomplishment that now another professional can contact the Native C.I.R.C.L.E., and even if something is not in a peer-reviewed journal they may be able to find copies of the material, or of the study that's been done, or materials that were developed, or what was learned. It may be written very informally, but it helps another program develop something similar.

A very significant accomplishment is that we now have national cancer conferences, and that key members actually started having national Native American cancer conferences before we had a cancer research network (1989). The Network for Cancer Control Research Among American Indian and Alaska Native Populations has now been in place since 1990 and it has been phenomenal in terms of what they've attained nationally.

They've continued to provide these Native American cancer conferences about every three years. They've jointly put together a series of publications, in which all of us have made an effort to write more. So there are now things available written by Native people that other people can draw upon and discover, "Oh, I didn't realize that wasn't true for all Native people." The network also has been responsible in many ways for the two ongoing American Indian–Alaska Native research networks that have just been funded by NCI this last year and for putting together a national training program for Native American cancer researchers.

By getting this group of people together and seeing the things they've been able to accomplish, we've been able to set up our program, establish an independent cancer survivors' support network, and be in a leadership role right now for genetic education for Native Americans. This is a major accomplishment.

Every day there is something new to learn about how the culture affects how something is interpreted.

None of this stuff is easy, but it's all fascinating. I've never been bored. Every day there is something new to learn about how the culture affects how something is interpreted and why you have to modify things so people can get the best care possible or understand a little better what is happening to them.

You're creating a way to expand the Native American community, connecting people all around the country who may be of different tribes but are of that community.

Clearly. Of the survivors we've talked to, about two-thirds are enrolled in the Network so far. It's amazing what we're learning by collecting data on all the people in this cohort of Native American cancer survivors. We've learned so much already from the survivors we've talked to, formally or informally.

What are the most important issues related to health disparities for American Indians?

There are cultural issues that come into play. A lot of the health messages promoted throughout the United States are along the lines of "You need to be a well woman. Take care of yourself. Go have your check-up." Well, that message has no impact at all in Indian country—absolutely none. The concepts of prevention and early detection are not common within our community except for children. Everything in the Indian community really is focused on bringing in a healthy next generation.

So immunization programs work, and certainly the IHS has done outstanding work with some of the immunization programs in terms of where kids are now.

But looking at adults who've been raised on the reservation, or been raised with a lot of traditional beliefs, their own health care is low priority. You have to tie things in to the family. "Be a well woman so that you're alive to teach your grandchildren the stories." Now, that works.

We find, too, that there are spiritual aspects. When we did a breast cancer screening in Los Angeles, we brought in a woman healer who did a spiritual cleansing of the mammography van and of the machine so that women would go through the screening. And this is in a very big urban area. L.A. has more American Indians than any other city in the United States. People think, "Well, if they're in L.A. they're very well acculturated." But the women wanted the blessing. So we had the healer there and she did the blessing, and the women were smudged when they left the screening so that if there was anything of cancer that came from the machine they would not get it. That helped improve participation in the screening.

Is poverty an issue?

A lot of people talk about poverty being responsible for the disparities. That's certainly a large part of it, but it isn't the whole story. We identified different poverty-related issues and how they affected Native people getting into health care and taking part in cancer screening. And from the survey, it looked as though transportation was an issue, and the need for childcare, and all these other things that were poverty-related barriers. So we developed interventions to address these barriers and it had absolutely no impact at all on screening. None.

So we went to the community and said, "We need to know what you want done. You said transportation was a problem, so we'll have someone come by to pick you up and bring you to the center to have this done." And a grandmother looked up and said, "Whuh. Now I have to think of another reason not to come." We asked, "What's

really going on here?" And she said, "Transportation is hard, but if I really wanted to get there—if this were bingo—I'd get there." Similarly, having access to childcare is helpful, but again it wasn't really the issue, because they know there will be another Indian woman sitting there who would watch their children while they went in for the appointment. It's just something you do.

So what's the issue? Well, a big part of it is that people feel that if they are diagnosed with the condition, there is no treatment. Or there is a treatment, but it's not available to them. So why go in? Why find out you have cancer if you won't be treated?

People feel that if they are diagnosed with the condition, there is no treatment. Why find out you have cancer if you won't be treated?

There's no oncologist with the Indian Health Service; they're all under contracted health service. You have to wait to be referred, and the number of nightmare stories that people tell us about waiting three months, six months, a year before they're referred for care is amazing. We found that the interval from the time of diagnosis—from the biopsy—to initiation of treatment is three to six months. Unless they have private insurance. But less than a third of these men and women have private insurance. They have to fight different systems to get care.

Some facilities do refer people right away. But do they get state-of-the art care? Rarely. And if you don't get state-of-the-art care, you're not going to be cured. It's the same with access to drugs such as Tamoxifen. There's no Tamoxifen, even in the IHS formulary based in Maryland. No one can even order it from that facility. And it's an expensive drug. Native cancer patients are not getting access to some of the better drugs. It also varies from setting to setting, what people have access to and what they don't.

Even if care is available, there are often other issues. Take a woman up in the Alaska bush who has a screening mammogram and needs to be referred for a diagnostic mammogram. Well, the diagnostic mammogram is in Anchorage—500 miles away—and she has to stay for three days so the providers will have a chance to completely read

the film. Then, if it's cancer, she has to stay there for treatment. The Alaska Native Medical Center is ready to take care of her once she's there, but this lady, she's got three young children. She doesn't know when she leaves if someone has to care for them for three days or three months.

She has to arrange things with her work and with her children, within her small village out in the bush. She can't ask her husband to do it because he has to hunt. They live on subsistence there. He has to bring the food in for the family or they'll starve. It takes her four months to get everything worked out, which delays her treatment. Other neighbors from the village take turns caring for her kids, shuffling them from one family to the next for a week at a time. She comes down to Anchorage and is going through this experience basically all alone. The nurses are wonderful at Alaska Native Medical Center—absolutely caring oncology nurses—but that is her only support until she goes back to her community.

That's a pretty phenomenal experience. We've gotten some of these ladies to talk with other women about it, but even to talk to another woman in Alaska, we're looking at bridging 500 or 600 miles to make the connection. Many of them walk to the local store and use the pay phone because there's no phone in their homes. It's amazing, the stuff they go through to deal with this disease while living in a rural area.

It's amazing, the stuff they go through to deal with this disease while living in a rural area.

Are there other issues as well?

Yes, another thing that relates to some of the disparities is that the health information produced isn't of relevance to Indian communities. They need to have culturally specific information and very proactive instruction about where they can go in the community. And often the communication of the message or a previous experience contributes to the disparities. For example, many patients feel they've been handled disrespectfully during a physical exam, and they won't go back—that's been male as well as female patients—because they did not understand what was happening to

them in the exam, and why they were asked to take off their clothes. You're looking at, in general, very modest people. And someone has them undress, and does something to them in a very quick, efficient manner because only five minutes per visit are allocated for this type of screening test.

Sometimes, too, providers think they're being understood, and they're not. It's not from lack of desire, by any means. But I think they don't know where in the communication process the patient isn't following what's being said.

In working on communication, we've found that the most effective form of health intervention is one on one, being able to sit down and really work with the person. That's why we have the Native Sisters and are starting a Native Brothers project as well. These lay health advisors are able to talk about things in a way that local people can understand. Even for prostate cancer screening, patients have asked for a Native Sister to be present. They know she'll help explain what's going on if they don't understand the terminology being used. Sometimes patients are asked to make decisions but they're not certain of what's being done. The Native Sister can come and ask them things differently.

We've found that the most effective form of health intervention is one on one.

For example, a provider says, "Do you understand? Do you have any questions?" and doesn't allow a long enough pause. We take a longer time to pause than most other cultures. So the Native Sister stops, turns to the client and says, "When you go home tonight, and you talk to your auntie, how are you going to explain to your auntie what the provider just told you?" And the patient will say, "Oh, well, I'm not going to die this winter." That's about all he or she got out of the message. The providers have no clue about how much they are not being understood by the patient. So when we're able to have one of the Sisters in the room, the provider learns as well as the patient. It really has a nice overall impact.

I think another thing that contributes to disparity is that many of the interventions rely on using volunteers. Every single community-based position should be a paid

position. Not doing that affects the disparities in multiple ways. One issue is that after you get people trained, they're not going to stay in your program if they're volunteers. You're going to have an incredibly high staff turnover, because now that they're trained, they can step into another job that pays something. They'll work for you for a few months, really be interested in what you're doing, but, you know, "Gosh, I have to buy shoes for my children." And you lose them.

Every single community-based position should be a paid position.

So many interventions are set up to be done by volunteers, and that is inappropriate when you're working with people who live in poverty. The same thing happens with interventions using survivors—people thinking that survivors should just want to donate time. But just because you're a survivor doesn't mean your bills get paid. It's incredibly naïve to set up interventions this way.

Another thing is that often the information collected is only collected through telephone surveys. But over half of the people we work with in the community do not have a working telephone at least two months of the year, and a good 10% don't have a phone at all, ever. So if you have an intervention based on telephone surveys, whom are you reaching? You get a skewed view about how effective a program is. You think something's working better than it really is because you can't reach the people who don't have functional phones. You ask a question such as, "Do you have a phone?" and the person says, "Yes, we do." Then you ask, "How many months of the year does it work?" and the answer is "Oh, sometimes seven"—it paints a completely different picture.

The biggest cause of disparities, I think, is the health care system. Most people do not know that IHS has been funded at around 60% of the documented health care need. Every Indian community knows that 40% of the documented health care problems are automatically going to go untreated. So the emphasis and priority setting by both tribes and the IHS has been to focus on the healthy next generation.

So you're looking at tremendous underfunding, unless it's a tribe that has a successful casino. More and more of the casinos that have had financial success have purchased independent health insurance for their communities. And we see a big difference in quality of care for those people who have independent insurance.

But I'm very disconcerted by the contracted health service. Even tribes that have their own health insurance program still frequently use the IHS contracted service for their cancer care. Contracted health service dollars run out in most communities by the latter part of June. Well, you sure don't want to be referred for cancer care in the summer then, because you don't get a new budget until October. So a lot of people have abnormal tests, but they're not being referred because there's no money in contracted health services to refer them. And of course with cancer care early treatment is the best bet we've got.

The documentation we're getting on this is very upsetting. It's infuriating. It's easy to get angry at IHS, but it's not an IHS issue. Cancer care is under contracted health services with them, but they can't spend money they don't have. It's Congress who allocates money. The IHS providers do the best they can with the limited funds, but there needs to be a different way to care for these types of conditions.

How do you think disparities might be addressed?

I think one way is to have more people who are trained and working in the community. They don't all have to be Native people, by any means—there's just not enough of them—but there needs to be more partnership in the programs.

One of the best ways to address disparities is to use participatory research.

One of the best ways to address disparities is to use participatory research between the community and whoever is supporting the health program. Participatory research takes longer to set up, and it requires constant mentoring and training people to do certain tasks. But the training goes both ways, because if you really do a participatory research project with the community, the researcher

gets as much training as the people who are being trained to collect data. The researchers finally learn how to work within the Indian community, so both sides benefit. The other big advantage of participatory research is that if the Tribal Council approves of the idea, that type of project is likely to remain in the community even when funding ceases, long after the researcher has gone back to his or her institution or health care facility.

Improving the efficiency of the system is also important. I visited twenty tribal health clinics in the spring and summer of 2000. You would not believe the stacks of files sitting on the contracted health service desk for referral. The providers I was meeting with were absolutely fit to be tied. They said they have had referrals for diagnostic mammograms that had been sitting on the desk for over six months.

Sometimes the contracted health service person says, "Well, I don't work for the tribe. I work for IHS. I'm a government employee." There's no local supervision, and so sometimes the contracted health services person is the one dragging his or her feet, or only processing the paperwork of certain people. If it's somebody in the tribe or community he or she doesn't like, it doesn't get processed. This was plainly discussed in focus groups with community members. They said, "No, I'll never get contracted health services if I need follow-up care. I know it won't be processed because so-and-so hates our family. She won't refer anyone from our family for follow-up care."

There's no one who really monitors how referrals are done. Or they're monitored from so far away that these petty neighborhood clashes can be supported. So the contracted health services person has more power than he or she should have. For example, one of them shows up for work two days a week in one of the clinics I visited. She's full time, but she's not working the other three days. No one's there to supervise her, and nothing can go forward without her signature. Part of the reason is, as she says, "There's no funding, there's nothing I can process, so why should I show up?"

But she would be able to contact national IHS to see if there are other places they can get money from, because tribes will swap their resources. I can informally call up

Porch Creek, and I can say, "Look, we've got somebody who needs to be referred. Do you have any money available that can help? She's a tribal member, but she's living out in California." And they've come through. They've provided the money to get her help.

What is your vision, your hope for the future?

My big dream? I would love to see a more efficient health care program that really provides the entire continuum of care for medically underserved populations. Of course I deal with Native people, but a lot of what we deal with crosses over, even though the cultural things we address would be different.

Cultural aspects need to be included, and so does traditional Indian medicine. I don't know of anyone in our support network who has not used spiritual and traditional healing as part of his or her recovery from cancer, some side by side with modern western medicine. It's been incredibly effective and very, very powerful in terms of allowing for spiritual healing by the person.

I don't know of anyone in our support network who has not used spiritual and traditional healing as part of his or her recovery from cancer.

There are programs in the country related to prenatal care where, just after the baby's born, someone comes out to the house and lives with the person. Rural people such as those who live in the Alaska bush, on many of the reservations, or in farm areas in the Appalachians have to leave their homes and families and go somewhere else to get cancer treatment. It's just not feasible to have a cancer care facility in each place because you wouldn't have that many patients coming through.

So why can't there be a program for cancer similar to these prenatal programs, where someone is sent out and works in the home? This person could help care for the rest of the family while the mother or father or child is away, fill the gap if there's a particular need or a major role the patient plays. We see this particularly because we have so many breast cancer patients. The women want someone there who will cook,

take care of the children, tell them stories at night, make sure they get a chance to talk to Mommy in the hospital so they hear her voice every day.

There's no reason we can't design programs like this where people can go from area to area to provide that kind of family support, whatever it may be. And, likewise, when the patient first gets home. We've had women who had bilateral mastectomy return to their home village when salmon was caught, and they go right out with the rest of the people and start cleaning salmon—clearly not an activity you should be doing right after a mastectomy. But they cleaned for three days, 16 hours a day, in shifts, because there's so much salmon, and they have to do it then. The same thing happens with the whale. When a whale was caught up in Alaska while I was there, a woman had just gotten out of surgery, but she went to help with cutting up the whale. Because that's the food supply. That's it.

Well, for a woman in that situation, what if there could be somebody there to make certain she sits down. Maybe the woman could talk the "helper" through how to clean the fish, and the helper would take her role until she was well enough to do it, to give her a chance to heal. Both the women I told you about got infections because, of course, their sutures opened while they were cleaning the fish and it wasn't a sanitary environment.

I think lay advisors or navigators, promotoras, Native Sisters and Brothers, are absolutely key. Every health care system needs to hire them, have them well trained, have them well paid. Let them go out and do a lot of the outreach and support work in the community. Clearly, this is one of the most important aspects of cancer care. I also think there are community people who could be brought in as team members.

Research projects and health education interventions need to be truly participatory, with tribal leaders and members having a leadership and decision-making role at every step. Not this tokenism, not a little advisory group, but actually side by side, doing anything that the outside researchers are doing, so they really develop the skills,

and so that the research being done is something of interest to the tribe and is a priority.

We also need more cultural perspective and support throughout health care. For example, spring before last, an investigator wanted samples of hair collected and sent to him so he could do migratory research on the tribe, not knowing anything about the issues around collecting hair. In some tribes, you are expected to dispose of even the hair that comes from your hairbrush in certain ways, because otherwise the hair can be used to put a curse on you. And this guy's just coming out of the blue and saying, "Go ahead and collect the hair, and we want the hair root with it, and put it in an envelope, and I'll pay for FedEx to send it back."

We need more cultural perspective and support throughout health care.

The tribes that he contacted had no interest in migratory research at all. But there *are* things they're interested in. They want to know if there's some type of genetic factor in the diabetes they're experiencing in their community. Now, if this were participatory research, researcher and tribe could work together to find a culturally sensible way to do this. Certainly not using hair, and certainly not looking at migration, but maybe on diabetes. They would need to address how the blood sample is going to be stored, and how it's going to be gotten rid of. Because you don't just flush the unused blood down the sink—there's a ceremony for something like that. There are all kinds of different things like that.

If it's a participatory project, it can be done in a way that allows leadership from the tribe, that gives the tribe control of the data and of the publications that emerge from whatever health intervention happens. That really is a critical issue. Participatory research guidelines need to be developed in the community.

From Science to the Spirit of the People

Malcolm Bowekaty

Malcolm Bowekaty, ba, ches, *is the governor of the Pueblo of Zuni in New Mexico. He has full responsibility for protecting the resources and ensuring the health of the people of Zuni Pueblo. Governor Bowekaty is a certified health education specialist (ches) with more than 20 years experience working in health and social services. As a health educator, he has been responsible for developing and implementing community and school-based health promotion and disease prevention programs in the Pueblo of Zuni and on the Ramah (Diné) Reservation.*

Governor Bowekaty provides leadership on several local, state and national commissions and boards including the University of Arizona Center for Native American Health; the All Indian Pueblo Council; the Environmental Protection Agency, National Tribal Operations Committee; the New Mexico Commission on Indian Affairs; and the Zuni Board of Education. He is the founder and president of the A:shiwi A:wan Museum and Heritage Center.

Who has inspired your work?

The people who have inspired me the most are a couple of tribal leaders, both no longer around: Joe DeLaCruz, who used to be the chairman for the Quinalt Nation, and Robert E. Lewis, the former governor for Zuni, who passed away about five years ago. They epitomize for me the sort of person who takes on the community's concerns and tries to be a role model in terms of living a healthy life. Mr. DeLaCruz used to be a chain smoker but gave it up. Mr. Lewis also tried to maintain a lot of his health promotion stances.

After those two men, I would look to Lawrence Green and his colleagues, such as Marshall Krueter, who created the theoretical models, and then Cheri Lyon, a public health educator for the Indian Health Service. She walked the talk and listened to the community members wherever she was in order to address their health concerns, identifying and translating the theory into practical applications in the community. We deal with a lot of rural communities. Often we have to take the scientific explanation and couch information in terms of behaviors that people can understand. Ms. Lyon was a whiz at that.

I also have to give credit to a couple of other individuals. One is Dr. Nat Cobb, a physician with the Indian Health Service in charge of the cancer program. The other is Dr. Roger Gollub, a pediatrician and Albuquerque area epidemiologist. They gave me an understanding of the numbers and ways to analyze those numbers, to look at community cohorts, to look at longitudinal studies, and then translate those so that people could understand.

In a nutshell, the heart and soul of my inspiration came from the two tribal leaders; the theoretical basis and modeling from Lawrence Green and Marshall Krueter; the community development angle from Cheri Lyon; and the hard science—how to use numbers to help people understand as well as justify the needs to people who have access to purse strings—from Roger Gollub and Nat Cobb.

What lessons do you have to share with others?

Based on my personal and practical experiences on the job, the valuable lessons we need to learn are how to translate information and how to incorporate what we call the "silent majority." For example, in a university setting, on average most students will have skills and understanding at about two years above a high school education. But within that university, there is a whole population of students—a silent majority—whose skills and understanding are below that average. How you reach those individuals is the key question.

We have to reach that silent majority, because they are the ones who suffer disparities.

This is true when we look at rural communities as well, Hispanics, Native Americans and similar groups. We have to reach that silent majority, because they are the ones who suffer disparities in terms of access to health care, knowledge and programs that will allow them to elevate their health status. This is where the exponential growth will be, both in terms of elevating the community's health status and decreasing the health care cost for preventable or easily treatable illnesses or conditions.

There are groups who are well educated and very assertive simply by circumstance. They're probably going to access services no matter where they go in the nation. But the silent majorities are usually locked into small geographical areas, and they are not going to be assertive enough to ask for free clinics, access to free state services and the like. And they're the ones who usually contribute to much higher costs in terms of tertiary care that might otherwise have been preventable.

I look at the whole arena of community development as being based on values that are translatable cross-culturally. A lot of values revolve around protection of the family, protection of the kids. We need to learn how to build on these ideas. How do you ensure a prosperous, healthy future? I think all cultures across the world emphasize that. So how do we incorporate health into that value system to make the idea readily acceptable to those individuals who may not normally have access to health?

Another lesson is to actively learn from experience—from work in the community, with organizations, and in the diverse communities I've had the privilege to interact with—to examine the barriers and why programs fail. This is very, very valuable.

When we look at program development, we always analyze what principles allowed us to succeed. But in those instances where we fail, we must examine the reasons for that failure. Because you can do reverse engineering once you've identified what and where the barriers might have been. You can also look at the epidemiology and what factors allowed a model to succeed in one community when it may have failed in another.

We need to examine and analyze real, practical experiences from a university-based setting, a community setting, an urban inner-city area, a barrio in the southwest suburbs of Albuquerque, and we have to synthesize and translate the lessons we learn. We may have to shift or fine tune some of our models, but experience offers many valuable lessons to share with others.

One of the dilemmas in health education or health promotion in general is that it is so very easy to change the knowledge, attitudes and belief systems of individuals, but it is so very, very difficult to maintain behavioral change for longer than six months. That's been the challenge.

Are role models important?

No matter what position you're in, how you conduct yourself and how you interact with colleagues, funding agencies, top decision makers, and the patients or people you're trying to reach matters. If you're going to serve as a role model, all of the people you interact with have to be treated with the utmost respect.

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The more positive and life affirming our perceptions are and the more respectful and life affirming we make the health information or programs we translate, the more receptivity and

responsiveness there will be. And, consequently, the more knowledge and attitudes will be changed. Then we can have an impact on behaviors, bit by bit, behavior by behavior.

Are there people you know who are strong, healthy role models?

A couple of gentlemen I've been privileged to interact with are Michael Bird and Danny Ukestine. Mr. Ukestine is a program director for one of the urban Indian Health programs in the city of Phoenix, and Mr. Bird has had a very prestigious position as president of the American Public Health Association. Their rise to the top was predicated on understanding and improving their own health behavior, and bringing forth the life-affirming values that they as Native Americans have in their psyches. You translate that by being in positions of high visibility, working with communities, trying to emulate positive behaviors, and replacing negative behaviors with positive ones.

Other people who come to mind are some of the Viet Nam veterans I know. The key thing that has helped them in eradicating substance abuse or coping with debilitating illnesses has been the way they've been able to change their mindsets to look at life's misery not as misery but as an opportunity to reflect on how they can change it. Basically, they understand that they do have a choice to be in misery or not be in misery.

These people have harnessed their knowledge and attitudes and seized the moment to start working on their own behaviors. It doesn't matter if they go ten steps forward and then five steps back—they're always moving forward. These individuals have highlighted for me that behavior change is a process. How do you look at your own lifestyle? You may always have goals that are higher than you'll reach. But being in tune with their goals and always looking for some forward movement are a couple of qualities that really stand out in these role models.

How have your life experiences affected what you've accomplished?

Going beyond the confines of a small space or geographic area such as the reservation, which is basically a small, rural community, and meeting people from different cultures allowed me to experience and explore. I learned that there are things greater than the sum of the community I grew up with. Often individuals from my tribe and from other Indian Nations who have succeeded have had similar experiences of moving beyond the reservation and our small, closed communities. I also remember the challenges and the harshness I faced by moving off the reservation and going to college. Those were tough times, but I would never trade the harshness I endured, because it taught me the value of hardship.

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Hardships are a reminder that you can't have good things all of the time. Hardship forces people out of their comfort zone in order to survive. I've tried to employ a similar principle with students or clients we've worked with—to move them out of their comfort zones. The more we can make them uncomfortable about health issues, the more it moves them to learn new things. That's what those individuals who have endured hardship have helped me see.

And there have been people who crossed my path who had inspiration and passion. They are gregarious, positive, super-confident. Those are the individuals who really highlighted for me the value of having goals throughout the lifespan.

This applies to our work as well. If a program is going to succeed, we have to look beyond the end of the program or the end of the funding period. We have to look at how this particular program fits into the social milieu of the tribal people or the minority communities we work with. What is it we're trying to accomplish for the community? You have to have goals and develop health behaviors that can become part of the community's collective consciousness if you're going to increase the level of health or elevate the quality of life for the individuals who live in that community.

Events that have allowed me to accomplish what I have include a lot of challenges, a lot of defeats and a lot of losses. I've lost colleagues and close friends to debilitating diseases such as diabetes or alcoholism, to mental health issues, or to injuries or motor vehicle crashes. One thing I've always emphasized is that if we personalize these issues the same way we personalize our hatreds, it focuses our attention and objectivity into finding solutions to these diseases, conditions or events that can take life at an early age.

Diabetes really encapsulates the point I'm trying to make. To personalize diabetes, I can look back at my grandfathers, my grandmothers, my parents, as well as my aunties and nieces. All of them have succumbed to diabetes in one form or another. My grandfather had a foot infection when he was 70 years old. The foot infection became a below-the-knee amputation, then both his legs were cut off. In the span of a year, I saw my grandfather who grew up ranching, mustang busting, farming—a very tough person—become like a baby. I couldn't stand that.

I have a grandma who refused to have a venograph done so she could be put on dialysis. One day while I was at work, the nephrologist said, "I need you to help me with a very difficult patient." I went into his office to help, and there was my grandmother. It was very difficult to explain to her that if we didn't do the venograph she wouldn't be around, and she wanted to be around for her grandkids. I also have a parent, my mom, who is a diabetic, soon to be on dialysis. All of those people have made me realize that I need to personalize these health issues.

I, of course, also personalize it by being in the health profession. The reason I went into health education was to look at the positive influences, the positive activities the tribes have been engaging in, and use those as part of a health-promotion model. It's challenging to rethink the paradigms. Every place I go, I challenge researchers to come up with a cure for diabetes. They always say we can't cure or prevent it. I ask, "Why not?" It's no different than John Kennedy asking the American people to place a man on the moon.

It's challenging to rethink the paradigms.

The more you raise the gold standard, the more somebody in the audience will rise to the challenge. We're on the right track. One of these years we *will* have something.

I also believe in the resilience, the spirit and the power of humanity to apply knowledge, change behavior and coalesce resources. It took almost two decades before research projects throughout the nation began to look at primary prevention. It took lobbying. And then it took a lot of networking to convince three separate tribes—Navajo, Zuni and Apaches, traditional warring tribes—to band together and collectively form the Southwest Indian Center and become participants in a national clinical trial to help quantify the contributions of exercise and drugs to the prevention of diabetes.

My life experiences, the people who have been in my life, and even my losses have allowed me to accomplish what I have and inspire me to continue to advocate and wave the banner throughout the nation. Indian Nations need to rally and say, "Hey, enough is enough. Our people have been suffering too much. Let's get together. Let's ask the hard questions."

Of all the things you've accomplished, what are you particularly proud of?

I'm proud of being able to be a conduit or facilitator between the hard sciences and the spirit and emotions of the people. It's a challenge to translate the sciences, theories and medical models to be practical, so that the people in the community don't have to understand the science to know what they have to do. Then I'm also working with the community to report the numbers, to put data into a form that will allow the researchers or physicians who work with us to write up the reports and ensure perpetuation of prevention programs.

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It took us 15 years at Zuni to get the diabetes exercise program up and running. But now these types of programs have spread

to rural areas throughout the United States. That's what I'm most proud of because we at Zuni Pueblo started on the ground floor. Fifteen years ago we had no idea there would be a growth of health promotion programs throughout the reservation areas. That encapsulates what I've been trying to promote.

The second thing I'm proud of is always keeping health at the forefront for our Indian communities—helping them realize that you can't succeed in economic development without addressing the primary health of the people. You can bring in businesses, but if the people aren't healthy or able to work, you're basically wasting money. People have to understand that investing in the health of the people makes good economic sense.

I believe those are two things I've done that can have helped facilitate an awareness of the practical principles and application of health in most Indian communities.

What are the most important issues related to health disparities for American Indians?

Diabetes and alcoholism are at the forefront. Then come chronic diseases such as cancer, heart disease, anything connected to cardiovascular disease—those are on the rise in Native American communities. A fourth issue that we hardly ever talk about but that has a very debilitating effect is mental health, whether it be social dysfunction, symptoms of alcoholism or substance abuse, or domestic violence—all of those are mental health issues.

I would label those four areas as the most important. If we look at the dollar and economic cost analysis for these four areas I'll bet they would take the lion's share of all budgets—hospitals, Medicare, state resources. And they're interwoven. One frustration in research is how can you really say that a particular death was due to diabetes. We have to backtrack on ICD codes or diagnoses and say that if this is the collective group of symptoms the person faces, this is diabetes.

It's the same with alcoholism. There's no definitive way to say that a death is alcohol related. We just have to deduce from going back to the reasons a person was hospitalized and looking at the certificates and so on down the line.

We have to refocus. If we are going to eliminate chronic diseases, we have to look at the hierarchy of needs, at primary shelter needs, at security needs. We have people who are afraid of not getting a job because they may not have the education, or the social skills, or the training. Let's get our people adequate shelter, education and jobs. Then we can tackle the issue of diabetes. Any treatment or prevention of diabetes will have to take all those lifestyle factors into consideration.

Let's get our people adequate shelter, education and jobs. Then we can tackle the issue of diabetes.

When we talk about disparities I think we also have to focus on the flip side, on the positive side. Some tribes have reduced their maternal and infant mortality to less than 2 to 5%. That's an almost unheard of positive movement. We need to emphasize those examples to make sure we have balance. When we talk about the negative we must also highlight the things that have been positive. It's only then that rural communities will realize that health promotion is a life-affirming process. Communities should celebrate because they have made those differences, and will continue to make those differences.

What is your passion, your vision, your hope for the future? What would you most like to see happen?

I would like to see a high quality of life for Native Americans as well as rural minorities—to have healthy babies, to know that they are going to be covered by health care, to know that if they go to the local clinic they will be treated with respect and dignity and their questions will be answered no matter how long it takes for them to understand. Only then will we eventually eliminate the costs for tertiary and

high-maintenance types of medical care in rural areas, so that we can apply our money, time and attention to birth defects and acute and catastrophic illnesses.

My passion has always been to look at the community's value systems and listen to the various segments of the community to find a solution or a direction I can offer that will elevate the quality of life for the people in that community. For me, quality of life is the primary goal in health. Without good health, economic development and quality of life are not possible. Health is the foundation for all of my people. Consequently, I will always be waving that banner and, I hope, being a role model for other tribal leaders.

For me, quality of life is the primary goal in health.

I'd like to see a cure for diabetes, simply because it is such a multifactorial issue. It is so inextricably woven with heredity as well as the environment that any new solutions will necessarily have to be derived at the genetic level. Right now I'm working in a lot of different Indian communities to discourage tribal leaders from totally opposing genetics research. Because we need to have them understand that there is a science to the madness. If we are going to solve the problem of diabetes, there are certain components that will give us exponential growth. We at Zuni are the lone wolf in raising that banner, because of the traditional resistance to cultural interferences. However, the Zuni as a community are trying to solve that. And to a certain extent we have. We're making slow, painful progress toward studying genetics as a tool to address the issue of diabetes.

It's important because the science behind the treatment of diabetes is going to have similar applications or principles that can be used to treat alcoholism or address domestic violence. These are all behavioral issues. You're going to have people who will be in compliance, then out of compliance. You're going to have people who will do well on drugs or pharmaceuticals and people who will not. So if we focus in on one of these problems, we can extrapolate the principles to help solve the others.

Could you say something about why genetic research has been an issue in Indian communities?

It's a generalization, but most Native Americans believe that any body part, no matter how minuscule—a drop of blood or spit, or a buccal scrape—is part and parcel of their being and should not be separated from the body. That's why when people die they don't want autopsies—that same belief applies. You may be damaging the spirit if you take a certain body part or even body fluid. Consequently, when you're talking about genetics research, there have to be limits or protocols around the collection of certain biological materials. That's the bottom line.

Many Indian communities haven't braved the next stage of research because of all the bad experiences with past research—biological samples being taken with promises to the community and those promises not being delivered upon. One example is a tribe in Canada whose blood samples were taken out of the country and used for research elsewhere, not necessary to solving the tribe's own medical issues as promised.

Another problem is researchers not fully informing patients that their biological samples are being used. I don't want to dwell on it, but that's why genetics has been such an issue and why so many Native American communities don't want genetics research to be done.

However, when we look at diabetes as a particular example, science has come up with treatments to curtail some of the symptoms. Different invasive measures as well as behavior modification are used to deal with this disease. All of these methods have been successful in certain combinations. But there are certain things we can do at the genetic level that will allow us to prolong life even further. We need to look at what will bring about the next phase of exponential growth toward a cure or treatment option, and I believe that means looking at genetics.

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We have to somehow respect the community's values and philosophical objections against sample collection, yet reach a compromise that allows us to collect body specimens for responsible genetics research. It's up to us to educate the community that there are gradations, and that genetics isn't simply the cloning of sheep and the like. At the same time, we need to address the general fears caused by the bad science that's occurred previously and taken advantage of our communities.

What recommendations would you make to the federal government and others who have the ability to eliminate disparities?

Take a regional sector approach to truly eradicate health disparities. Do work across the nation. Work in Indian communities. Work with rural communities, minority communities. It's very obvious that success will depend on the growth in understanding and sophistication of each particular community. You can't take a national approach and say that, for example, patient drug rehab programs are going to work equally in all sectors—you're bound to fail in 75% of them.

It's got to be a very detailed, science-based re-evaluation of particular communities. What are the leading causes of disparities? What are the community's beliefs? Then, based on that, highlight one particular illness they can deal with, or a set of behaviors that can be targeted.

You need to involve major agents of change such as the schools or the government, any organization that has students or clients so you can have a captive audience. You need to follow up with monies targeted to specific community-based programs and issues and not do a shotgun approach. I think that will be one way to address the disparities.

Return to the Circle

Patricia Longley Cochran

Patricia Longley Cochran *is an Inupiat Eskimo born and raised in Nome, Alaska. She serves as the executive director of the Alaska Native Science Commission, a cooperative project of the Alaska Federation of Natives, University of Alaska, Anchorage, and the National Science Foundation. Ms. Cochran has previously served as administrator of the Institute for Circumpolar Health Studies, executive director of the Alaska Community Development Corporation, and director of employment for the North Pacific Rim Native Corporation.*

She serves on many committees and councils that address health, science and economic development of Alaska Natives, including the position of science advisor to the Arctic Research Commission; member of the Alaska Global Change Planning Team; member of the Science Steering Committee for the National Science Foundation, Human Dimension of the Arctic; and board member of the American Society for Circumpolar Health and International Union for Circumpolar Health. Ms. Cochran has also served as chair of the American Indian, Alaska Native and Native Hawaiian Caucus of the American Public Health Association.

Who has inspired you in your life?

The Creator has been my inspiration for everything in my life, and the influence of my family has really been important to me. My extended family. My brothers and sisters. Certainly my mother, who taught me everything I know about the knowledge of my people, my land, the animals—all of the traditional knowledge and ways of living. My son has also taught me an incredible amount of information as we've grown up together over the years.

Without question my extended family as well as aunts and uncles have always provided different role models in my life. Traditional healers, tribal chiefs and other people in my community who are either related to me, or have adopted me, have been part of my inspiration in everything I do.

The ancestral knowledge, the kind of information that was generational, that was passed on… I so much appreciate having that knowledge.

A few teachers in my western education made a real difference in my life as well. They encouraged me to be everything I could be in the modern world and really supported my education and formal training.

Is there one person in particular who comes to mind?

There's no question that the person who has been most influential in my life is my mother. I learned things from her I never knew I was learning. I never understood as I was growing up and living off the land all of the things I was being taught—respect for the land, how to work with crafts, reading the signs of the earth and looking at the weather—all these things I wasn't even aware of. I really understand now how rich that education was and how important it is to me.

Anywhere that I travel now I can look at a tree or a plant or a root and understand what its meaning is, and its purpose, and how we use it. That vast amount of information came not only from her but from all the people who came before her. The

ancestral knowledge, the kind of information that was generational, that was passed on—I absorbed all that without even understanding that I was getting it. And now I so much appreciate having that knowledge.

I rarely talk about my father for a number of reasons. My mother was Native and my father was non-Native, so I've grown up with a foot in both worlds. My father died when I was very young. I didn't get a chance to know him.

As I've grown older, I've begun to learn more about who he was and where he came from. He was one of the first attorneys in the Territory of Alaska. He was one of the people who wrote and sponsored the anti-discrimination bill that was a turning point for Native people here. I think all that had a lot to do with his love for my mother and the family. It's not part of my Native ancestral roots, but it's certainly an important part of who I am, because I am Native *and* I am Scotch, Irish, Dutch from my father. I didn't learn any of his ways. I'm trying now at this time of my life to honor that part of me as well. I've honored him by taking his name as well as my family name.

I was really fortunate to have been brought up in the Native way after my father died. My brothers and uncles became the male figures in my life. They were some of the chiefs of the area, and I learned a lot from them.

What lessons do you have to share with others?

I'd like to share several things that are important to me. Probably the most important thing is that, at this stage in my life, I am becoming an elder. My credentials and the things I've done in the western world aren't as important to me as the credential I am working on now as an EIT, an elder-in-training. That really identifies who I am and what I'm doing in the world I live in—training to be the next generation of elders and to be the best I can be.

Each and every day you live you should look toward that opportunity of becoming an elder.

One of the lessons I'm learning is that each and every day you live you should look toward that opportunity of becoming an elder. It really helps you focus on what's truly important. It's a lesson a lot of us in the baby boomer generation don't always realize. We get caught up in so many other things going on around us that we forget we are the next generation of elders.

Another lesson is to honor and use our traditional practices. I have really tried to build my life and base everything I do on the foundation of being raised as an Alaska Native. The spirituality that comes to me naturally is an important part of who I am, and of who all of us are in the Native world. We strive to honor and cherish our spirituality and the things we learned as children, to remember and respect our Creator, to honor our elders, to honor our ancestors.

Whether I'm testifying before Congress or talking to community members in the remotest village in Alaska, I always remember to introduce myself in the formal Native way. In the way I was trained, you talk about who you are, where you come from, and what your roots are. So people understand from the very beginning that you're setting things apart.

Even when I'm before Congress I do that. I honor my ancestors. I honor my elders. I honor my Creator. I invite them to come into my world, to look at things from the Native's world view and not just in the way they are comfortable living. That's also an important lesson I've learned as I've grown—to share my experience with other people and allow them to be part of this Native world view and the richness it brings to all of us.

It's so important to pass on the information we have.

One last lesson is the critical need to be a mentor and friend to those coming behind us. It's so important to pass on the information we have and bring our kids into the same kind of understanding we have. I was fortunate that this was given to me, and it's my job to make sure that it's given to those coming after.

Is there anyone in particular whom you've been able to mentor?

I hope I do it every day. I'm fortunate in the position I'm in now in an educational institute. I have Native students who come to me almost every day when they need someone to talk to, when they need an idea for a project, when they need a shoulder to cry on, or when they just need some space. I try to provide that for any of our students who need it.

I do a lot of talking to our community schools. Since my own son was in kindergarten, I've gone into the schools and done storytelling, and taught people how to play string games and do some of the beadwork and crafts I do. It was important to share that, not just with the Native people in the classroom but so everyone in that classroom understood the creativity and value of cultural diversity.

I've taken under my wing a couple of people in particular who've asked me to be their mentor. I'm working now to train them to do some of the things I've been fortunate enough to have learned myself—traditional healing work, conducting talking circles—understanding and transmitting the knowledge I have.

I myself have been mentored by several of the very best traditional healers in the state of Alaska. I'm still working with my Auntie Rita, whom I go out and pick herbs, berries and roots with at almost every opportunity I have to learn more from her. She's been an influential part of my life in teaching me the things she knows. My knowledge originally came from the Northwestern Arctic area of the state, and I knew relatively little when I moved to the Anchorage area. Everything is different. The regions are very different. So I've had to learn much, and Auntie Rita has really helped me.

What have your life experiences allowed you to accomplish?

My experiences and people I have known have set a real direction for me in life. It started with my own name, the name that I carry, the name that was given to me by my mother and my aunties. My Inupiat name is Sigwana. This name was given to me

as a namesake. Sigwana was a young girl who died very early in her life, and I was given her name to carry on her life and to remind me that I live not only for myself but for other people. That's been a critical part of who I am—understanding that my name from the very beginning has meant I have to live my life for others. That has set the tone for everything I do.

My name from the very beginning has meant I have to live my life for others.

Almost every position I've held in my adult career has been committed to working with Native people in Alaska. Everything I've learned from doing my own traditional training in dancing and stories and crafts, as well as from my western education, has brought to me that idea of service to community.

As a community development planner I worked on the reestablishment of one of the villages that was destroyed in the earthquake here in Alaska. I directed a program to develop economic opportunities and jobs in Native communities. That meant a lot to me, to be able to bring job training and experiences to other people within the Native community. I've been able to work in the university setting where I could influence the education and training of our people, as well as influence the people who teach our children and our young people in educational settings.

The job I'm in now with the Alaska Native Science Commission allows me to bring science and research together with Native communities and to develop partnerships. It's important to bring to the table the Native voice, which is not normally represented.

Because of where we are located and the kind of work I've been involved in, I've also had the opportunity to work in the health community not only in Alaska but with all of the indigenous communities of the Arctic—in Canada, in Greenland, in Russia and all of the circumpolar nations.

What are the most important issues related to health disparities for Alaska Natives?

Some of the disparities are obvious—the problems we have with diabetes, obesity, cancer rates, suicide, violence and drug abuse. Those are all conditions that have a higher incidence rate within our community. People need training, education and a base of information about how to make better health choices. We need to learn not only what science and health research can tell us, but also remember what we know from our own communities about choosing healthy lifestyles. This can help address the issues of diabetes, obesity and cancer prevention.

I see the problems of suicide, violence and drug abuse, however, as being much more the result of social conditions and the losses so many of us have experienced in our communities due to a number of reasons. In my own family, for example, my mother was one of the young people who was removed from the village and sent outside to school. At the age of 8, she was sent to Chemawa Indian School (in Salem, Oregon) and did not return again to her village until she was a senior in high school. This forced her to be away from her family for all of those years and I'm sure in many ways the experience changed the kind of person she was and might have been.

I think a reason we're seeing certain health issues… is because we have a lost generation of people.

I know there are many other people, especially Native people, who have experienced similar losses. I think a reason we're seeing certain health issues, especially those in the areas of mental health, depression and spirituality, is because we have a lost generation of people. They were removed from their communities, lost touch with who they were, and had to re-learn so much when they came back.

My mother lost her language. She had never spoken English until she was sent to Chemawa. There, as with many others, the language was beaten out of her and she lost it. Consequently, I too lost the language, until I made an effort to reclaim it for myself. Those kinds of things I think are very relevant to the conditions we see now—

the health problems having to do with the spiritual, physical and emotional well-being of our communities.

The use of our own Native knowledge and the passing on of our Native traditions in the training of our young people—that's one of the things we don't do enough of today. I see that as a major factor in the problems our young men and women are having in the modern world. They didn't get education in the roles, the responsibilities, the social mores. The training of young women and the training of young men have not been passed along in many cases.

The training of young women and the training of young men have not been passed along.

I see it in our young boys in particular, especially in Alaska, where suicide is astronomical, because they have lost their place in the family. The women have remained the educators and the trainers in the community, but the young men aren't always the suppliers of the food, the animals, the clothing. Those kinds of things really aren't a part of their training in the world they live in now. I think that's why they lose their sense of identity and experience the problems they do.

I think another issue in health disparities is that we're not using our own traditional medicine and healing practices. We're not looking at our health in a holistic way because the modern western health world divides everything into neat little boxes. That doesn't fit our Native pattern of the circle of life, where everything is connected. These things make a real difference, and those are key issues we need to address in order to come back to health in our Native communities.

Something that relates to this is the use of modern technology. For example, telemedicine is becoming much more a way of providing care here in Alaska, because of the delivery issues we have due to distance. Most of our remote communities only have community health aides. They don't have doctors; they don't have nurses or nurse practitioners.

I think we need to be more aware of the kinds of changes modern technology is bringing to our communities.

But they now have access to doctors and other professionals through this telemedicine project and can get the kind of assistance they need. On the other hand, telemedicine also changes the way things operate in our society and our communities. It adds a different role to the ways we've always provided our own traditional knowledge, medicine and healing practices. So it has both pros and cons.

I think we often don't think about the negative as well as the positive effects of using modern technology—computers and everything else. It bothers me to see young people clicking on and off their grandmothers' stories that are posted on the Internet. I think we need to be more aware of the kinds of changes modern technology is bringing to our communities. And Native communities need to be at the forefront in deciding which kinds of technology are appropriate for them and which are not.

Are there other issues linked to health disparities?

Genetics research is one that's cropping up more and more, not only in Alaska but in other Native communities across the world. Samples of blood and serum taken in thousands of research projects across the United States are being used without the knowledge or consent of the individuals. I think we've come to a point where we need to start setting some protocols for genetics research, in particular for use and storage of samples collected within our Native communities.

We need to look at setting protocols for use of our knowledge and use of our medicines and plants.

Another issue is bioprospecting. We are dealing with that quite heavily here in Alaska where a number of national and multi-national corporations want access to the wonderful medicinal plants and herbs, but don't recognize the intellectual and cultural property rights of the communities these plants come from. Again, we need to look at setting protocols for use of our knowledge and use of our medicines and plants.

Do you have suggestions to help individual providers work with their Native patients in meaningful ways?

Here in Alaska we finally have the first tribal doctor associated with our Alaska Native Medical Center. So people have the opportunity of going not only to a western doctor but also to a traditional healer and practitioner. They have the opportunity to get Native foods when they are in the hospital. In hospital settings, clinics or social service programs, I think it's critical to bring in those people who look at the world holistically—the elders, the healers—the people who have the knowledge, experience and wisdom to help develop a holistic approach to a person's health and well-being. It can't be just physical health.

For the Native person to be whole, the physical, the mental, the emotional, the spiritual all have to be in the circle.

For the Native person to be whole, the physical, the mental, the emotional, the spiritual all have to be in the circle. All of those things have to be in balance for a person to be healthy. And that's not what western training teaches you. So if providers aren't getting that, they're not affecting the real health of the individual. Providers need to partner with the people in the community who understand the circle of health and the circle of life. They need to know that all of those aspects are equally important and how to bring them into balance.

What is your passion, your vision, your hope for the future? What would you like to see happen?

Here at the Alaska Native Science Commission we're looking at how the world around us affects everything we're doing. One of the projects we're deeply involved with is determining the safety and benefits of subsistence foods within our communities. We're looking at what our communities know about the earth, about the cycles, about the world, and we're bringing that Native traditional knowledge and understanding into the western world. A definite passion in my life is the world that

We need to ensure that our Native ways are being taught as well as the ways of the western world.

we live in and partnering to make that world a better place in all aspects, whether it's the environment, health or anything.

Another passion is working with kids and elders. One of the best things I can do is help bring them together—our young people and our elders, including that lost generation, the parents, as well. We often forget that there's a middle step between the youth and the elders. The parents get lost in the equation.

I want to see our Native ways of knowing, learning and teaching recognized. We need to ensure that our Native ways are being taught as well as the ways of the western world.

I'd like to see local control of local issues—everything from health issues to political issues—so that our communities are given sovereignty and learn to deal with their issues themselves. I'd like to see them have the power and the wisdom and the resources to make improvements in the conditions of their lives.

One thing I'd like most to see happen is restoring the soul of Mother Earth by reclaiming our world as stewards in the health of our lands, our air, our water, our animals and our people.

How do you think health disparities might be addressed?

The first thing we have to do is bring Native communities to the table as full partners. I think that's the key to making things work. The Native communities end up being advisory boards to decision making rather than managers of the decisions to be made. We need to change that process and bring into full partnership the communities that are most drastically affected. That's where the answers lie. It's not just up to outside influences. For us to make things better in our Native communities, we need to be responsible and accept the responsibility for bringing change.

All of the things I talked about—the mentorship, the inclusion of Native ways of learning and teaching—to me those are things we have to do in order to start seeing some change in the health of our communities. Another major part of the answer is to have more of our Native community in leadership roles and positions so that the decisions made at the top are made by people who not only understand but live the Native way of life and have a Native world view. It's time for us to claim our places in positions of authority.

We need to be responsible and accept the responsibility for bringing change.

Negotiating for Health

Pamela J. Everingham

Pamela J. Everingham *is affiliated with the Onondaga Nation in New York, the Six Nation Iroquois Confederacy, and is a member of the Snipe Clan. She began her career as a dental assistant and technician, and since then has worked in office management, inventory control, quality control and public relations. She is currently a monitor for the Indian Health Program of the Onondaga Nation and is completing her Bachelor of Science degree in business administration.*

Ms. Everingham has served on many boards and committees, including the Diversity Enhancement in Clinical Research Steering Committee at Upstate Medical University in Syracuse. She is a member of the advisory board of the American Indian Community House, also in Syracuse, and was recently awarded their Native Leadership and Community Service Award.

When she was young, she was introduced to a Seneca medicine woman who became her mentor in traditional medicine ways. In her continuing efforts to improve the health of her Nation, she always remembers her mentor's words: "Our people must never forget who they are and why they are here. We are only the caretakers of the medicine. We must always remember to be respectful and thankful for the gifts that we've been given."

Who has inspired your work?

My family. I was the oldest girl out of eight children. Both of our parents were dead by the time I was 13 years old. So having the responsibility of taking care of the younger children and staying together as a family, I would say that's basically where the whole process started.

Can you say more about how those experiences guided you toward a career in health?

Let me start with the family situation. I was 13 and had younger brothers and sisters to care for. The medical facility located on the Nation had a state physician and a state nurse who would come in one day a week, on Thursday afternoon for four hours. Indian Health Service (IHS) has never been here on our Nation. We are a sovereign Nation and our traditional government will not accept federal money.

One day my little brother, who was ten years old, woke up with a fever and a stomach ache. Fortunately it was a Thursday morning, so I took off from school and took him to the clinic. The doctor listened to his symptoms then handed over a bunch of penicillin pills, saying, "He has an infection or something going on. We don't know what it is." They didn't do any tests to find out exactly what it was.

So, a week later, my brother has the same symptoms only a lot more magnified. I told our grandmother (who was our guardian at that time) that I was going to take him back to the doctor. But she said, "No, you're going to go to school and I'm going to take him." She took him to the family doctor who was off the Nation. He was possibly the best person I've known in my lifetime, Dr. Leon Burak. My grandmother took my brother in, and Dr. Burak said, "You get him to the hospital right now. His appendix has burst."

It was a touch-and-go situation. The penicillin held off the infection for a week, but then peritonitis set in. He was in the hospital for a good three weeks and the physician

there said we were fortunate that he could pull through. When he came home I was in charge of keeping the drainage they'd put in clean and going back to Dr. Burak so he could check the wound. Dr. Burak told me I would be a very good doctor or nurse. At that time the only thing women were doing professionally was nursing, and you didn't see many minority nurses.

I think that whole experience was an eye opener, because after that I refused to take my brothers and sisters to the Nation clinic for any serious symptoms. I always took them to Dr. Burak. That experience with my brother is the sort of thing that never leaves your mind. It's something you never want to have happen to anyone else. That was really my first recognition of how poorly we were treated in terms of health care on the Nation.

Throughout a lot of my career, what I've done is negotiate services.

So on a very personal level the medical part was critical to me. I also had to make sure my brothers and sisters had dental care. I negotiated paying the dentist just a certain amount of money that we could afford so that he could take care of their teeth. Throughout a lot of my career, what I've done is negotiate services.

My first husband and I moved back from Indiana in the early eighties so my husband could go into partnership with his father on the family farm. I was working for the Nation as a dental assistant in 1985, and my husband was killed in 1986. At that time, everything within the state system that controlled our health care on the Nation changed because the secretary who took care of the program was retiring and her replacement was getting married. They asked me to step into that administrative role. It was really a matter of timing. I had only so many hours as a dental assistant, and they saw an opportunity to give me more hours. So they were helping me out in my situation and I was helping them out as well.

Once I took a look at the records, I found that in some instances the state was paying for people who weren't even Natives or from the Nation. We began to discuss how to handle the billing system, and also how to handle patient referrals for x-rays or other

treatment off the Nation, because the things that could be performed at the clinic were very limited. I really got into it at the bottom level, but that's normally a good place to be in order to gain a better understanding of why things work or why they don't work.

I went into the state office in the city and reviewed every bill that came across their desk for payment for different people from the Nation. I had to identify whether they were members, whether the service was viable, and then I had to take the case to the program manager who made the final decision on whether a bill was paid or not. That was the beginning of what I've been doing the past 17 years.

What lessons do you have to share with others?

We all have it within ourselves to do what is best, not only for ourselves or our families but so other people benefit. I think that despite or even through personal tragedies, you can be in the right place at the right time with the right attitude and be able to make a difference. We've been able to see tremendous changes in caring for our people—getting them to have routine checkups, which was totally unheard of, or working with the elderly population who were used to being sick only on Thursdays so they could actually get to see a doctor.

I think it's so important to talk to younger parents or even to people within your own family to impress on them that you can't just ignore your health—because families carry the possibility of diabetes or heart disease or any of the multiple things that tend to be getting a whole lot worse in our population. We need to encourage people to get preventive care. We need to talk to them and say that just because you had that baby five years ago doesn't mean your body doesn't change and that you shouldn't go for an annual checkup. We need to convince them to not just wait until they have babies to think they'll need a doctor.

We all have it within ourselves to do what is best, not only for ourselves or our families but so other people benefit.

What have your life experiences allowed you to accomplish?

I feel good to have made a difference, to have helped improve a system that was so outdated. I did a lot of the public relations in order to expand our referral system. We now have an ophthalmology group. We have specialists. It's not a full array, but it consists of providers who are really willing to give their time to our people, regardless of what the price happens to be. They continue to provide their services to our Nation.

That personal touch lets you know that you can work together to resolve a problem.

I still have an ongoing relationship with many of the office managers I began negotiations with many years ago. That personal touch lets you know that you can work together to resolve a problem, and that normally ends up paying the bill. I think that those relationships really help the system work. And you know that you can call on their offices once in a while for a favor, to see an emergency case.

We now have the statewide vision program that not only benefited our Nation but has benefited many of the other Nations within the State of New York. I met with the manager of the local division in his office and saw that he had a map of New York State. He said, "Yeah, our services are statewide." I said, "Well, we're just implementing a pharmacy program that's going to be statewide. This whole vision service could work for us too." He said, "I don't see why not." So through that introduction we now have a statewide vision program for the Native people.

I was also part of a statewide commission to investigate conditions on the different Indian Nations in New York. I got to meet a lot of people, a lot of relatives I hadn't seen in a while, and got to learn exactly how far ahead our program was in some instances or how far behind it happened to be in others. Because of the IHS system, the medical facilities and care were a little more advanced or a bit further along the road in some other communities than in ours because we're strictly state funded. But as a result of the state report that was written, we were able to negotiate a brand-new health care facility for the Onondaga people from the State of New York. We may be

the first and only state facilities that they provide for an Indian Nation. We built the clinic in 1997 and it's a beautiful place. People come out to the clinic and can't believe we have such a gorgeous facility.

Can you say more about your role in facilitating some of the communication that led to having a clinic like this?

I called myself the liaison. A lot of times I was taking things into the Council, which is the traditional government that we have here. My role was more or less keeping the negotiations for this building in front of the Council to remind them that this was what they've wanted for so long, keeping it in front of their minds and enlisting certain Council members who were willing to push for it.

I was also involved in working with contractors, working with the builders, the architects. It was exhausting, but it's been the best part of anything I've done—just knowing that I was a part of it, and knowing that it makes a difference. Today we have more doctors who work at the clinic. We're there Monday through Friday. We have dental services two days a week and we're trying to boost those hours.

It's like the Field of Dreams—if you build it, they will come. And that's what's happened. We have an explosion of people throughout the state who have either moved here or whom we see when they're passing through. We've expanded our patient files. It's nice to see that people appreciate medicine as it is today, and it's also nice to work with people who believe in the herbal medicines. It's working. It's a slow combination but it works.

Do you have traditional healers working through this clinic?

No, unfortunately, because we're regulated by state code. Our contractor right now anticipates that we will be under the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) federal guidelines. This puts some limits on the services we offer.

We've gotten the state to see that there's a difference between our sovereignty and the state rules and regulations by not only getting the building built but also getting it built on the Nation according to the traditional Council requirements. But state acceptance of traditional healing is more down the road. It happens now, but it's more on an individual basis.

Traditional healing methods have better reception when they're not confined by a medical facility.

Because our community is small, traditional healing methods have better reception when they're not confined by a medical facility. It's better when the general community brings traditional healing in to the communications office, or what we call the cookhouse—someplace where they don't have to worry about whether they're violating any type of medical code. That's kind of where it is right now. We do have people who do acupuncture and different herbal things, but our doctors don't know enough about it to really get involved. Because of their contract with the state, they're a little bit tight on regulations.

Between the Tribal Council, the State of New York and the medical team, I'm struck by how many different constituencies you are trying to work with.

It's a lot to juggle, especially when the State of New York has regulations. For example, they have a state rule that says contracts for medical supplies or equipment—and also medical providers—have a shelf life of five years. After five years, the whole contract has to go out for bid. It's a governmental process that really should never enter the health care system because it's disruptive. It creates mistrust within the community and the clinic staff when there's no clear-cut future to focus on.

What are the most important issues related to health disparities among American Indians?

Unfortunately, many of our people are uninsured. We live near a state-run university hospital where many of our uninsured people get care. The state has talked about allowing the hospital to go free in the marketplace. But our people can't afford that because the State of New York does not pay for in-patient care for our people. They'll pay for ambulatory care. They'll pay for diagnostic testing as long as it meets the Medicaid requirements; but if it doesn't, well then, sorry, these providers don't get paid. So as a Nation we're dealing with what the general population is dealing with among the uninsured. Also the state government has made it very difficult for single mothers with families to be on Medicaid for any length of time. There just seem to be more governmental issues working against us and the public in general.

As a Nation we're dealing with what the general population is dealing with among the uninsured.

In terms of health issues, we're seeing diabetes at younger ages. My grandmother was diagnosed with it when she was in her fifties, but now we're finding it in children. We're seeing a high concentration of respiratory problems in children—purchasing nebulizers and medications for breathing. Is it the environment? Is it genetic? I don't know. I wish we could come up with an answer. Cancer is another issue for people on the Nation.

Maybe it's because we never really had records in one particular spot, or the records weren't maintained so that we had vital statistics like other places have, but it seems as if we're being overwhelmed by our people being diagnosed with these diseases at a younger age. It's sad. What do we do to stop it?

I look at the initiatives such as the one the State of New York gave in 1988-89 when we did the statewide report on Indian health care. In 1999, I wrote to the state and asked for an update. I wanted to know if we've made a difference. I've not heard back from them. Initiatives bring people's attention to what the health care issues are, but

if you don't update us on how successful we've been or where we're lacking, then what good is the proclamation?

And things shift with the election of a new president, governor or whatever. That's what I've seen. I watch the state politics, and I watch U.S. politics to at least get a feel for where Indian people happen to be in the mix. We don't vote in New York because we're sovereign people and we elect our own chiefs. Even though we might live off the Nation, that's the government we have allegiance to, our bloodlines. So you have to be perceptive enough to look and listen, so you pick up on what's going on nationally.

What do you want readers to understand about the Onondaga Nation?

As a whole, we are trying to make a difference. We have the new clinic. We have a diabetes prevention program and the AIDS program, and they've recently built a drug and alcohol rehab center on the Nation. So I think that we in our own way are attempting to deal with what our individual situations happen to be in terms of health disparities.

I think that one key to potentially reaching beyond where we are now lies with the next generation. Many have gotten their college educations. They've come back to be part of the community. They're teachers. They're drug and alcohol counselors. They're newly appointed Council members. I think that, slowly, each generation is going to make the improvement we need. They're looking outward, not just inside themselves.

One key to potentially reaching beyond where we are now lies with the next generation.

It's so important to recognize that there's somebody on the outside who needs your help, and to be open to that and not critical of what that person's situation might be. That makes a big difference, especially with your own people. I'm very hopeful for the future because of the work of the younger generation.

What is your vision, your hope for the future?

If you gave me a magic arrow and I could wave it over our Nation, my wish would be that within our own community there would be no divisiveness among families, that people could all understand one another and get along.

The next hope would be that we would have every opportunity to obtain services when we need them, instead of waiting for an opening in a clinic three or four months down the road to address our medical needs. That's the unfortunate lot of the uninsured. They sit in clinics. They wait. Some people can't afford to wait; some of these diseases are too far advanced.

We've gotten the system to a point where at least we're in it, we can get services, but it doesn't work quickly enough. I wish that we could all, at least within the tribes of New York, create a united health care system. So that if I'm taking care of an Oneida in our clinic who needs services, we would share the responsibility of that person's care. Patients would have the choice of going to Oneida or to us, but we would work together to make sure that they obtain the proper services.

I guess it all comes down to money and power. Who has enough of that to make all the health disparities and health care issues disappear? We're trying to do the best we can. If somebody out there knows the solution to the problem of the uninsured, I want to hear about it.

If somebody out there knows the solution to the problem of the uninsured, I want to hear about it.

Anything else you'd like to share?

All of us, as human beings, have the potential to want to do good. It's there within us. It just depends on our different situations and the ways our lives direct us.

Some people are the best people in the world, but circumstances have led them to an involvement with drugs or depression. That can be a hopeless situation, but sometimes people are able to move out of it and use the experience to do something

better. They can look at the situation and try to turn it toward something positive, to say, "Well, I'm down here. I've seen it. I know what it's like. So let me make a difference in someone else's life."

We all possess the capacity to contribute. It's just a matter of how we choose to use it.

That's the way I've learned—the death of my parents, my younger brother, my husband. You can come from the depths of despair and help make something good. It's a matter of going out there and just doing it, and of having an opportunity to do it. I think we all possess the capacity to contribute. It's just a matter of how we choose to use it.

Recommendations

The elimination of health disparities will require a concerted effort by individuals and institutions in the public health community and beyond. Reliable data about the health status of specific populations is essential to this endeavor. There are excellent data sets being developed by the federal government, state and regional entities, and various health care organizations. Some of that data is included in the Introduction to this publication. Using this data and other information, different recommendations have been developed to guide the effort to eliminate disparities.*

One thing becoming evident is that data alone will not be enough to accomplish the task. To effectively reach populations affected by disparities, providers need to have a personal understanding of the communities and people within those populations—who they are, what matters to them and how they can be supported in building a stronger foundation for health. To achieve meaningful change in American health care, data about disparities must be linked to experience and wisdom about people, and power must be shared. This bringing together of science and wisdom, data and heart, has been one of our primary goals in offering these interviews.

The leaders who have shared their ideas, experiences and inspiration with us here have articulated a set of recommendations critical to success in eliminating health disparities among American Indians and Alaska Natives.

*See, for example, *Revised CLAS Standards from the Office of Minority Health,* outlining 14 recommendations for culturally and linguistically appropriate services, at www.omhrc.gov/CLAS; and *Healthy People 2010, 2d ed.*, U.S. Department of Health and Human Services, Washington DC.

General Recommendations

- Support capacity-building in the areas of health and economic opportunity within Native communities. These two factors are inextricably linked. Improvements in one cannot succeed without strength in the other.
- Fully fund the Indian Health Service. Improve the efficiency of the health service system, including contracted health services, so that all patients are seen in a timely fashion and referred promptly for appropriate, state-of-the-art care.
- Support Indian and Alaska Native students in the fields of public health and health care through scholarship programs and active mentoring relationships.
- Establish means by which providers can learn the social cues that communicate respect to Indian people and follow these cues during medical history-taking, physical exams and provision of treatment. Use interpreters or lay medical advocates to enhance quality of care.
- Support and facilitate the use of traditional Native healers as a complement to western medicine. Recognize the importance of spiritual traditions when setting up prevention programs, screenings and health care services.
- Use participatory research models to guide researchers and engage community members in exploring a broad range of relevant questions about health. Establish research protocols that respect the traditions and beliefs of Native communities.
- Promote greater sensitivity among mainstream researchers about Native perspectives on genetic research, in particular the use, storage and disposal of tissue, blood, hair or other samples, and the appropriate kinds of questions to pursue.
- Support the presence of Native people in a broader political and social arena. Promote their visibility in regional and national health organizations, mainstream organizations and general American society.

- Produce health information relevant to Native people. Focus on the healthy next generation and the importance of family. These are more compelling than messages about self-protection and personal benefit.
- Recognize the strengths and positive capabilities of populations experiencing disparities, not just the negative conditions that lead to those disparities. Note areas where a tribe or community's health status is in better shape than the general population. Positive findings are often overlooked, and they can be powerful reinforcers for greater movement toward health.
- Support Native communities' efforts to develop their own capacity to address health and social issues. Recognize and respect the strengths and wisdom that already exist within the community. Support leadership development, especially in the areas of health promotion and care.

Michele Suina

- Connect Native students with national networks that allow them to interact with fellow students and professionals from Indian and Alaska Native cultures.

Michael E. Bird

- When planning services or examining disparities, use new models that are based on commitments to inclusiveness, diversity and social justice. Avoid models that are based on who has the most power, the most money or the most friends in influential places.
- Create opportunities for Natives and non-Natives to meet, talk and know one another's stories and issues.
- Honor the existing treaties between the U.S. government and Native tribes. This would ensure appropriate funding of health care services and promote economic development in tribal communities.

Linda Burhansstipanov

- If you are working with Native people, publish. Write about the things you're doing, whether in professional journals, local press or other vehicles. This lends credibility and influence to the work.
- Provide payment for all positions involved in health programs. A volunteer model is not practical or appropriate for people living in poverty.
- When Native people are receiving treatment away from their homes, create ways for them to stay in touch with their families, their spiritual leaders and their traditions.

Malcolm Bowekaty

- Develop programs that will stay in a community and be part of its ongoing consciousness and resources.
- Ensure that tribal members will be treated with respect and dignity at health care facilities, and that there will be time to answer their questions.
- Use a regional approach to examining health disparities and suggesting solutions. Work in individual tribes, across a state, or across a region. National approaches are too broad, and do not address the specific concerns in each sector.

Patricia Longley Cochran

- Remember that we live not only for ourselves, but for other people as well, including those who have not had the privilege of living to adulthood.
- Commercial interest in plants and other resources has the potential to exploit Native people and ancestral wisdom. Protocols should be established to control the scope and purpose of bioprospecting.

- The circle of the physical, the emotional and the spiritual must be in balance for the Native person to be healthy. Providers who understand this will be able to provide better care.

Pamela J. Everingham

- Look at the front-line provision of care to discover the strengths and weaknesses of a health program. "Bottom up" perspectives provide unique and useful information.
- Develop personal relationships with people representing different systems (such as a health care facility, individual providers, the payment agency). Use these personal relationships to facilitate better services.
- Support families and communities in working through differences and reaching common goals.

Resources

Information and Support

- National Native American Cancer Survivor Support Network
  1-800-315-8848 (toll free)
- Native C.I.R.C.L.E.
  1-877-372-1617 (toll free)
- Suicide Prevention and Crisis Information–Healing of Nations
  www.indian-suicide.org

Talking About Health

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  www.doi.gov/bureau-indian-affairs.html
- Centers for Disease Control and Prevention
  www.cdc.gov
- Centers for Disease Control and Prevention, National Center for Health Statistics. 1996. *Deaths: Final data.*
- Indian Health Service
  www.ihs.gov

- National Indian Child Welfare Association
  www.nicwa.org
- National Indian Health Board
  www.nihb.org
- National Native American AIDS Prevention Center
  www.nnaapc.org
- Office of the Associate Director for Minority Health
  www.cdc.gov/od/admh
- U.S. Census Bureau
  www.census.gov
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Eliminating Health Disparities
Conversations with
American Indians and Alaska Natives

is one of a series of *Public Health Profiles* published by ETR Associates, a private, nonprofit agency committed to providing health education/promotion resources for underserved populations. Each book in the series focuses on a cultural group that has traditionally experienced health disparities, profiling leaders working to promote health and prevent disease. The content includes background information on existing disparities and recommendations to improve practice and outcomes in the future.

Eliminating Health Disparities is for:

- Health care providers and prevention specialists
- Health educators
- Teachers and students in health promotion
- Community health workers
- Public health policy makers
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