

# *Eliminating Health Disparities*

*Conversations  
WITH  
Asian Americans*



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BUTCH DE CASTRO  
TESSIE GUILLERMO  
KAYING HANG  
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**ETR**  
Associates

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# Health Disparities Among Asian Americans

Asian Americans and Pacific Islanders (AAPIs) are one of the fastest growing racial groups in this country, numbering 11.9 million and representing 4.2% of the population in 2000. Of these Asian Americans, 10.2 million reported themselves as “Asian alone” on the 2000 Census, and 1.7 million reported Asian as well one or more other races.<sup>1</sup> In the 2000 Census, Chinese, Filipinos and Asian Indians accounted for 58% of those who reported a single Asian group and a similar percentage of those who reported Asian and other races.

Like other broad demographic categories, the AAPI designation masks tremendous diversity within the group. For example, the AAPI group includes people from 30 Asian nations and 25 Pacific Island nations—which could be subdivided into even more languages, cultures and immigration patterns. Some AAPI groups have much higher rates of poverty and linguistic isolation than others. For example, 63% of the Hmong population, 51% of Laotians and 47% of Cambodians live in poverty—and are more likely to have no health insurance. Sixty percent of Hmong households have no member over age 14 who reports speaking English “very well.”<sup>2</sup>

Geographically, AAPIs are located in the 50 states and six Pacific Island jurisdictions (American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of the Marshall Islands and Republic of Palau) spanning over 12 time zones, with most Asian Americans living in western states. In

<sup>1</sup>Barnes, J. S., and C. E. Burnett. February 2000. *The Asian population: 2000*. Census 2000 brief. U.S. Department of Commerce, Economics and Statistics Administration, U.S. Census Bureau.

<sup>2</sup>Hong, B., and N. Bayat. May 8-9, 1999. *Improving the cardiovascular health of Asian American and Pacific Islander populations in the United States*. Proceedings of the First National AAPI Cardiovascular Health Strategy Workshop, San Francisco, California.

fact, over half of AAPIs (51%) live in just three states: California, New York and Hawai'i. While many are fourth- and fifth-generation Americans, within specific Asian ethnic groups, as many as 75% are recent immigrants and refugees.<sup>3</sup>

### *Data Limitations*

The diversity within the AAPI category is seen not only in nationalities and languages, but also in disparate poverty rates, educational attainment and other socioeconomic characteristics.<sup>4</sup>

Unfortunately, while data collection on health for AAPIs is slowly improving, published information on health and health barriers among specific AAPI ethnic groups is still very limited. In some cases, health and population data only includes the category of AAPIs as an aggregate or as "other." In other cases, data are simply not available. For example, data are missing in over half of the leading health indicator data sets in the *Healthy People 2010 Objectives for the Nation*.<sup>5</sup>

### *Debunking the Myth of the Healthy Minority*

The myth of the healthy AAPI or model minority continues to be perpetuated in health settings and policy arenas.<sup>6</sup> Even the limited data currently available show that specific AAPI subgroups face significant health issues and excess burden of disease. Vietnamese Americans have the highest rate of cervical cancer, southeast Asians have some of the highest rates of tuberculosis and hepatitis B, and there are indicators of lifestyle disparities as well. Many of these lifestyle risk factors relate to

<sup>3</sup>U. S. Department of Commerce, Bureau of the Census. 1993. *We the Americans: Asians*. Washington, DC.

<sup>4</sup>Ro, M. 2002. Moving forward: Addressing the health of Asian American and Pacific Islander women. *American Journal of Public Health* 92:516-519.

<sup>5</sup>Asian and Pacific Islander American Health Forum. 2001. Healthy People 2010 Policy brief. From website: [www.apiahf.org/policy/hp2010.html](http://www.apiahf.org/policy/hp2010.html).

<sup>6</sup>Chen, M. S., and B. L. Hawks. 1995. A debunking of the myth of the healthy Asian American and Pacific Islander. *American Journal of Health Promotion* 9:261-268.

the leading causes of death for Asian Americans, which are cardiovascular diseases, cancer, cerebrovascular diseases (stroke), chronic obstructive pulmonary diseases and unintentional injuries. For example, although data for AAPI tobacco use still remains limited, tobacco use prevalence among males from specific AAPI groups is significantly higher than the general U.S. male population (45–71% for Cambodian males).<sup>7</sup> This high prevalence of tobacco use contributes to increased rates of lung cancer and other tobacco-related diseases. Lung cancer is the most common cancer among Chinese, Hawaiian, Korean and Vietnamese men living in the United States.

Another area of disparities includes those health areas where AAPIs have high rates as well as the added challenge of cultural and social stigmas. For example, HIV/AIDS and mental health continue to be major priorities for AAPI communities.

Other indicators of disparity in addition to specific diseases and lifestyle indicators are health insurance and access to health care. Two million, or one out of every five Asian Americans, do not have health insurance. Korean Americans (52%) and Vietnamese Americans (32%) have some of the highest rates of non-insurance among all racial/ethnic groups.<sup>8</sup>

Health disparities in AAPI communities are further compounded by lack of cultural and linguistic access; social, economic and political inequities; immigration status; and other community issues. For example, environmental factors, such as poor ventilation in garment factories or exposure to toxins in the neighborhood, can contribute greatly to the poor health status of some AAPI communities and, in some cases, the widening of disparities relative to the general population.

<sup>7</sup>Lew, R., and S. P. Tanjasiri. 2003. Slowing the epidemic of tobacco use in Asian Americans and Pacific Islanders. *American Journal of Public Health* 93: 764-768.

<sup>8</sup>Hughes, D. 2002. Quality of health care for Asian Americans. Commonwealth Fund Publication No. 525, March.



### *Increasing Inclusivity and Advancing Parity*

While recent efforts have focused on eliminating disparities, another way to address health issues is to focus on advancing or achieving health *parity* for all communities. Parity, or equity, is a positive vision for eliminating disparities that requires a closer examination of the process involved in providing health services and health promotion, as well as the desired health outcome.

Parity can also be defined as the ability of representatives from heterogeneous communities to equally participate in the planning and implementation of key activities, programs and policies. As stated by the Out of Many One coalition, “In order to achieve the fullest health potential for our communities and ourselves, we must begin by achieving health parity with the *best* level of health achieved by *any* group.”<sup>9</sup>

A major factor in achieving parity is to develop substantive policies and mechanisms to secure diversity and inclusivity. A recent publication stated that “Inclusivity refers to actively involving representatives from heterogenous communities in a substantive way, in the process, decision making and outcomes of any organization’s mission, goals and objectives. True inclusivity, as opposed to diversity, works more closely towards equity and parity.”<sup>10</sup>

### *AAPPI Initiative and Other Recommendations*

In 1999, President Clinton issued Executive Order 13125 to increase the participation of AAPIs in federal programs and established the White House Initiative on Asian Americans and Pacific Islanders. Under this Executive Order, members of the President’s Advisory Commission on AAPIs were appointed to advise the President

<sup>9</sup>Out of Many One is a multicultural effort emanating from a meeting of 75 leaders from all racial and ethnic groups in Washington, D.C., November 2000, who together created A Multicultural Action Plan to Achieve Health Parity.

<sup>10</sup>Task Force on Advancing Parity and Leadership for Priority Populations. 2002. *Moving toward health: Achieving parity through tobacco control for all communities*. From website: [www.appealforcommunities.org](http://www.appealforcommunities.org)

through the Secretary of the Department of Health and Human Services. While not specifically focused on health, the White House Initiative on AAPIs had important ramifications for addressing health disparities. The five cross-cutting priority areas identified in the Commission's first report included the following:

1. Improve data collection, analysis and dissemination for Asian Americans and Pacific Islanders.
2. Ensure access, especially linguistic access and cultural competence for Asian Americans and Pacific Islanders.
3. Protect civil rights and equal opportunity for Asian Americans and Pacific Islanders.
4. Strengthen and sustain AAPI community capacity.
5. Recognize and include Native Hawaiians and Pacific Islanders in federal programs and services.

The Executive Order was amended in 2001 to continue the Commission until June 2003, and the priority areas are currently being revised.

### *Conclusion*

The challenge for effectively eliminating health disparities and achieving parity in diverse AAPI communities requires a comprehensive multi-level approach. This approach must incorporate a better understanding of disparities and move toward reducing and eliminating social, political, cultural and institutional barriers to health care services and health promotion. And this approach must ultimately build community capacity and empower communities to respond in health and social policy arenas. Only with a combined approach of program and policy implementation on the local, regional and national levels can we realize the vision of health parity for Asian Americans, Pacific Islanders and all communities.

# Finding Opportunities

**BUTCH DE CASTRO**



**BUTCH DE CASTRO, PHD, MSN/MPH, RN, PHN**, is currently the Senior Specialist for Occupational Health and Safety for the American Nurses Association in Washington, D.C. He also worked at the U.S. Department of Labor, Occupational Safety and Health Administration (OSHA) in the Office of Occupational Health Nursing, Washington, D.C.

He earned a PhD in Environmental Health Sciences from the Johns Hopkins University School of Public Health in 2002 and completed a joint MSN/MPH degree at its School of Nursing and School of Public Health in 1998. He also attended the University of California, Los Angeles, where he graduated with BS in Nursing. He is the current chair of the Asian Pacific Islander Caucus of the American Public Health Association.



### *Choosing a Mission*

Working as a public health nurse for the county health department gave me firsthand experience of the profound health issues urban communities face. Problems such as environmental hazards, communicable disease, nutritional deficiencies, resource limitations and health care access barriers appeared daunting. Making home visits to families gave me insight into the complex challenges and threats to health that communities have to deal with on an everyday basis. Moreover, what struck me back then, as a young health professional, was the severe impact on health status that is largely assumed by minority peoples. Being a person of color, I developed a sense of responsibility to devote part of my life to efforts concentrated on the betterment of such communities.

*I wanted to prepare myself to be a confident representative advocate for underserved communities with unique sociocultural needs.*

While I certainly felt that I was part of the solution, a point came when I felt like I wasn't enough of it. I asked myself how I could contribute to the efforts to care for such communities in a greater capacity. Having a basic understanding of public health, I decided that a graduate education in public health would give me the knowledge and skills to better serve. The thought that I could enhance my nursing training with a formal public health perspective motivated me. Moreover, I wanted to prepare myself to be a confident advocate for underserved communities with unique sociocultural needs.

### *Why Public Health?*

Hearing that I'm a registered nurse, people ask why I don't work at the bedside as a so-called traditional nurse. Providing direct patient care is certainly rewarding, but it didn't seem to get to the heart of the macro-level social problems that threaten wellness and cause disease for people. I was working on the back end of things rather than on the front. Thinking about health in terms of populations, prioritizing the

prevention of disease, and intervening in real-world contexts rather than within the “sterility” of a hospital setting made much more sense to me. I valued the idea of finding ways to keep people healthy and out of the sick bed.

My public health education proved to be much more than I ever expected. Aside from learning the core competencies of epidemiology and biostatistics, discussing the concept of health in terms of groups and the inter-relatedness of actions profoundly altered my worldview and outlook. Further, consistently distinguishing vulnerable, marginalized groups and identifying specific factors of risk sparked my sense of social justice. It became clear to me that public health practice was a powerful means to combat forces that endanger well-being on a broad scale. In addition, sharing ideas with like-minded individuals led to the insight that, as a public health student, I was now part of a movement.

### *Defining Self-Identity*

As a first-generation Filipino American in Southern California, ties to native Filipino culture were woven into everyday life and became a valued part of my identity. I came to easily appreciate the richness of my heritage that led to a distinct level of pride and growing connectedness to a larger Asian-American identity. Along with this, of course, came an awareness and sensitivity to the issues and needs of communities of color.

A defining moment with respect to identity came for me when I spent two months in the Philippines to perform a community assessment for a community health course. Going into the project, I was filled with excitement since this would be both an opportunity to work for a population with tremendous needs as well as to get in touch with my Filipino roots. I learned many lessons from the project, though one of the most valuable was slightly difficult to accept. I had expected people there to

*I came to easily appreciate the richness of my heritage that led to a distinct level of pride and growing connectedness to a larger Asian-American identity.*

mutually identify with me because of shared ethnic roots—I was, after all, Filipino. On the contrary, to people there, I was American and, thus, different. This certainly threw me for a loop. Though initially taken aback by this, it helped me to better appreciate that, indeed, I am Filipino American. I am Asian American.

### *Opportunity—Seeking, Seizing and Creating*

*I truly believe that a limitless number of opportunities exist out there for the taking.*

I truly believe that a limitless number of opportunities exist out there for the taking, particularly as a student. The variety of projects, internships, financial assistance and

research prospects that actually matched my particular interests amazed me. Furthermore, as a student, I took note of how receptive and willing people and organizations were to help out—“student” seemed to be the magic word.

A crucial step, though, is that one must seek out opportunities. A small amount of searching went a long way to uncover an abundance of things that met my ambitions and goals. Another important step was taking the initiative to pursue opportunities that presented themselves. When it came to competitive intern projects or financial awards, for example, I often felt as if I had no chance when I read the desired qualifications for candidates. Sure, there were many that I didn’t get, but there were many that I did. Initiative also went a long way to creating opportunities for myself. Showing the interest and the gumption to approach individuals was essential, though.

I recall a leadership course in which students had to identify a public health leader to observe and partner with for a program evaluation. I always wondered about national-level policymaking in the area of occupational health and minority worker populations, so I contacted the Occupational Safety and Health Administration national headquarters in Washington, D.C. I spent three months with the director of the Office of Occupational Health Nursing, examining how silicosis prevention efforts reached the immigrant workforce.

## *The Gift of Mentorship*

I have been fortunate to establish mentoring relationships during graduate school with two special people that continue today. They each served as influential role models and supportive advocates for me. The most distinctive quality that they both shared, though, was that they always made a concerted effort to find opportunities for me to succeed. This was tremendously helpful to build my confidence as I grappled with everyday academic travails such as coursework and dissertation writing. Also, they encouraged me to set more ambitious goals after every achievement.

Shortly after starting my master's degree program, I came across a professor, Dr. Jacqueline Agnew, who took time to listen to the issues I was interested in. She listened intently as I talked about my concerns regarding the exploitation of immigrant laborers, such as migrant farm workers and sweatshop workers. At the time, you could say she found me filled with passion, but lacking some focus. She told me that my study interests fit precisely into the specialty area of occupational and environmental health, which was her primary research area. I immediately asked if she would be my academic advisor, to which she agreed. After completing the program under her guidance, she asked if I would be interested in pursuing a PhD—which had never crossed my mind. She told me that I had demonstrated the abilities to thrive as a doctoral candidate. She was very instrumental throughout every step of the doctoral process and also served as a primary advisor. Without her encouragement, I don't believe I would have made such a commitment—and no words can express how grateful I am.

Also, during the early weeks of starting my master's program, I met a doctoral student, Marguerite Ro, who had helped start a group called Asian Americans in Public Health. Through her, I was introduced to the specific public health issues affecting

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Asian Americans and Pacific Islanders. She was an important resource for me as I developed my understanding of the unique needs shared by these populations. She shared with me a perspective and insight that I couldn't find elsewhere at school. Several years later, serving as chair of the Asian Pacific Islander Caucus of the American Public Health Association, she got me involved in the group by recommending that I help review abstract submissions with her in order to learn the process. Now, a few years after, I find myself honored to be the current chair of the group. Her teaching and guidance that started during my student days instilled in me the responsibility to take on a series of participation and leadership roles that I never anticipated.

### *Anticipating the Next Wave*

While I believe that some preliminary steps have been taken toward recognizing the public health needs of Asian-American communities, we have much more to do to address them. Acknowledging and prioritizing the issue of health disparities only serves as a first stage towards their eventual elimination. What comes next is the need to set the agenda for action with a comprehensive breadth of goals that lead to a definitive picture of desired outcomes.

*We can look to students of public health not only for new ideas, but also for new ways of thinking that will push efforts forward toward the equity of health status among all communities of this nation.*

Because many previous leaders have located strong footholds and continue to point the way, I believe it is incumbent upon the current and future wave of leaders and activists working within the community to actively contribute in deciding the who, what, how and when. Students of public health are a large part of this next wave. We can look to them not only for new ideas, but also for new ways of thinking that will push efforts forward toward the equity of health status among all communities of this nation.



# *A Strong Nation, A Healthy Nation*

**MOHAMMED N. AKHTER**



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He is a frequent source for journalists at the New York Times, the Washington Post, the Wall Street Journal, USA Today, Voice of America, ABC, CBS, FOX and NPR. His knowledge and dedication have furthered the awareness of public health issues in this country and around the world.



*What are the most important issues regarding health disparities for Asian Americans or others?*

*Asian Americans are a very diverse community. We come from more than 60 countries around the world, speak over 100 languages, and come from different cultural and ethnic backgrounds.*

Asian Americans, and minorities in general, have a relatively high rate of chronic disease. But Asian Americans have distinct concerns as well. First of all, Asian Americans are a very diverse community. We come from more than 60 countries around the world, speak over 100 languages, and come from different cultural and ethnic backgrounds. We are all lumped together, but there are great social and cultural differences.

Generally, Asian Americans are also looked at as a “model” minority because we have, as a group, longer life expectancies than other segments of the population, higher median income and higher educational level than the nation as a whole. Once you go beneath the surface, however, you find that we suffer from similar problems as other groups experiencing health disparities.

For example, one out of five Asian Americans does not have health insurance. We also have had higher rates of certain diseases when we arrived in this country, perhaps because of genetics, environment or other reasons. The rate of cervical cancer among Vietnamese women is five times higher than the rest of the population. The rate of hepatitis B, tuberculosis and liver cancer among Asian Americans is much higher than for others. We also have more severe mental health problems.

Two-thirds of Asian Americans in the United States are foreign born. We are a very diverse community with unique problems, and that has not been recognized because there has never been serious data collection. We’ve always been a footnote to the major categories of Black, White and Hispanic.

Once you start looking under the surface you see that distinct groups within the Asian population have serious problems. These include difficulty accessing care

because of lack of health insurance, or finding providers who understand their language and are familiar with their culture.

*What are some of the specific issues facing South Asians?*

South Asia includes countries such as India, Pakistan, Bhutan, Bangladesh, Nepal and Sri Lanka. All these folks have some things in common, but they are very diverse. The common things we face are the issues of civil rights and social justice. In 1996, the U.S. Congress passed a law that bars immigrants from social services dependency within five years of arrival. They may be sent home or their residency may be terminated if they get social services. That creates a difficulty—people who are ill would rather remain untreated than face expulsion. Since September 11th, there is additional pressure. They are afraid they may be arrested and deported. These are concerns across all Asian communities—particularly people from South Asia.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

My parents were refugees from India to Pakistan. They were farmers. My grandfather didn't know how to read and write. Once we became refugees, they lost their cattle and their land and they were homeless. My mother had an eighth-grade education, and she was able to find a job. She told us that education was the way out of poverty and out of our difficulty. She made sure we all got a good education, that we were dedicated to continuous learning.

*My mother told us that education was the way out of poverty and out of our difficulty.*

I have also been fortunate to have some of the very best teachers: John Humes who was Dean of the School of Public Health at Johns Hopkins University and Kurt Deuschle at Mt. Sinai School of Medicine. They not only taught me medicine, but also coached me as a recent immigrant. It is hard to get yourself established. Moving

into a leadership position is even more difficult. To have such good teachers was very inspirational, and whatever I have been able to do is because of teachers like these.

Our leaders in the United States, people like Martin Luther King, Jr., and Surgeon General David Satcher, were great folks who mobilized the community to do bigger and better things.

*Could you describe more about the specific work you have done to promote health among Asian Americans?*

I was a medical missionary with the Methodist Church. My wife and I went overseas to Pakistan and worked in the villages to provide services to folks who otherwise would not get them. The important thing was to empower the people, in particular

to educate the women to take care of their families and children.

*Health is the responsibility of many parties, not just the public health community.*

That was very, very successful. I've also discovered that health is the responsibility of many parties, not just the public health community. The faith community can play a critical role in health promotion.

When I served as health commissioner in Washington, D.C., we faced very serious problems—African-American infant mortality, heart disease, high blood pressure and cancer. We worked diligently and we turned around infant mortality in Washington, D.C. It's been 12 years and infant mortality is still going down—after going up in the 1980s. This has been a collaborative effort between the faith community, the health community and the people in the area. It's been very refreshing to be able to do that at the ground level.

In terms of disparities, I had the opportunity to look at national issues with Dr. David Satcher, then the surgeon general. We are a nation of immigrants—the most diverse nation that ever existed. The disease rate is much higher among the minorities than the general population. You can't have a strong nation when there are so many people sick.

Right now 25% of all Americans are members of these ethnic groups—Asian Americans, Hispanic Americans, African Americans. By 2030, 40% of all Americans are going to be in these categories and by 2050 half will be. In California it's already happened—there's no group that's a majority. So if the disease rate continues the way it has been, we will not have a strong nation.

*If the disease rate continues the way it has been, we will not have a strong nation.*

So, in 2000, Dr. Satcher and I invited 25 key business and political leaders, and 25 government leaders, to the White House and outlined these health disparities for the first time. They are especially compelling if you look at life expectancy. African-American men live 8 years less than white men and African-American women live 5 years less than white women. The differences in chronic disease are also not acceptable. We needed to issue a call to the nation to deal with these disparities.

This was an important part of our thinking when we developed Healthy People 2010, which is a ten-year prevention agenda for the nation at the state and federal levels. We had two objectives: to increase the life expectancy and quality of life of all Americans, and to eliminate health disparities between different segments of the population. It's now part of the federal government's program, and all of the states have set up programs as well.

In addition, we were able to work with the Congress to create a center at the National Institutes of Health for minority research. This is the first time that the nation is looking at these disparities, explaining them, and outlining what can be done scientifically to eliminate them.

In 1999, President Clinton issued an executive order that for the first time said that we need to collect separate data on Asian-American health and ensure better access for Asian Americans.

As a result, other organizations—the American Medical Association, the National Medical Association, the American Cancer Society and American Heart

Association—are looking at these disparities. So the whole nation is paying attention and that’s a big achievement.

It’s time for the nation to mature. There was a time when this nation thought that slavery was acceptable. Many felt inequity was acceptable. Women and African Americans didn’t have the right to vote. Then our nation moved forward and reached a point where we said, “This is no longer acceptable.”

Now many of us believe that the nation has matured to a point where health disparities are not acceptable either.

*Do you have lessons to share with others based on your experiences?*

I had some really wonderful teachers who pushed me a bit, and encouraged me to participate in the affairs of the school or institution, wherever I was. I was the president of the Student Assembly at Johns Hopkins when I was a student. I was president of the House Staff Association at Mt. Sinai in New York when I was doing my residency training. This exposed me to issues that the whole community faces and

*I had some really wonderful teachers who pushed me a bit, and encouraged me to participate in the affairs of the school or institution, wherever I was.*

made me part of the community, part of the process. We simply can’t be separate. You need to have many bees to make the honey. So one of the lessons I have learned is to really get involved, and to get involved in such a way that I don’t simply advocate my own needs.

The Asian-American community cannot do these things alone. We need to have coalitions with the Hispanic community, the African-American community and the other minority organizations. We must not take away from others for ourselves. This creates resentment. Instead, we must come together in a coalition and move the agenda forward, to help our nation be strong and our communities be more productive. This has been a very important lesson for me.

The second thing is that we must take responsibility for our own community. We can't rely on federal, state and local governments, or other agencies to come along and help us.

Many of our people are first generation immigrants. Language and cultural sensitivity are big problems. Providing people the opportunity to be involved in their health is a very important part. I stay involved with the Asian community from India and Pakistan, where I come from. I try to help by writing articles in the newspapers and appearing on television shows to educate my community. I speak the language and understand the culture. I can put health education in a cultural context.

This has been very helpful several times in my career, like when the AIDS issue came up. It's very hard for Asian-American people to talk about, but it's my responsibility to address it. Bioterrorism is a similar subject. These are things that are very hard for people in our communities to understand. Only we can do this for our communities and we need to take responsibility to speak up so people will understand.

The third thing is that there is a continuing need for new leadership in the Asian-American community. We did not get the right to become citizens and vote until 1952. So we don't have a long history of political participation.

*There is a continuing need for new leadership in the Asian-American community.*

When I was running for the student assembly presidency at Hopkins, many of the Asian students discouraged me. They said if I ran against the local candidates, it would create animosity and might hurt Asians. Asians are willing to do the hard jobs, but some don't want to get involved where politics are an issue.

Many Asian-American immigrants look back to their home countries to participate politically. A lot of Indians are participating in Indian politics, Pakistanis in Pakistani politics. But these people may not have paid attention to politics in this country, or created a leadership structure so they can participate in politics here.

The fourth big challenge is to have access to health care for our people. As I said earlier, about one-fifth of Asian Americans don't have health insurance. Those who

do often cannot find a person who is culturally sensitive at their HMO. Many of them have difficulty communicating with their physician, and compliance with medication is poor. That continues to be a serious problem and we have not been able to come up with a good solution, even though we have a lot of physicians who come from Asian countries—India, Pakistan, the Philippines and elsewhere.

*When people don't have access to social or health services, a small problem becomes a bigger problem.*

The last challenge is civil rights. As I said earlier, the 1996 law requires immigrants to be self-sufficient for the first five years in this country. With changing economic conditions, it's easier to lose a job and become dependent on the state. With job losses all around the country, how can recent immigrants survive without assistance? These laws are unfair and unrealistic. When people don't have access to social or health services, a small problem becomes a bigger problem. That's something we really need to work against.

The recent Patriot Act in response to the September 11th terrorist attacks also creates problems. People have been detained without access to lawyers or any quick ways of resolving the issue. It creates an uncertainty and unease in the Asian-American community. This creates, in turn, mental pressure that leads to mental illness and other difficulties. So certainly there are health consequences when people feel that they are under siege, when they feel they are being chased or harassed.

*What kind of leadership do you think is needed to address disparities to provide health care that Asian Americans need?*

Three types of leaders are needed. The first type are those who will lead their communities. It is not the availability of doctors that is the biggest problem, but problems in communication between doctors and patients. This often makes it difficult for patients to understand diagnoses or follow the treatment plans. Peers can help people deal with language and culture barriers. In San Francisco's Chinatown,



people were able to go with patients to the doctor to translate. When children are asked to be translators for their families, it's not good for the children or the parent.

Having sustainable ethnic organizations dealing with such issues can help provide capacity at the local level to support the community. This is especially important in areas where Asians are concentrated, in states such as California, New York or Illinois.

The second type of leadership must come from politically active people who can bring the issues faced by their communities to the political process. They can help create mechanisms to collect data on Asian-American problems and provide resources to serve these communities. That's really a bigger gap than at the community level. There's nobody at the state level. I've gone to Michigan, Illinois and Missouri and seen firsthand that there's nobody advocating at that level, bringing these issues to state government.

The third type of leadership is the leadership that is willing to work with others to make this nation strong and powerful. Health disparities are an issue not only for Asian Americans, but also for Hispanic Americans, Native Americans and African Americans. We cannot have a strong nation without healthy people in all segments of our society. Leaders must be willing to join hands with other ethnic organizations, with the private sector and with the public sector, to design and develop programs for elimination of these disparities, in their communities, in their states, and, of course, in the nation.

*We cannot have a strong nation without healthy people in all segments of our society.*

### *What is your vision and hope for the future?*

Addressing health disparities is the last frontier of the civil rights movement. I would like to see the nation rise up and say, "These disparities are not acceptable." Whether we are Democrats or Republicans, we need to have national legislation, like the Civil Rights legislation, that specifically directs state and local jurisdictions and provides resources to deal with these disparities.

The best way to approach this is to make sure that children of this nation, regardless of whether they are African American, Asian American, Hispanic American or Native

*Make sure that children of this nation, regardless of whether they are African American, Asian American, Hispanic American or Native American, have the best health care possible.*

American, have the best health care possible, before disparities begin to take shape. If you don't have prenatal care, if you don't have services for young children, it does not matter if they have all the money or food they want when they grow up. They cannot compensate for the things that happened when they were children.

In the last century, the strength of a nation depended on who had the most bombs, who had the most tanks, who had the most money. But, in this century, the strength of a nation will be dependent upon who has the healthiest and most educated people. Whatever nation has those people will lead the world. The United States happens to be the leader of the world right now, and if we can focus on our children, and bring up a next generation that's healthier than the last, there's no doubt we will remain so.

My hope is that this will be recognized by the federal government at the highest level, and that Congress will pass legislation that will say, "Regardless of your family status, your children will have an equal opportunity to be healthy." Because right now there are 10 million children who don't have health insurance or access to services.

Health disparities are not something new. These problems have been with us for thousands of years. But this is the first time in the history of the world that a nation has paid attention to them. These disparities exist all around the world. The whole world is looking at the United States to see how we deal with them. So we are not only doing this for our nation, but also providing a roadmap for other countries. Action on these issues is very critical for the health of the global village in which we all live.

# Infrastructure & Inspiration

**TESSIE GUILLERMO**



**TESSIE GUILLERMO** is president and CEO of the Community Technology Foundation of California (CTFC), a public foundation established in 1998 to promote social justice through technology access for underserved communities in California. Prior to the CTFC, she served for 15 years as CEO of the Asian and Pacific Islander American Health Forum. She is a cofounder of many nonprofit groups, including the California Pan Ethnic Health Network, the Community Technology Policy Council and the National Coalition of Asian Pacific Americans.

In 2000, she was appointed by President Bill Clinton to serve as an inaugural member of the President's Advisory Commission on Asian Americans and Pacific Islanders. She was appointed in 2001 by California governor Gray Davis to the Board of Trustees of the Health Professions Education Foundation. She is a member of The California Endowment Board of Directors and serves as a Board member of Catholic Healthcare West. A published author and frequent keynote speaker on nonprofit leadership and public policy issues, she holds a degree in economics from California State University, Hayward. She is also a graduate of the Gallup Leadership Institute and a 1997 Fellow of the Asian Pacific American Women's Leadership Institute. She is a native San Franciscan, and she and her husband are raising their three children there.



*What do you think are the most important issues related to health disparities for Asian Americans?*

My concern is with how we actually get around to addressing health disparities, particularly in terms of infrastructure in the health arena. There is very little research infrastructure focused on the Asian-American/Pacific-Islander population. The services are only as good as the infrastructure.

For example, there are community health centers focused on AAPI populations, but who gets to take advantage of their services is very scattered. There are only 15 of them throughout the country.

On another level, I am concerned with the infrastructure necessary to promote AAPI health issues in the political, policy and broader public health arenas. As much as issues of access and cultural competence and primary care and specific diseases are important, there's really very little that can be done with those unless we have the infrastructure with which to address them.

*Because we had a presence in Washington, we had the ability to visibly bring issues to the table where federal policy is being made.*

*You mentioned the need for infrastructure that allowed policy to go forward and included Asian Americans in research and other areas. Can you say more about what that would look like if it were in place?*

It would probably be a multitiered infrastructure. I used to work at the Asian and Pacific Islander American Health Forum, a national policy organization headquartered in San Francisco, with a branch office in Washington, D.C. Our California office allowed us to be located in the geographic area where the majority of the Asian Americans and Pacific Islanders reside. Because we also had a presence in Washington, we had the ability to visibly bring issues to the table where federal policy

is being made. There weren't any other organizations dedicated to AAPI health improvement that looked like that.

On the state and local levels, you need organizations to apportion some of their energy and efforts toward policy advocacy at every level. On the local level, they could work with city councils, county boards of supervisors and county health departments. On the state level, they could promote informed policies at the State Department of Health, at the Health and Welfare Agency, and with the governor and the legislature. And that just doesn't exist.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

The movement to improve Asian-American/Pacific-Islander health is still relatively young—maybe 20 years old. There are some pioneers in the field whom I've been very fortunate to know. I learned from the vision and foresight of individuals such as Art Chen, Sherry Hirota, Rolland Lowe and Harry Lee, who was the Board president for my organization for years.

They showed me you could have a desire to change the conditions of a population that was otherwise invisible if you really were clear about what you wanted to do. These folks were clearly focused on the goal, and also realistic about having a strategic view. They knew you couldn't accomplish everything in one day, or one decade, or with one set of partners. Folks like these opened my eyes to an analytic, strategic focus—an approach that has characterized my work to this day.

They also showed me the value of networking, coalition building and playing leadership roles. When I say "coalition building" I don't just mean within the Asian-American and Pacific-Islander

*You could have a desire to change the conditions of a population that was otherwise invisible if you really were clear about what you wanted to do.*

community, but with other groups and individuals who were concerned about social justice. These were individuals and organizations concerned about minority health, about the well-being of society. That broader view was invaluable for me to experience.

I hope that I also do this in my work.

*The establishment of an organization that was going to be looking at promoting AAPI health on a national level was fairly bold. But because we were bold, we were able to make our presence known.*

Before the Health Forum was established, there was no entity in place that addressed Asian-American/Pacific-Islander health on a national level. In fact there wasn't anything beyond a county level. The establishment of an organization that was going to be looking at promoting AAPI health on a national level was fairly bold. But because we were bold, we were able to make our presence known.

At the time, people were asking, "Who are you? What issues could the Asian Americans possibly have with regard to their health?" A lot of my work, in the ten years preceding the White House Initiative, was about trying to get a seat at the table. We were legitimizing ourselves as a population that deserved to be part of the mix.

Then when the opportunity to establish the White House Initiative came into play, the question became, "So what are you going to do with your place at the table? What is the message that you're going to convey? What changes are you going to try to make?" This went beyond getting a seat at the table. You had to do greater public good. That was the focus of putting that initiative together.

With many things that are pioneering, there's some serendipity. Hopefully, you take advantage of opportunities that come into play. The White House Initiative was initially just a call to the Clinton administration's Department of Health and Human Services to establish a strategic plan for improving the health of Asian Americans and Pacific Islanders. Much of this was a sort of patchwork quilt, tagging along with other initiatives that were in place for other at-need populations.

But the effort gathered momentum because a call came from the community that said, “We really need to organize this. We need to be more strategic about how we advocate for resources and put services in place.” This caught the attention of some key folks at the White House who really cared about the community. Some of them were Asian Americans themselves. They said, “Let’s not just look at health. Let’s look at all the issues that need to be investigated and addressed in the AAPI population. They’re a growing percentage of the overall population. They’ve made a lot of contributions. They could make more if we pay attention to them.”

That initial advocacy grew into an initiative that addressed a whole range of health and welfare needs of Asian Americans and Pacific Islanders. Then, rather than it just being an initiative in the Department of Health and Human Services, we had the opportunity to push this to the level of the President and call for an executive order. An executive order sticks around in perpetuity unless a subsequent president decides to revoke it.

This really galvanized AAPI communities throughout the United States, as well as the public and government employees, both on an executive level and on a front-line level, who were themselves Asian American or Pacific Islander. They began to use their roles in government in a more active and strategic way. The initiative created a partnership between the government sector, the political sector and the community sector.

*See the possibilities and be very focused on what you want to achieve in order to be successful.*

This is one of those things that only comes along once in a while, and you have to be ready for it—see the possibilities and be very focused on what you want to achieve—in order for it to be successful.

The White House Initiative on Asian Americans and Pacific Islanders was broadly stated. That translated to more funding, more programs and more partnerships throughout all of the government departments, from Department of Education, Department of Health and Human Services, Department of Commerce, to other

government agencies such as the National Endowment for the Arts. It mandated that each of those agencies was to do an inventory of programs and services it had in place at the time to address the well-being of Asian Americans and Pacific Islanders. Then, given that inventory, they were to develop a strategic plan that earmarked programs, resources and services that would improve the well-being of Asian Americans and Pacific Islanders. Depending on the department or agency, “well-being” might mean health, bilingual education, small business opportunities, or things like that.

*Could you say something about the specific work that you're doing now having to do with technology issues? What will technology make possible in terms of sustaining coalitions or establishing collaboration?*

*There are so many applications of technology for people to explore, and virtually all are getting cheaper to use.*

Think about the whole range of technology applications out there. There's the Internet, all the web-based ways of communicating and sharing information. There are now digital technologies—for instance, using digital cameras or video—where you can quickly and relatively cheaply capture stories about best practices or things going on in a particular community. These can be shared easily on a CD or DVD.

The ways to use technology in coalition building, collaboration and providing services have not been fully explored. But you can be much more content specific when you use information and communications technology on your own, as opposed to waiting for other content providers to do that for you.

One mechanism for using technology that our foundation has funded is video-based translation services. You have a physician in the room with a patient, and you have a translator available elsewhere, and all you need is a monitor in the exam room and you



can have simultaneous translation going on. There are so many applications of technology for people to explore, and virtually all are getting cheaper to use.

*There's something powerful about being able to use technology to instantly document the work that is being done.*

Yes. The other thing that technology does is give you a place in the conversation or activity that is equal with everybody else. Theoretically, all websites are equally accessible, equally participatory. If you're good at it, your web-based use of technology can help bring about collaboration or build coalition. It may be even more effective than gathering together with individuals or organizations physically. You can get very much right to the work. Everybody really is an equal player. You don't have to stretch resources to fund someone's travel. We are just being to scratch the surface of effective use of technology in health policy and promotion, and in community building.

*Could you describe any lessons you have to share with others?*

Maintain a focus on your mission while remaining flexible in your response. Perhaps you have a mission, for example, of improving the health of Asian Americans and Pacific Islanders. But health status for our populations has not been well documented. As it becomes better documented, the important issues are going to change.

*Maintain a focus on your mission while remaining flexible in your response.*

You may chart out a course that addresses a set of issues relative to the information you have today. But data collection and analysis and proof may raise a whole level of awareness about other issues, so you have to be able to change tomorrow.

That's why I try to take an analytical approach to almost everything I do, to look at both the internal and external factors that affect a particular problem or issue.

A lot of people say, “Here is what the story is because this is what I observe.” That may be valid, but it’s all the more powerful if you have data to back that up. On the flip side, if your data describes something and you can say, “Yes, that is confirmed by the actual experience of people,” then it’s again that much more persuasive.

*Let’s dig down deep, establish a methodology, a presence, a depth of investigation and service delivery and advocacy.*

I’ve also learned to have a strategic approach that allows me to plan for the long term. We’re not going to achieve our goals for improvement of health status for Asian Americans, or any population for that matter, in a matter of a few years. So let’s dig down deep, establish a methodology, a presence, a depth of investigation and service delivery and advocacy that will allow us to continue doing that for the next round.

Another thing I’ve learned, and that I very much believe in, is the importance of coalition building. In our community alone, we don’t have enough resources to do everything we need to do. My most effective victories and successes have come from the ability to form coalitions not only within the AAPI community but also outside of our community. This allows us to establish partnerships where we can incorporate one another’s issues, and move forward in changing conditions and improving health.

Here’s an example dealing with policy at the federal level. Many advocates from different underserved communities have long wanted the National Institutes of Health to provide more attention resources and priority to the study of minority health—or of the health of people other than white males. Over a period of years, many of us who had done advocacy on the national level formed a coalition. We weren’t necessarily thinking strategically, but we were trying to join on similar issues, and trying not to step on each other. At some point we realized that we were having more success because we could back each other up.

So we formed a body in Washington of organizations looking at minority health—the National Medical Association, for instance, the Asian and Pacific Islander

American Health Forum, the Hispanic Nurses Association. We advocated for legislation that established what is now known as the Center for Research for Minority Health and Health Disparities at the National Institutes of Health. It's a major victory in terms of getting NIH to acknowledge minority health and the health of the underserved and raise it to the level of a Center. This couldn't have been done by any one of us or all of us, even at the same time, without working and strategizing and advocating together.

We've had a similar success here in California. A group called the California Pan-Ethnic Health Network established cultural and linguistic standards for Medi-Cal managed care. This coalition of people concerned about cultural competency in the provision of health care worked with the Department of Health Services to set standards all medical contractors have to follow in order to be certified contractors with the State Department of Health.

### *Can you comment on leadership development in the Asian-American community?*

What we need is an infrastructure of leadership. This includes leadership that knows about the specific health issues, ethnic communities, and geographic dimensions in the AAPI community, but it also includes political leadership. People have to be willing to be part of that process—discussions that require trade-offs, communicating in public about what our community needs in relation to other communities. We're not going to be able to move our community forward on any agenda unless we're willing to enter into public debate at the political level.

There really wasn't anything on a national level before the Health Forum and its ally organizations were established back in 1986. There still isn't much of an infrastructure on a national level.

*We're not going to be able to move our community forward on any agenda unless we're willing to enter into public debate at the political level.*

*What happens at the local level is absolutely tied to what happens at the state level, and this in turn is tied to what happens at the national level.*

What are the other things we have to consider? What is the long-term plan? Whom do we have to build coalitions with? Whom can we support today, who will in turn support us tomorrow? That's the kind of consciousness raising required of the leadership in the AAPI community, not just for health but for a whole range of things.

Vertical integration is crucial. What happens at the local level is absolutely tied to what happens at the state level, and this in turn is tied to what happens at the national level. I'd like to see community-based organizations set aside a portion of their resources, whether they be human, financial, technical or otherwise to really engage in policy and advocacy efforts.

They can't leave it up to those of us who have established ourselves explicitly as the advocacy community. Everybody does advocacy, so organizations may as well set a time for it and do it in a structured, organized fashion. It doesn't need to be a whole lot of time, but it needs to be focused, effective and tied to other efforts.

Many nonprofit organizations at the community level say, "Our funders won't let us do policy or advocacy work," or "We're nonprofit so we can't do it." That's not actually correct. Sometimes there are restrictions on specific political issues, but these guidelines are interpreted very narrowly. The IRS says that nonprofits cannot engage in explicit campaigning for a candidate. But they can certainly go out and say, "These are the issues that concern us. Here are the people who support these issues." That's very different.

*What is your vision and hope for the future?*

An infrastructure or network of focused activities that work together as a whole, so nobody feels burdened to do everything alone, without support. The activities can be

issue based, they can be ethnic, they can be geographic, they can be professions based. The point is to work with others to achieve your mission.

There's an organization that has been established recently that just focuses on cancer in the AAPI community. That's fine, but go all the way with it. There may be organizations addressing any of a range of chronic diseases. If an effective network exists, those organizations can be hooked up to other entities who will deal with access to health care. You can't improve cancer outcomes if you don't have access to health care. If those activities are networked, they can be much more effective as a whole.

Because we're newcomers to the policy debates and the advocacy scene, the AAPI community often feels as if, "We have to do it now because we're so far behind." That's why I believe in taking this longer view. What would we do if we got all the resources today? Do we have the infrastructure to put those resources to good use? Do we have enough researchers? Do we have enough culturally competent providers? Do we have the education mechanisms? It's important for people to understand that it's not just about "going for the gusto." It's taking stock of what's in place, and identifying the gaps. What are the needs? How can what's already in place be strengthened?

# Personal & Political

## KAYING HANG



**KAYING HANG, MPH**, is senior consultant with Blue Cross and Blue Shield of Minnesota Foundation, where her work includes research and recommending funding approaches, analyzing grant proposals and monitoring the progress of active grants. She has served as state coordinator of the Refugee Health Program for the Minnesota Department of Health, and assistant regional coordinator of the Refugee and Immigrant Health Program for the Massachusetts Department of Public Health. The oldest of seven children, her family fled to the United States as political refugees from Laos in 1976. She has an MPH from Boston University.

*She has published numerous papers and given presentations at national and international conferences. She received the 2001 Alumni Hall of Fame Award for Mounds Park Academy in St. Paul, Minnesota; the community services award for Hmong National Development, Inc., in Washington, D.C.; and a Ford Foundation Fellowship at Brandeis University.*

*She has been a member of the American Public Health Association, Asian Pacific Islander Caucus, and the Massachusetts and Minnesota Public Health Associations, and an executive board member of the National Association of Refugee Health Coordinators. She has also served on the boards of the Asian American Pacific in Philanthropy, the 21st Century Democrats and the National Asian Pacific American Women's Forum (NAPAWF), and is a cofounder of the Minnesota Asian-American Health Coalition.*



*What do you think are the most important issues related to health disparities for Asian Americans?*

The Asian-American community is very large and diverse. In order to be able to identify health disparities, we need to take into consideration immigration status, length of time in the United States, ethnicity and even access to information. All of these are very critical in identifying the most pressing health disparities.

Many people talk about health disparities in terms of specific trends or conditions. For example, cardiovascular disease is broadly prevalent in the Asian-American/Pacific-Islander community. Certain other diseases such as obesity, breast cancer and cervical cancer are more likely to affect the Southeast-Asian population. The Hmong population faces chronic illnesses such as renal failure, diabetes and other related conditions, and so on.

I like to think of health disparities in terms of root causes, instead of the incidence of certain diseases. This means I'll take a step back and look at contributing factors such as economic, educational, housing and other social issues.

As a first generation Hmong refugee—my family came to the United States in 1976—I know that a Hmong person who arrived in the 1980s has a different health care experience than someone who immigrated in 2000. My family has been in the United States for more than 20 years and can better navigate the health care system. They understand different types of insurance coverage, or how to get what you need from your provider. Different generations have different understanding. The longer people have been in the United States, the more they'll understand these concepts.

*I think of health disparities in terms of root causes, instead of the incidence of certain diseases. I'll look at contributing factors such as economic, educational, housing and other social issues.*

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

*Personal experience navigating the health care system with my family cemented why I do the work I do, why I went into public health.*

My interest in public health has been spurred by an uncle who has a graduate degree in public health and is a doctor. He opened the door to many possibilities for me. But I would say it was my mother who's been most instrumental in this area. As the oldest of seven children, I had to serve as the interpreter in medical settings. My mother was diagnosed several years ago with chronic renal failure. That personal experience navigating the health care system with my family cemented why I do the work I do, why I went into public health.

It doesn't matter how familiar you are with the health care industry, when something like this hits you personally, it's a whole new world. You can always find areas that need improvement. Earlier this year, I made the decision to donate a kidney to my mother. This came about as part of a long process with my family. I think my mother allowing me to do this is a prime example of how far our own family has evolved in our interaction with the health care system.

*Is organ donation a foreign concept in the Hmong culture?*

Yes, it was a foreign concept for my family, as it is for many cultures. It raises many questions. Five years ago, when my mother had her first kidney donation, it was a cadaver kidney. At that time, we had a lot of discussion in our family as to whether she would be willing to take a kidney from a living donor—one of her children. We were all much younger, and at different stages in our lives. She said that as our mother, she was not going to allow that. There is a traditional, cultural perception that it is not good to be in the afterlife without an organ. For this reason, many Hmong resist autopsies for family members.



It was a very tough decision when my mother decided to accept a kidney from me. She knew she was going against a lot of Hmong cultural norms. But it also signifies that she now, as a Hmong American, has a different understanding of what this all means. She weighed the different risks involved. She had the choice to accept a kidney from a living donor and prolong her life—in which case she would be around for a longer time with good quality of life, and be able to function as a mother to her children. Or she could chance it by not having the surgery, or waiting for another cadaver donation, and decrease her quality of life.

She really struggled between these two cultural norms. But she also saw that a strong component of the Hmong culture is to be a good parent.

In the old country, if something happened, if people became seriously ill, they often died. The possibility of medical intervention was never an option. The culture developed ways to explain and understand this.

Now, as our community becomes more sophisticated and mature here in the United States, people are exposed to different possibilities such as the possibility of medical intervention. They may experience this as good or bad. But in most cases, as with my mom, it's a good intervention.

My mother understood the different options involved. It helped that she had family in the field who could explain things to her, and help her gather all the information she needed to make her decision.

*As our community becomes more sophisticated and mature here in the United States, people are exposed to different possibilities such as the possibility of medical intervention.*

*You've worked at a lot of different levels. Could you talk specifically about being Hmong among Minnesotans? Is there a sense of isolation in your role? How does your local work compare with work at the national level?*

Some unique local issues can get lost in the national arena. The National Asian Pacific American Women's Forum (NAPAWF) is an organization that grew out of the Beijing International Women's Conference in 1996. Many AAPI women from the United States who attended the conference wanted to continue similar discussions when they returned here. I had the privilege of being the first national co-chair of the organization back in 1998. It provided me an opportunity to be involved in the development of a national agenda around AAPI women and girls. Several platforms are particularly health related—violence against women, reproductive health and health care access. The beauty of this organization is that it is grounded in the local chapters. Minnesota has one of the most active local chapters in the organization.

There's been a lot of discussion about domestic violence and how it affects the community here. There are some intergenerational and adjustment issues, particularly with an immigrant community that has gone through a lot of change. There is tremendous pressure for people to make the transition to the new culture, but some do not make the transition easily or well. We see some of the results of this when we hear news reports of domestic violence, especially spousal abuse, or of homicides and suicides.

Because NAPAWF is a local program, there are opportunities for the community to pull together and address these issues. We see a real tension between the younger generation wanting to move ahead, and the older generation who feel they are misunderstood and their culture is not respected. I think it's probably not unique to the Hmong community, but happens to anyone trying to bridge the gap between traditional culture and moving forward. I'm optimistic that these things will get better with time.

I'm on the advisory committee for Asian Pacific Partners for Empowerment and Leadership—APPEAL. It's gratifying to interact with folks from different parts of the country who are working on a specific health issue—reducing and preventing tobacco use in the AAPI community. It's real interesting because, with a lot of the national efforts, I've had the opportunity to see not only the regional differences, but to see how each different community is tackling these issues.

*It's gratifying to interact with folks from different parts of the country who are working on a specific health issue.*

Until two years ago, I worked with the State Department of Health as the manager of the state's Refugee Health Program. This provided me an opportunity to better understand community health issues and health policy. I've been able to combine my personal with my academic and professional experience. And I learned a lot more about the state public health infrastructure, and how it works with the local one.

Currently I work for the Blue Cross Foundation where I'm a program officer. It provides me with an opportunity to address health improvement through grant making. This has helped me provide many different kinds of support, whether through capacity building, base building, technical assistance or program support, to help Minnesota programs serving AAPI communities.

The Midwest hosts a very new and young Asian community with a large Southeast-Asian refugee population. The Hmong community is by far the largest AAPI community in Minnesota. This provides a good opportunity, as well as some challenges. In some ways, the Hmong community has been able to move forward, to be pioneers in many aspects of our engagement with the state. On the other hand, there's always the tug where others perceive the Hmong as a refugee community. This carries with it a whole host of perceptions about what that means.

Within the Minnesota Hmong community you see the extremes. You see the new arrivals and those who've been here 30 years, since the first Hmong came in the mid-

1970s. You see people who are highly educated and those who don't have a high school education. You see those who are in secure jobs and those who are unemployed. You see those who own their own homes and those in public housing. What's beginning to happen is a sort of social stratification. I wonder how that parallels other immigrants as they become more established here.

For a very long time, the Midwest was not looked at as an area with a viable Asian community—at least this is true for Minnesota—because so much of the AAPI population has been concentrated on the coasts. A lot of people talk about things happening in California, Massachusetts, New York. Only recently has the national AAPI community started to turn its attention to Minnesota. That probably has a lot to do with the growing population of Southeast Asians, many of whom were drawn to the low unemployment rate we had here.

*Based on both the challenges and opportunities in your experience, what lessons do you have to share with others?*

I would like to share the lesson of true compassion and true commitment. These will make it easier to tackle any challenges, and can serve as a great entry to opportunities that may come.

*If you are committed to a really great idea, you have to act on it. I've had the privilege to be able to do so.*

The people I admire as role models have demonstrable leadership qualities. This means that they not only “talk the talk” but “walk the talk.” I think that is a lesson, too. If you are committed to a really great idea, you have to act on it. I've had the privilege to be able to do so.

One of the reasons I am a strong advocate for refugee health is because I am a refugee. I've experienced the health care issues at the personal and professional levels. That allows me to be an effective and engaged person. It's very personal.

*If you were speaking to other providers—policy makers particularly—about refugees, what would be the most important thing that they could bring to the issues?*

The willingness to learn, the willingness to hear—and the genuine commitment to engage and have an impact on the community. So often the refugee community looks to people they see as leaders and waits for them to say, “Here’s how it should be done.” They don’t feel they have an opportunity to participate as equals. If policy makers and providers see their patients as constituents and equal partners in developing a solution, that is going to give them all the more strength to reach and communicate with the community.

*What kind of leadership is needed now to effectively address Asian-American health disparities?*

Leadership development for youth is going to be enormously important, especially in the Hmong community, which is very young. More than half are in their teens. Teens are straddling two cultures. Some are new arrivals and some were born in the United States. Those born here are usually “typical” American teens.

Because young people are such valuable assets to the community, the more we can increase their capacity, the better for all of us. We have to provide the kids with the tools they need to tackle everyday issues. We haven’t done enough of this. I’m not aware of any culturally competent program other than the Asian Pacific Partners for Education and Leadership (APPEAL) youth group.

The word *leadership* is so fluid. There are people who don’t want to be called leaders, but are seen as leaders in the community. There are others who proclaim themselves as leaders for whatever reasons they believe legitimize them, but they may not really have people’s support or trust.

*Young people are such valuable assets to the community. The more we can increase their capacity, the better for all of us.*

For our young people, I think a better way to approach this is to ask, “What criteria can help someone bring good leadership skills to the community?”

*There is an important opportunity to encourage other people in the AAPI community to become engaged in this discussion of health disparities and how we can move forward with it.*

*Do you have an opportunity to do any mentorship?*

Yes. I'm currently the chair of the Minnesota Asian-American Health Coalition—the only pan-Asian health organization that advocates on behalf of the Minnesota AAPI community. This group has been working hard to raise the awareness level within the AAPI community of health issues that impact them. We've been working very hard to educate and to conduct outreach, but a lot of the folks who are involved are busy professionals and leaders in their fields. So it's been very tough to pull everyone together. However, there is an important opportunity to encourage other people in the AAPI community to become engaged in this discussion of health disparities and how we can move forward with it.

*What is your vision and hope for the future? What is one thing you'd most like to see happen related to the issue of health disparities among Asian Americans?*

It's going to take a real hard look at some of the policies that are currently in place. Perhaps there's an opportunity to develop new policies that would be immigrant friendly. This vision for the future would also address some of the larger social conditions that contribute to health disparities. Those of us in the Minnesotan Hmong community will have to be more aggressive in trying to identify the most effective strategy for reducing health disparities given the environment and the landscape.

*Anything else?*

I'd like to reiterate that there is real value in being able to address health disparities for the Asian-American community from a broader perspective. I think that is crucial to fully appreciate the whole AAPI dynamic.

I've been so pleased that different ethnic groups have been able to come together under this umbrella of AAPI. That leverages a lot of strength. Out of our diversity comes this solid, collective unity. That is what is really exciting at the national level. It's also great to see AAPIs come together with American Indians, Latinos and African Americans to really build a unified coalition of color. That is really exciting.

*Out of our  
diversity comes  
this solid,  
collective unity.*

# Agents for Change

**SHERRY M. HIROTA**



**SHERRY M. HIROTA** is the Chief Executive Officer of Asian Health Services, Inc., in Oakland, California. She has worked in Asian-American community organizations for over 30 years and in health care for the last 26. She helped found and serves on the Board of Directors of the Asian and Pacific Islander American Health Forum and the Association of Asian Pacific Community Health Organizations. She also currently serves on the governing board of the California Endowment, the largest health care foundation in California, and served as a founding board member of the Alameda Alliance for Health, a managed care plan with over 80,000 members.

She has participated in key committees and task forces at the local and national levels to address issues of racial and ethnic disparities in health and the problem of the uninsured. She has served on the Advisory Committee on Research on Minority Health of the Office of Research on Minority Health, National Institutes of Health, and the advisory board of the Bureau of Primary Health Care's National Center for Cultural Competence. She also led the Oakland Kellogg Initiative Community Voices for Immigrant Health, and chaired the Strategic Alliance Committee of the California Endowment and Rockefeller Foundation.

She is a 1994 recipient of the Robert Wood Johnson Community Health Leadership Award, the 1997 recipient of the San Francisco Foundation Award, and was Woman of the Year 16th Assembly District of California in 1993 and 1997.





*What do you think are the most important issues related to health disparities for Asian Americans?*

The first and most important issue is the lack of data on the status of Asian health. We have only aggregated data on Asian Americans/Pacific Islanders. The second issue is the basic lack of access to health services which skews our understanding of the morbidity and mortality rates. Other studies that would help lend some insight into Asian health disparities have been limited because of language issues. In California, something like 88% of all Asian mothers giving birth in any given year are foreign born. We're not capturing health or behavioral information on these women in our general English-language surveys.

On the political side, restrictions to basic health coverage for immigrants are a major problem. These really limit people and scare them away from health services.

So I define disparities as broader than, for example, differences in mortality rates between Asians and others. I also define it in terms of access and how that affects the statistics.

For example, we ended up being very concerned about how many people were uninsured in California. In Alameda County we did a 1,500 household survey in eight different languages—55% of the uninsured in our county are immigrants. We have policies that make undocumented workers ineligible for social services and health care; now legal immigrants are also ineligible. We're trying to facilitate a policy or method to get more of the uninsured covered. If people are talking about how to address the problems of the uninsured, looking at immigration issues is a key factor. If you don't do this, you're really not going to get that far on the matter.

*If people are talking about how to address the problems of the uninsured, looking at immigration issues is a key factor.*

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

The Asian population has very few role models. One was Jane Lin-Fu, who worked in health research in Washington, D.C. Margaret Heckler's 1985 study on minority health acknowledged there was no good data on Asian health, and as a result Asians were identified in that report as being healthier than the rest of the U.S. population. She was essentially saying, "Because we have no data, we assume there are no problems."

Jane Lin-Fu was sort of a hero in my mind, because she knew there was other information out there. Through a lot of personal initiative, she pulled that together and wrote a statement about the status of Asian health and the implications of immigration. This provided a benchmark for all of us.

We were building a primary care health clinic in Oakland around that time. We were dealing with people's presumption that Asians were a "model minority" who took care of themselves even if they were uninsured. We took a gutsy approach and said, "Let's just grapple with what we know to be true based on our experience." A couple of Lin-Fu's publications looking at what she understood, how little data there was, how access was an issue, helped us to do pioneering work to address these issues.

In 1990, we ended up having a public hearing sponsored by our lieutenant governor. We had everybody we knew who had experience serving the Asian population get up and testify. We recorded and published it. It began the process of highlighting what we felt were unmet needs and disparities—thalassemia, hepatitis B, TB, etc. Other Asian researchers around the country began to use it and quote it for their own literature reviews, which began the building of this body of literature. We literally did it on our own.

I grew up in the era of the Civil Rights Movement. This really developed my understanding of the disparities in our society, both in terms of social, economic and political power, and in terms of potential and opportunity. Both kinds of issues framed my early education, in high school and college, and created a desire for a life of community service. Health care became the means by which I carried that out.

In 1976, I had the opportunity to become involved with a clinic. It only had nine staff people and a \$100,000 budget and was directed toward serving the needs of Asians in Oakland. We addressed the basic community issues—language access and the lack of insurance—and built an important model of a multi-language, accessible service. More important, we helped the community advocate for its own health care needs. We were challenging ourselves to go beyond the traditional service model.

Our model says, “The measure of our success is not how many visits we provide, but how much our community understands and asserts its right to health care.” At the time, there were very few services available to Asians who didn’t speak English. If you didn’t speak English and you were uninsured, you were basically out of luck.

Once we got started, we knew that our ability to provide services would be outstripped by the demand. So we knew that it was not only pragmatic, but in the long run better that the community know that under Title 6 of the Civil Rights Act, they had a right to services, to an interpreter or a bilingual provider. We instilled in our community a sense that they could go to the county or federally funded hospitals and ask for and receive service in the language they knew.

*I grew up in the era of the Civil Rights Movement. This developed my understanding of the disparities in our society, both in terms of social, economic and political power, and in terms of potential and opportunity.*

*You have 20 years of experience working at a community grassroots level and fighting for health care access. Can you give us some sense of the historical perspective? How have issues related to health care access for Asian Americans changed over this period?*

When Asian Health Services first started, language access and lack of coverage were the greatest barriers. Today, the fundamental issues are the same. They've just multiplied. In Alameda county, Asians went from 3% of the population in 1970 to 20% in 2000. There are more challenges because of this.

The same issues arise in any urban, immigrant Asian or underserved community. Whether you're talking to Koreans from L.A. or Southeast Asians from San Francisco, language and lack of affordable coverage are the issues identified by the communities.

The basics for our clinic are the same. We've had to struggle to get support for advocacy efforts. The funding comes more easily for direct medical services. But we have this commitment about finding creative funding for advocacy. If you don't make

*If you don't make advocacy a priority, it can get lost, swept away by other issues.*

advocacy a priority, it can get lost, swept away by other issues, and then it's like putting a Band-Aid on, instead of looking for real, fundamental solutions.

For example, we put a lot of effort into our general community meetings through our clinic. In 1976, we had a general meeting and only one patient showed up. Our former director said, "That just shows our patients—immigrants—aren't interested in getting involved in their own health care."

Well, I took my own political orientation and training—being a community activist in a couple of different Asian communities in California—and said, "No, this is really

about finding a way to reach our patients, bring them in, get them involved.” It was a matter of how we were doing it, not whether or not it was worth doing.

So we changed our approach. We did more active outreach. And, in 1977, we had over 100 patients come to our general meeting. Since then, we’ve built on that model. The difference is that it’s all gotten a lot more sophisticated. There are a greater number of distinct Asian populations involved in our community. We’d started mainly with Filipino and Chinese. Then we had Vietnamese and Korean. Now there’s Hmong, Cambodian and a number of other groups.

*This is really about finding a way to reach our patients, bring them in, get them involved.*

At our last annual meeting, we had 500 people attend. We have headsets and simultaneous interpretation, so the issues get shared with the patients in their own language. This gives them respect and involves them in the dialog.

It’s been really exciting. Tom Perez, who was then the head of the Federal Office of Civil Rights, attended. He heard our patients speak about the very basic problems they’ve had. For example, they love coming to the Asian Health Service for primary health care. But when they go to a referred specialist we hear horror story after horror story about people feeling they’d spent their entire day walking over to see a specialist, and then having the provider say, “If you don’t speak English, that’s your problem, and I’m not going to help you,” even though this is against the law.

### *Can you comment on the Disadvantaged Minority Health Improvement Act?*

As early as 1985, it was clear that there was no data on Asian health and virtually no funding for it. In response, we created two national Asian health organizations to bring together the few organizations and individuals around the country addressing Asian health issues: the Asian/Pacific Islander American Health Forum (APIAHF), and the Association of Asian Pacific Community Health Organizations

(AAPCHO). We pooled our data and experience and examined what was not being discussed in the legislature and government health agencies. Basically, there was a minority health bill that ended up being called the Disadvantaged Minority Health Improvement Act. Asians were not specifically mentioned in it. This stemmed from the view that Asians weren't a minority, or weren't disadvantaged.

*We created two national Asian health organizations to bring together the few organizations and individuals around the country addressing Asian health issues.*

AAPCHO and APIAHF worked with Congressman Norman Y. Mineta, who created a separate piece of legislation on Asian health, and ultimately negotiated its inclusion in the Disadvantaged Minority Health Improvement Act.

We ended up doing some of our own research looking at the AAPI morbidity rate, as opposed to the mortality rate. There you're looking at a younger Asian immigrant population. We found a lot more disparities. Many of the national studies had focused on mortality, so this data had not been uncovered.

So the Disadvantaged Minority Health Improvement Act gave us some hooks—a little bit of funding for translation services throughout the country, and research on health issues more specific to Asians/Pacific Islanders—thalassemia, hepatitis B, etc.

Lastly, we've struggled in the political arena to reassert that Asians are a minority. There are many disadvantaged minority populations within the concept "Asian." Asian is, after all, only a political category. People often don't see in that category Koreans, Vietnamese, Laotians, Thai, etc. But if you disaggregate the data, you will uncover large disparities.

As Asians become a much more significant segment of the population, it is important for health policy makers, health providers, educators and students to understand what those disparities are. If there are areas where there are positive health status indicators—where an immigrant group is doing well in some area of health—we

need to explore whether these worsen in subsequent generations. What are those factors? That would also be very instructive.

*Based on both your challenges and opportunities, what lessons do you have to share with others?*

Have the vision and the courage to keep pushing the envelope. When you understand there is a discrepancy between reality and what is understood in the field, you can be an agent to change it, no matter what your role. Even if you are the receptionist at a health facility, if you have one story of someone who is not getting adequate health care, document it.

*Have the vision and the courage to keep pushing the envelope.*

There was a case where the mother of two-year-old twins was being sent back to China without her babies because she got onto Medi-Cal (California's Medicaid program) after welfare reform. Somebody from our clinic's eligibility department documented that case, and we took it to the Office of Civil Rights. It's been quoted in White House discussions. It was used to clarify and limit the interpretation of welfare reform. It shows that no matter where you are in the system, you can make change.

*What kind of leadership is needed now to effectively address Asian-American health disparities?*

I like debunking the idea of leadership as an individual personality trait—that someone just has the charisma, or some inherent leadership skills. Rather, like a health care center, leadership is a collective effort. Leadership means bringing people together—one person as the mouthpiece, the other as the documenter and so on. A sense of collective effort increases individual and collective payoff.

I think health centers are great vehicles for training young people coming into the health care field. They are community-based institutions, accountable to a community

board. They demonstrate that you can have a profound impact on a community. For example, we're doing really interesting things on pedestrian safety. That's a powerful model—to identify this as a health care issue, to say we need to take steps to stop pedestrian injuries and fatalities.

*A sense of collective effort increases individual and collective payoff.*

This is a genuinely local institution, identifying and addressing the needs of the underserved community. It's a great training ground for young people.

Hopefully, some of the local organizations—clinics, public health programs—can begin to see they have a role to play in identifying young people who may have an interest in health care. I was just in Waianae Coast Comprehensive Health Center in Hawai'i, and they have this wonderful community health academy reaching mainly Native Hawaiians. We have to create more vehicles like this for the training and mentoring of young people, to produce a sense of movement for social change.

With help from a Kellogg initiative on public health, we created our own community health academy. I would have liked to see that have been a training ground for people from the emerging communities—Laotians or Cambodians, as well as some of the young people of other Asian communities—to spark interest in health care. They could take first steps toward a public health career. Our academy actually took a little different turn from this, which was also very admirable. But I'd like to explore these other structures. There's too big a gap between Asian health services and the public health schools.

I try to network with many different public health instructors—Marjorie Kagawa-Singer is one. Ninez Ponce, who also teaches at UCLA, has brought in some great new staff people. In hiring and mentoring them, we try to create an environment in which they can become the next leaders.



I think it would be an interesting challenge to have some mechanisms so front-line professionals can synthesize those lessons and participate as mentors more efficiently. It can be a problem when you have someone who is spending all his or her time in the health center running operations. When do these people have time to mentor? We have a very narrow opportunity to reach out to young leadership. We might want to look at ways to bring some of the more seasoned leadership into these mentoring efforts.

I'd like to see more cross-training and cross-mentoring as well—not just Asian to Asian. To be a good leader, you have to really understand your interrelationships with the African-American struggles with infant mortality, for example, or other fundamental disparities. I think we're missing the vehicles to do that. Most sabbaticals and fellowships that reward individuals as long-term leaders do not encourage knowledge exchange. We need to find ways to transfer that knowledge to the next generation.

I was meeting once with a group of people who were running nationally recognized health programs for Asians/Pacific Islanders in the Bay Area. We were all questioning how we could pass on our experience not only as a legacy to our organizations, but more broadly as well. In other ethnic populations, we've sometimes seen that agencies are spread thinner, and their leaders' impact as teachers becomes very individualized. They become Surgeon General or public health officers or something, and the knowledge goes with them. When leaders are promoted to the policy level, there can be a lack of sustaining institutions to bring up that next generation of leaders.

How wonderful it would be if a group of today's leaders could sit down and cross-mentor some of the people we think have the greatest potential to lead the next generation, and do this in an organized and concentrated way. I think this could respond to dilemmas about leadership across all of the different ethnic communities—among Latino, African-American, Native-American, and, of course, Asian-American health organizations.

*We might want to look at ways to bring some of the more seasoned leadership into these mentoring efforts.*

# Understanding the Cultural Framework

**MARJORIE KAGAWA-SINGER**



**MARJORIE KAGAWA-SINGER, PHD, MN, RN**, is an associate professor at the University of California, Los Angeles, School of Public Health and Asian American Studies Center. She has a masters degree in nursing from UCLA School of Nursing and a masters and doctorate in anthropology from UCLA. For the past 30 years, her clinical work and research has been in oncology, focusing on the disparities in physical and mental health care outcomes of ethnic minority populations with cancer, primarily with the Asian-American and Pacific Islander communities.

She serves on multiple local, state and national committees addressing issues of ethnicity and health care, and has published and lectured extensively on issues in cross-cultural health, cancer, pain, grief and bereavement, end-of-life decision making and quality of life. Her current studies related to cancer include intervention studies to promote mammography and cervical cancer screening in Southeast Asian and Pacific Islander women; quality of life; spirituality; and doctor/patient communication with Hispanic, African-American and Asian-American women post-breast-and-cervical cancer. She also focuses her efforts on defining and developing standards of cultural competence in health care.



*What do you think are the most important issues related to health disparities for Asian Americans?*

Visibility is the primary issue. First, we are Americans, and we exist in larger numbers than we did even 20 or 25 years ago. The second issue is a lack of data. Asians are lumped into a group called “Asian Americans or other,” which researchers can’t do much with due to the extreme heterogeneity of our population. A third issue is the lack of political representation. The last is having to dispel the “model-minority” myth. All of those together end up making us invisible in most research areas and limit the collection of relevant data that would enable us to make our issues known.

In terms of political representation, like the old adage says, “If you’re not at the table, you don’t have a voice.” Ethnic minorities across the board experience unequal burdens of disease—we are similar in this respect. But where do the monies get allocated at the local, state and national levels? For Asians, this is reflected in the small numbers of legislators and representatives who can speak knowledgably about the issues in our communities and advocate for our needs.

*Like the old adage says, “If you’re not at the table, you don’t have a voice.”*

Our representatives are hampered because we don’t have the numbers to back up what we know is happening. It becomes a vicious sort of “Catch 22”—we can’t advocate for research monies, so we don’t have the ability to produce the evidence that we need to advocate for necessary resources.

The model-minority myth started in the Civil Rights era. The government used Asians as part of a “divide and conquer” strategy. The movement was demanding more representation, voters’ rights and all of the other issues of the civil rights platform. The government held up Asians as the model of how minorities could succeed in this country without federal assistance if they only tried hard enough. That set us apart from the other ethnic minority groups, both outside the movement and within minority populations, excluding or marginalizing Asians from the

movement to some extent. Many of us participated in those protests—all the advocacy issues—but we were not seen as fully part of that minority coalition. That has continued into health research because we are still seen as not having any health issues.

In the late 1960s and early 1970s, the federal Office of Management and Budget set up racial categories. This came as a direct response to the Civil Rights Movement, to track the allocation of resources to minority communities. These were some of the earliest efforts to address health disparities.

*Fallout from the model minority myth set us back about 15 years in terms of research and building community capacity.*

Asians were excluded from this because of that model minority myth. For example, there were 5% set-asides for ethnic minority research provided by the National Institutes of Health. Asians were not eligible for those monies. This kind of fallout from the model minority myth set us back about 15 years in terms of research and building community capacity, compared with other minority populations.

“Asian and Pacific Islander” is a huge umbrella term, with over 50 different national groups represented. Within that umbrella, if numbers are given at all, they are given in aggregate. This renders the smaller groups invisible. The smaller groups tend to be the newer immigrants, many of whom are facing horrendous economic and social conditions.

Much of this is sequelae to the Vietnam War. The Southeast Asian populations—from Vietnam, Laos and Cambodia, for example, and other more recent refugees from Thailand and Burma—have experienced civil turmoil in their countries of origin. This exacts a cost in terms of the kinds of adjustments people are able to make once they arrive in the United States. We have, for example, Southeast Asian populations with 65% to 75% poverty rates compared with 6% to 8% poverty among the Japanese Americans who’ve been here for four generations. By sheer numbers, when these figures are averaged in, they don’t look so bad.

In the research we're starting to do now, we're getting some informative new numbers. We know, for example, the poverty rates for Asians in Los Angeles are higher than the state average. We've got poverty rates in the 13–16% range, versus 11% for the general population. The numbers are discouraging, but because we are now able to document those disparities, we can also direct our advocacy more effectively.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

They've helped me make these health issues more visible. I started out as a cancer nurse, working at San Francisco General and in L.A. County Hospital. I worked with people I grew up with—Latino and African-American populations. I grew up in Berkeley, and at that time the city was segregated so that Blacks and Asians were only allowed to buy in certain parts of town. So the African-American community was sort of my reference community. I found that what I had been taught in school, in the area of psychosocial support, for example, really didn't fit well. What I learned growing up in those communities was much more helpful. That's when I began noticing ethnic differences in coping styles.

In the mid-1970s the area of psychosocial oncology care was emerging as a professional focus. Asians, African Americans and Hispanics were being labeled as passive and described as not participating in their health care. A lot of pejorative terminology was being used to describe their coping strategies. I thought that was totally wrong and uninformed.

I'd been working for ten years at the bedside, and felt I had a good sense of what cancer did to families. The National Cancer Act had been passed, the National Cancer Institute was formed, and there was a lot of money coming out to fund the "War on Cancer."

*What I learned growing up in those communities was much more helpful. That's when I began noticing ethnic differences in coping styles.*

I wanted to participate in informing the direction of that research. I was working for the American Cancer Society at that time, and felt I came to these research questions as a representative of patients. But I was told that since I only had my masters, I wasn't qualified to do this.

*I began to study medical anthropology in the early 1980s to try to figure out how to capture cultural differences in coping with cancer.*

So I got thoroughly ticked off, and said, "OK. If I need a ticket to sit at this table, then I'll go get my ticket." That's why I went back to school. I began to study medical anthropology in the early 1980s to try to figure out how to capture cultural differences in coping with cancer.

I was doing my dissertation in 1982 on the influence of culture on coping with cancer. I found there was absolutely nothing in the literature about this. That really frightened me. I thought, "Somebody must have looked at this." That was my awakening of how silent ethnic minorities were in research—especially in the social sciences. That launched my path in the work I do—teaching, community work, research—trying to give voice to the health needs of ethnic minority communities, particularly Asian Americans.

It was also the early days of "quality of life research." The research tools included physical, mental and social domains. This was in about 1983. I looked at all the measures that were available and wondered, "What about spirituality?" My patients invariably told me that spirituality was what got them through the experience of cancer. And I thought, "Why aren't people listening to the patients? Why is the only focus on the cognitive ways people are coping?"

When people demonstrated a so-called passive attitude, this was said to be negative because you were supposed to "fight" the cancer. That's when visualization and those kinds of strategies were coming to the fore. People would visualize the good white cells eating the cancer cells, or killing them, like in a video game. This was a very war-like mentality—the "war" on cancer being part of the terminology. The American Cancer

Society where I worked utilized military terminology. We had the national “headquarters”; we had the state “divisions”; we had local “units”—they were all military terms. It was a very aggressive response to cancer, or any disease for that matter.

For Asians you can use a different metaphor. The title of my dissertation became “Oak and Bamboo.” I wanted to show some of the different cultural idioms of a world view—the diversity of these. I also wanted to show that different behavioral responses to illness could be considered normal and healthy. Bamboo is an extremely strong plant, but it bends—whereas oak doesn’t. Oak represents a very different behavioral response to illness. Bamboo bends with the wind but when the storm is over it rises again. The researchers and practitioners didn’t understand the cultural framework in which people’s responses are expressed.

I worked with a researcher named Jerome Cohen who was one of the early pioneers of psychosocial cancer care. I did a review of 1,200 psychosocial oncology articles. All of them looked at the 25% of patients who were having major difficulties getting through the cancer experience. The other 75% who seemed to be getting through pretty well on their own weren’t being looked at. Those were the patients I was interested in. They would help us understand more about successful coping strategies than looking at the 25% who didn’t have sufficient resources and trying to figure out what those resources should be.

The more mainstream approach has been to look at the negative, to look at what’s broken and try to fix it. I think that reflects a different cultural perspective on problem solving. I’ve tried to turn that perspective on its head in my research. I wanted to look at the ways mainstream research labeled—or mislabeled—groups that were culturally distinct from the dominant research community.

*Cultures are designed to help people survive and thrive, to give some meaning to life.*

Every culture that exists in this world has existed for thousands of years. Cultures are designed to help people survive and thrive, to give some meaning to life, to give a purpose, a reason to get up in the morning and face each day. And, yet, the Euro-

American perspective tells us there's only one right way—and that we have to teach everyone else how to do it—rather than looking at the resiliency of diverse cultural groups and realizing that there could be hundreds of different ways to do it “right.” If we could just honor those cultures, figure out how we could learn from them, the best way to address these issues, I think that would enrich everyone's experience.

*Through research, I can be a sort of mirror, reflecting the different perspectives and trying to empower both communities.*

Being raised Buddhist was a different experience than being raised in a Judeo-Christian world in the United States. I had a different perspective, and always felt like an outsider. I was talking with a colleague and friend of mine, and we were laughing about the fact that we were sort of professionalising our outsider status, because an anthropologist is always on the outside, being an observer of activity rather than being at the center of it. But formalizing those skills of observation, through research, I can be a sort of mirror, reflecting the different perspectives and trying to empower both communities.

For example, there are different ways of framing the issues for research design and methodology. An area that's considered relatively new in some research circles is Participatory Action Research in which you actually involve the community as a partner. The research design is based on genuine community and the findings that emerge from the collaboration can be more easily applied and utilized.

*Based on both the challenges and opportunities in your experience, what lessons do you have to share with others?*

When I started twenty years ago, there were only a handful of Asian Americans doing work like this—people such as Harry Kitano and Stanley Sue. You could probably count them on two hands. Now I go to conferences and there are literally a couple of hundred researchers.



As an example of how this has changed things, the California Health Interview Survey (CHIS), led by Rick Brown and Ninez Ponce, is the first population-based survey that's been done with an over-sample of Asian Americans/Pacific Islanders surveyed in their languages. The national surveys have never over-sampled Asian Americans or administered the survey in AAPI languages. Because they don't over-sample, their numbers are too small for analysis. So the data is deleted from the analysis, or they aggregate the data. They administer the surveys in English, so they don't even gather data from many individuals in communities where over 70% of the population is monolingual. So the CHIS expressly over-sampled Asians in six different languages. We now have, for the very first time in our history, representative numbers of some Asians in a national health database.

The California Health Interview Survey principals have held ethnic information conferences for African Americans, Latinos and Asians. Dr. Brown mentioned to me at the Asian conference that this was the largest number of researchers who had attended any of the gatherings. "That must be because you have the largest number of PhDs," he said.

I said, "That's absolutely wrong!"

He said, "Then why are there so many Asian researchers here at the conference?"

I told him, "Because who you see here is all we've got. This is our entire body of Asian researchers. This is our first opportunity to have representative data in subpopulations of particular Asian groups."

I told him, "Look around and see all the young researchers here. Ten years ago few of them could have done their work in Asian-American health because there was no data. They could not stake an academic career on their own community because there was no data, and they would have done their work on Latino or African-American health or other mainstream health issues."

*To see young researchers able to do what we couldn't is really exciting. They can just take off now.*

The CHIS survey is the first to give them data from their own community that's rigorous enough to be recognized in professional journals. When I was young, we worked with small sample sizes. That's all we could get. To see young researchers able to do what we couldn't is really exciting—their energy, their intelligence. They can just take off now.

*What kind of leadership is needed to effectively address Asian-American health disparities?*

*When we do our health education outreach, it's often the first time community members realize there's a problem.*

The role models are really important. As I mentioned, we had very few until recently. Part of it is just getting the word out. The model-minority myth works both ways. Mainstream researchers and policy makers don't see numbers, so they think there's no problem. Then the other side is that the community doesn't see leadership or numbers reflective of their community, so they think there isn't any problem. When we do our health education outreach, it's often the first time community members realize there's a problem. For example, I do work on breast cancer. My mother said to me, "Why are you focusing on breast cancer? Asian women don't get breast cancer."

And I said, "Well, what about...," and I named five of her friends, all of whom had died of breast cancer.

She said, "Oh my gosh. I guess you're right."

Susan Shinagawa was the first Asian-American woman who came out publicly and said that she had breast cancer. She was young, in her early 30s when she was diagnosed. Prior to her biopsy, her surgeon told her, "You're too young and you're Asian, so you don't have breast cancer." About two years ago we had a forum of breast cancer survivors—one in Los Angeles and one in the Bay Area. Of those dozen women, probably ten of them diagnosed within the prior one to four years said that their surgeons told them that they couldn't get breast cancer because they were Asian.

We need the data, and we need the advocates like Susan. We have many more young women coming forth. For example, here on the UCLA campus we have the oldest Asian-American sorority on campus. The young women in this program want to use breast cancer as the focal point of their fundraiser. Even on the undergraduate level, the word is getting out.

There are more people interested in health education in the community. They see what's happening to their families and they want to make things better. So we're getting UCLA students from different majors coming forth to be activists in the community. We have more Asians who are now professionals in community-based organizations, or at the local, state and federal level. They are now at the table, advocating so that we aren't overlooked and underserved to the degree that we have been over the last 100 years.

Economics is a large part of it. For example, the Korean community has the lowest level of insurance. But they also have the largest number of small business owners. Many are family-owned businesses. They don't have the money for insurance—nor is it a familiar concept to them, coming from a country with socialized medicine. So those kinds of issues require advocacy in the economic, employment and labor arenas.

Because health overlaps with these issues, the President's Initiative on Asian-American/Pacific Islander Health was placed within the Department of Health and Human Services. It involves all the federal agencies that impact health, such as the Departments of Labor and of Transportation. Health needs were recognized as a broad-based issue.

*What is your vision and hope for the future?*

One major need is having us recognized as Americans. There is a sense by many people here that Asians still aren't Americans, but foreigners. When Michelle Kwan skated in the 1998 Nagano Olympics, she was favored to win the gold. As it turns out, she

*One major need is having us recognized as Americans.*

took the silver. There was a major news headline after the event that said, “American beats Kwan for gold.” Michelle Kwan was born in Torrance, California. She is an American! As Americans we must be counted. We must be disaggregated so we can look at and identify high-risk populations. We must have representation at all levels and at every table. We need resources and programs to address the needs in our communities. We’re building that now, but we’ve got a ways to go.

*I feel I can make an impact in the research realm.*

For Asian Americans and ethnic minorities in general, research models must be more inclusive of different ways of coping with disease and illness. There are many right ways to do things, and currently the perspective is too narrow. Here’s a good example.

Spirituality is now being included in many of the quality of life scales used with patients. However, the scales may not identify spiritual elements that differ from the views of the dominant culture. In one measure, there are ten questions, and eight of them mention God. As a Buddhist, I’m not going to score very high on that scale. God isn’t part of the Buddhist perspective. But that doesn’t mean that I don’t have a very strong spiritual orientation. It’s just not related to Christian concepts. We know that the majority of scales tend to be monocultural. So those have to be changed. I feel I can make an impact in the research realm.

We have people who are developing the advocacy and leadership that we need on the community side. And I feel that I can do this within the walls of academia, making it known that the current research approaches will never address the health disparities until they’re made more relevant to the communities.

# A Passion for Public Health

**HOWARD K. KOH**



**HOWARD K. KOH, MD, MPH**, served as Commissioner of Public Health for the Commonwealth of Massachusetts from 1997 to 2003. As commissioner, he presided over the Massachusetts Department of Public Health. He is now Associate Dean for Public Health Practice and professor of health policy and management at the Harvard School of Public Health in Boston.

A noted cancer and public health specialist, he previously served as director of cancer prevention and control at Boston University Medical Center and professor of dermatology, medicine and public health at Boston University Schools of Medicine and Public Health. A graduate of Yale College and the Yale University School of Medicine, he trained at Boston City Hospital and Massachusetts General Hospital. He has board certification in four medical fields (internal medicine, hematology, medical oncology and dermatology) as well as a Masters of Public Health degree from Boston University School of Public Health.

He has been recognized for his past leadership of the Massachusetts Coalition for a Healthy Future, which pushed for the Commonwealth's groundbreaking tobacco control initiative. He has published over 200 articles and is nationally known in the areas of cancer prevention, tobacco control, Asian-American health issues and skin oncology. He received the 1999 national Distinguished Service Award from the American Cancer Society, and, in 2000, was appointed by President Bill Clinton to a term on the National Cancer Advisory Board.



*What do you think are the most important issues relating to health disparities for Asian Americans?*

There are so many. Most Asian Americans were born overseas and do not have English as their first language, so the linguistic barriers can be substantial. There are obviously cultural issues as well. There are challenges in terms of whether people accept and understand American medical systems and American medicine, as opposed to traditional ways of healing. Tobacco is a tremendous challenge because cigarette smoking is very much a part of the Asian male culture, having infiltrated the entire Asian society. There are also studies that show cancer screening rates for Asian-American women are generally lower than the rest of the population—particularly Pap smears, but also mammography.

*One of the challenges with Asian Americans is that they are such a heterogeneous group.*

I'm just finishing five and a half years as Commissioner of Public Health for Massachusetts. I'm the first Asian-American health commissioner for our state and one of less than ten in the history of our country. So it's an honor to use that different perspective to try to serve all people.

One of the challenges with Asian Americans is that they are such a heterogeneous group. Also there's a huge difference between Asian Americans born overseas and someone, like myself, who was born in this country and speaks English as a first language.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

My parents are heroes to me. They were born in Korea and immigrated here as graduate students. They journeyed to this country searching for the American dream. They sacrificed, moving their family, so my brothers and sisters and I could pursue that dream too. Education is very important to everybody in my family. Also the

sense of serving the public is very important to my parents and therefore to my entire family. What led me to the commissioner post was the strong commitment to service to society that my parents instilled in us.

Another wonderful figure in my life is Reverend William Sloane Coffin. He is a former chaplain at Yale, where I attended college and medical school, and internationally known in the area of human rights, peace and antiwar activities. He sent a message, as chaplain and minister, about the importance of the dignity of each human being, and the responsibility of government leaders like myself to protect all people.

That's something that I've tried to live by as commissioner. As a Korean-American commissioner, I could stand up before many groups who ordinarily would feel disenfranchised and tell them that health commissioners and government leaders should care for all people regardless of ethnicity or place of birth, regardless of disability or social class. Those are some critical issues for me.

My new title will be Associate Dean for Public Health Practice and Professor of Health Policy and Management at the Harvard School of Public Health. Eliminating health disparities is one of the major goals of our division. It's a part of my life's work regardless of where I am.

*Could you describe more about the specific work you have done to promote health among Asian Americans?*

As health commissioner, I did my best to keep the issue alive through public appearances, speeches and discussions on major public health issues. I kept stressing that we have an increasingly diverse society and that an effective health system cares for all people.

I toured all the health facilities in the state that served Asian Americans and met with community groups. During my tenure, I helped implement a law requiring medical

*My parents are heroes to me. They journeyed to this country searching for the American dream.*

*I kept stressing that we have an increasingly diverse society and that an effective health system cares for all people.*

interpreter services in all Massachusetts emergency rooms. I think that was a major step forward. We also had special outreach in Asian languages aimed at prevention.

We had special initiatives for tobacco—particularly in Boston’s Chinatown. We even had a project for Chinese restaurant workers. I remember with pride hosting a ceremony for Chinese restaurant workers who quit smoking. We launched—I think it was the first—Asian-American advisory committee to the American Cancer Society in New England. I’m very proud of that.

I’ve also been working with Rod Lew and Dr. Moon Chen on a whole range of cancer-control issues. We hosted the first-ever national Korean-American cancer control academy last year. That was a great meeting. I never thought we’d have a meeting dedicated specifically to Korean-American cancer issues. We’re publishing a monograph on that. Korean Americans are celebrating the centennial of their arrival in the United States this month. So Korean Americans are a fairly young breed.

We need both broad themes and specific initiatives, such as the Asian American Network for Cancer Awareness, Research and Training (AANCART). Dr. Moon Chen is the principal investigator for that initiative. I’ve helped advise that effort as it has moved forward. Dr. Chen founded the first public health journal dedicated to Asian-American and Pacific-Islander health needs—the *Asian American and Pacific Islander Journal of Health*. I am proud to serve as the chair of the Board of Editors.

We had some very dedicated medical and public health students promoting hepatitis B vaccinations for high-risk immigrant groups. I was proud to support that effort as commissioner too.

We have a growing effort in domestic violence prevention in Asian-American communities. There’s an Asian-American domestic violence task force building strength here in Massachusetts.



*Can you describe some of the things you hope to be able to do through this move to Harvard?*

Harvard is dedicated to advancing the health of people around the country and the world. I'm hoping to take some of the experience I've had at the state level and use it to connect with students from all over the world. As the Associate Dean for Public Health Practice, I'll also be helping to educate the next generation of public health professionals. I want to make sure all of them have the issues of diversity and disparities as top priorities.

*Based on both the challenges and opportunities in your experience, what lessons do you have to share with others?*

To make a difference and leave a legacy, a person must understand how government works, how policy is made and how to bring issues to the attention of the public. Keeping all these issues alive is critically important, and to do that you need a broad, interdisciplinary education and training. That's what public health is all about. That's why I love the work I'm doing. It's just endlessly fascinating.

*I love the work I'm doing. It's just endlessly fascinating.*

I have found, as a physician, that some of the best and most effective public health practitioners have no formal training in health care. They know how government and the media work. They're outstanding at fundraising and advocacy. They know how the political system works.

*What kind of leadership is needed now to effectively address Asian-American health disparities?*

The ability to communicate succinctly and the ability to inspire with communication is something that we always need. We also need to develop a critical mass of activists.

I think we've done that within the Asian-American community within the last few years. Fifteen or twenty years ago there was only a rudimentary Asian-American public health movement—now we have a vibrant, growing one. I mentioned some of the leaders such as Dr. Chen and Rod Lew. We have built a nationwide movement and we are developing a critical mass. Some of the efforts such as AANCART were a result of funding support from the National Cancer Institute. Groups like the American Cancer Society have dedicated Asian-American divisions and advisory groups. Part of leadership is perseverance. We're starting to see tremendous progress because people didn't give up.

*If you can pinpoint your passion and tap into it, that's a huge step forward.*

*Can you provide any suggestions for other professionals in terms of mentoring or encouraging students?*

There's a wonderful phrase I heard of "pinpointing your passion." If you can pinpoint your passion and tap into it, that's a huge step forward. It's also important to keep your goals high and broad but not get discouraged. Be in it for the long run. Next, learn from the people you admire. Building a group of colleagues who work well together is also very important.

*What is your vision and hope for the future? What is one thing you'd most like to see happen related to the issue of health disparities among Asian Americans?*

A huge contribution to eliminating disparities would be for society to reaffirm its dedication to the health of all people, regardless of ethnic background or place of origin. That involves overcoming linguistic and cultural barriers that face so many people who adopt this country as their home.

Particularly with respect to tobacco—I have a real passion for that—denormalizing that addiction for Asian cultures is critically important. We have started to do that

in this country but we've been less successful in Asia itself. Since the whole world is getting smaller, public health has to have an international scope to successfully address the issue of tobacco addiction.

Making the American medical system one that can be trusted by all ethnicities, social classes and countries of origin is very important. And then there are specific issues in terms of outreach, insurance, primary care and language.

*Can you comment on trust in the American medical system?*

One of my many responsibilities as commissioner was overseeing quality of care in long-term care facilities—nursing homes. It's always struck me how different American attitudes toward the elderly are compared to Asian ones. An elderly person in Asia is revered and adored. In this country, elders are often not treated that way and not respected for their life experience and wisdom. If you're an older Asian immigrant in this society, chances are you aren't going to receive the respect from the American medical system that you would if you were still in Asia. That's one concrete challenge that has struck me time and again—the health care for the elderly here as compared to that in Asia.

*Anything else?*

One of the major challenges—and we are making progress—is reliable data collection and analysis for Asian Americans. For years there was no data. The message was, "There is no data, therefore there is no problem." Obviously that is not the case. We need more of a commitment to collecting racial- and ethnic-specific data—and making sure that state and national organizations are producing it. Sometimes that data has to be collected in languages other than English to make sure it's accurate.

*Since the whole world is getting smaller, public health has to have an international scope to successfully address the issue of tobacco addiction.*

That's a big commitment of time and resources, and a challenge in these times when resources are limited.

On a very positive note, until about 20 years ago the theme was, "There are too few Asian Americans and then there's no data, so we can't really address any of the issues for this population." As we move into the twenty-first century, we have developed a critical mass. There's information on specific ethnicities—such as Korean Americans, and even Pacific Islanders, which is a very small group.

*There's so much progress to share now. It's a very, very exciting time.*

The new age of information sharing—e-mail and conference calls, etc.—has helped tremendously. There's so much progress to share now. It's a very, very exciting time and I think it's only going to keep improving despite the challenges of our times.

# Leadership & Empowerment

**ROD LEW**



**ROD LEW, MPH**, has over 16 years of experience in developing and leading diverse community and international health programs. His experience and skills include community-based research and advocacy, coalition and network development, program implementation, strategic planning and multimedia materials development. He holds an MPH from the University of California, Los Angeles.

For the past 9 years, he has been the Director of the Asian Pacific Partners for Empowerment and Leadership (APPEAL), a national social justice network with a focus on tobacco control. He is a frequent speaker on tobacco and disparities at regional and national conferences and was a contributing author to the Surgeon General's Report on Tobacco Use Among U.S. Racial/Ethnic Minority Groups.

In 2000, he was appointed to California's Tobacco Education and Research Oversight Committee. He serves on the board of directors of Education, Training and Research (ETR) Associates, and was the chair of the Asian Pacific Islander Caucus affiliated with the American Public Health Association from 1998 to 2000. In 2002, he was the recipient of the Christopher N.H. Jenkins Cancer Control Award.

He has his own video production company and has written and produced numerous community educational videos and tobacco control advertisements. He is currently working on a documentary on the impact of tobacco on communities of color.



*What do you think are the most important issues related to health disparities for Asian Americans?*

First of all, the issue of health disparities is a complex issue, particularly for such a diverse group. There are many different ways to look at disparities for Asian Americans. You can look at morbidity and mortality and the five top causes of death, which brings about a focus on cardiovascular disease and cancer. You can look at the lifestyle behaviors that result in those diseases, such as tobacco use, diet and lack of physical activity. You can look at diseases such as hepatitis B that affect Asian Americans and Pacific Islanders more than other groups, or at health issues such as HIV/AIDS and mental health that carry a tremendous amount of stigma in the community.

But you can also look at the underlying core issues. Those include things such as lack of access to health care, or cultural and language access, and institutional issues such as lack of infrastructure and discrimination. A recent Institute of Medicine study found that disparities among communities of color go beyond even lack of health insurance and income status.

*Institutional differences, discrimination and subtle racism may be responsible for disparities in health care quality.*

There may be disparities resulting from cultural misunderstandings or challenges in communication between provider and patient. The report suggests that institutional differences, discrimination and subtle racism may be responsible for disparities in health care quality. How this happens and what to do about it should be the focus of our attention on disparities.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

There are many individuals and organizations that have been influential in the development of my professional life. First of all, my parents instilled in me the values

of taking care of family and also giving back to others. This wasn't conveyed directly, but it was something that was expressed by the way they lived their lives and communicated with us. My sister, Candace Lew, has also been a role model for me with her commitment to health as an ob/gyn. She has been recognized as one of the top doctors in Arizona but has always been a person of great humility. The way that she's balanced her work and family life well has provided inspiration and guidance for my own.

Professionally, I've learned many things through involvement with activism in the Asian-American community—not just in terms of health issues, but in political and social issues as well. During the early 1980s, I was president of the Asian Student Union at Humboldt State University and we organized activities to educate others about Asian Americans. Over the years, I've been involved with anti-nuclear and peace protests as well as in using various media—writing for a newspaper and producing videos—to highlight certain health and social justice issues. These activities were very important in developing a sense of belonging to the Asian-American community and working on behalf of that community.

I've also learned a great deal from traveling all over the world—recognizing the diversity but also becoming aware of some of our commonalities even though we speak different languages and have different cultures. We want similar things such as food, quality health care and family.

When I first started working in the community here in Oakland in 1989 my first job was at Asian Health Services (AHS). This organization has been the birthplace of many exciting and important efforts to address health care in the Bay Area and I credit AHS for providing me an education on community health that I didn't get in school. I worked with several folks there who've inspired me and who helped guide me early on as a public health professional. I have been amazed at those who have worked for a long time in the community, particularly the support staff, who have become the direct link with the communities.

One person in particular who has been an important influence is Dr. Art Chen. He has an incredible way of building trust with community members and leaders. He showed me how to involve community in a community-sensitive and meaningful

*Particularly in leadership positions and as peers, it's critical for us to help guide, support and sustain each other.*

way, particularly in research studies. He has taught me to challenge myself and, over the years, has provided a tremendous amount of support and guidance.

In the past several years, I've worked very closely with a growing number of colleagues in the AAPI community for whom I have great respect. Sora Park Tanjasiri, JoAnn Tsark, Bobbie Benavente, Elaine Ishihara and Mary Anne Foo, just to name a few. I respect their deep passion, compassion and understanding of what it takes to be successful in community health—it's a lifetime commitment for them that they balance with their family lives. Working in diverse communities can be challenging. Particularly in leadership positions and as peers, it's critical for us to help guide, support and sustain each other. They and others have been the sustaining force for me.

*You're doing specific work now in tobacco control and other areas. Can you talk about some of the work you're doing to promote better health among Asian Americans?*

I'm currently the director of the Asian Pacific Partners for Empowerment and Leadership (APPEAL). It's a national social justice network for AAPIs on tobacco control. We founded APPEAL in 1994 when I was still at Asian Health Services, and have developed it into a successful network with the dedication and commitment of the staff, advisory committee and the fellows who have gone through our leadership program and the youth leadership program.

Many of us have known that tobacco has become a major problem in the AAPI community. But tobacco has not been a high-priority issue for community organizations, partly because there are so many other critical health issues to address.



In California, there was a greater level of involvement in tobacco control in the AAPI community, but outside California there were basically no efforts being made. Funding was a key. But in the beginning, we asked “How do we get tobacco to be more relevant for AAPI communities?”

Through APPEAL, we pulled together individuals from all parts of the country and began to focus on five different priority areas: network development, capacity building, education, advocacy and leadership development. Today, we have over 300 members. We’ve had many successes over the years, increasing awareness of tobacco’s impact on the AAPI community, as well as advocating for greater resources and understanding of our issues by the mainstream tobacco control community and policymakers.

One of the great challenges in addressing tobacco, different perhaps than other issues, has been the role the tobacco industry has played in convincing many of our community members to use tobacco products and how it has bought its legitimacy by providing money to key community organizations. Marketing to minorities is something that’s been talked about a lot, but there hasn’t been a good recognition of the ways the AAPI community has been targeted specifically by the tobacco industry. We recently released an article using the secret tobacco industry documents in Minnesota to demonstrate that there was a conscious effort to reach the AAPI community during the late 1980s and 1990s. It requires a different type of leadership to respond to the tobacco industry and what they’re doing, both in our communities here and also globally. This challenge of countering some of the wealthiest multinational tobacco corporations that are targeting our communities with their deadly products has led us to frame tobacco control not only as a health issue but as a social justice issue as well.

*One of the great challenges has been the role the tobacco industry has played in convincing many of our community members to use tobacco products.*

At APPEAL, we’ve attempted to address disparity and parity issues overall in the field of tobacco and tobacco control. That involves not only the AAPI community but the African-American, Native-American and Latino communities, and also the gay,

lesbian, bisexual, transgender communities, and communities with lower socioeconomic status. These communities have faced the brunt of disparities, particularly with tobacco.

*We've focused much of our efforts on community capacity building.*

We've focused much of our efforts on community capacity building. Communities are at different stages of readiness to respond to different health issues and needs. Tobacco is a clear example of that. When we start working with communities around tobacco or some other health issue, it's important to know their readiness to respond. And then to interact with them and provide them resources on that level. We shouldn't expect that, even with funding, all of a sudden they're going to be able to eliminate that particular disparity. Developing capacity within the community is something that takes time. A lot of pressure is on the community to respond to the issue, to take care of the problem. But the responsibility is a shared responsibility. We have to look closely at the mainstream organizations such as health departments, who have the responsibility of serving all communities, to provide equity in funding and resources for tobacco control.

The issues around parity involve applying what you're talking about to the way that you run your organization. For example, how many people in your organization or on your board of directors are from those communities and represent those communities? How much are those communities involved with the strategic-planning processes or decision-making processes that could ultimately have an impact on resources or program focus? Those are the things we are beginning to do within the field of tobacco control—something which hopefully can translate to other fields.

At our most recent National Conference on Tobacco and Health we were able to get issues of parity and disparities onto the main agenda as the theme of the conference. As a result, our opening plenary session and the conference itself was dedicated to addressing this issue specifically. It was a very strategic and important step for us to take within the field of tobacco control. Similar efforts have been made in a few other

health areas such as HIV/AIDS. We would like to see these steps replicated in regard to many other health and community issues.

*So disparities are focused on differences. When you talk about parity issues, you're really talking about bringing a better balance to disease prevention and health promotion perspectives.*

Yes, but it's more than that. When we talk about parity, we're talking about equity in health. A lot of times we focus on what is lacking in the different communities rather than what we want to achieve. Parity is a way of focusing on what we would like to see, as a positive vision for the future. We need to be more inclusive of diverse communities in the process so that we can achieve equity in health. It's a way of bringing us all together to achieve a common vision.

*Parity is a way of focusing on what we would like to see, as a positive vision for the future.*

*What are some lessons you have to share with others?*

One of the important lessons is the building of relationships and the building of trust. It's something that I believe needs to be at the core of much of the work we do in public health, much of the work that needs to be done in diverse communities. It's difficult to do. It requires a lot of time, working collaboratively and identifying individuals who can bridge the gaps in relationships within the community and with the broader community. It's absolutely vital to do these things for us to be able to move toward achieving parity. Because it takes time, it's really important that the time we invest now can lead toward building important relationships. As I said before, it's not only important for the outcome, but also for the process.

Trust develops from positive experiences and outcomes, and from recognizing that people are true to their words. If you say something is going to happen, then it needs to happen. If something doesn't happen, then the community begins not to trust.

Here's an example. Several years ago when APPEAL began, there were very few national AAPI organizations working with the six U.S.-associated Pacific Island

jurisdictions (American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, Guam, Republic of the Marshall Islands and Republic of Palau). These jurisdictions had often been included in the AAPI category but were not often included in activities and programs organized by AAPIs in the continental United States. These jurisdictions would receive visitors from the United States, but I think that there was a lack of trust, much less relationship, because U.S. programs had not generally been responsive to Pacific Islander issues. Recognizing this, I paid for travel out-of-pocket to go to the Pacific and learn from meeting with various communities in the jurisdictions. And when we launched many of our APPEAL activities, we made great efforts to involve Pacific Islanders in our leadership summits and tobacco control activities. There's so much we can learn from each other. I've felt good about developing our relationship with the Pacific, even though I think we need to continue to be more inclusive.

*What kind of leadership is needed now to effectively address Asian-American health disparities?*

Through APPEAL we've developed a leadership program. We've actually had two cycles of the program so far, and it's been very successful in terms of bringing together people from different AAPI communities across the country. Our program believes that many individuals have the potential to be leaders. There are many different types

*There are many different types of leaders and many different roles leaders can take.*

of leaders and many different roles leaders can take. We believe in the ability of individuals to take what they have innately and use it to become excellent advocates around tobacco or other health issues. So we provide them an opportunity to share their experiences, develop some skills, and then go back into their local communities and increase awareness and advocacy around tobacco control for AAPIs.

Our goal is to nurture individuals who can help mobilize communities against tobacco. But, ultimately, our goal is also empowerment, to help individuals be agents of social change. I know it's a term that's sometimes overused, but *empowerment*

describes well our goal of enabling individuals or communities to influence or direct their own futures. And it's also important to create community empowerment.

This has really created successes. Many leadership fellows launched tobacco control activities in their communities where there had been nothing before. We saw the building of tobacco control coalitions for AAPIs in places such as the Pacific Northwest through the efforts of some of the fellows. We saw policy changes such as the passing of clean indoor air legislation in Guam when a couple of senators participated in our leadership program. And we can visibly see the difference in terms of a movement growing within the AAPI community and a growing recognition by the general public about tobacco's impact on AAPIs.

*Who were the people who were invited to participate in your leadership program?*

Our goal was to be as inclusive as possible and recruit leadership participants who represented diverse communities—ethnically and geographically. We also wanted fellows from different professions and fields. We believe that as long as you have the ability or potential to mobilize community members or promote tobacco control in the community, you're an excellent candidate for the leadership program. As a result, we had people who were new to community work and people who had worked in communities for more than twenty years. We involved youth in the program and now have a youth leadership program.

It was interesting when we brought people together. You could see the diversity of the community represented and the tremendous experience and leadership potential in the room. It helped them to think more about competency skill areas such as collaboration. How they perceived working with other community members also changed. In some cases it was very dramatic. Some people were very used to a hierarchy in their work. As a result of participation in our program, they began to realize the contributions of many

*Our goal was to help create community mobilization, change and empowerment.*

different individuals on many different levels. But, again, our goal was to help create community mobilization, change and empowerment.

*Some people worry that there is a lack of leadership, particularly at the national level, in the Asian-American community.*

I think very differently about this. Our leaders may not get as much attention as leaders in other communities, but I think we are moving in the right direction. Our community is diverse. Some are from countries in Asia that have historically been at war with each other. So it's a challenge. But we are identifying opportunities to work collaboratively among the different ethnic groups, as well as between AAPIs and other communities. I think that's an important lesson, because we alone do not have as much political power as we do when we work collaboratively with others. It then becomes a collaborative or collective leadership.

There may still be a perception that Asian Americans are not in visible leadership positions. In some ways that's true, because not that many are hired in leadership positions in national political office for example. But it's not because there's a lack of qualified Asian Americans or those with leadership experience and potential. We're making progress, but we still need to push to become more visible in the news and popular media, and to increase the leadership opportunities nationally.

*What is your vision and hope for the future? What is it you want to see happen?*

It would be great to get to a point where we have a clear plan on how we're going to address disparities in the Asian-American community and see actual changes in health outcomes and community infrastructure and capacity. In some ways the initiative that was developed into a presidential executive order helped outline those areas. But I'd like to see a clear timeline, resources allocated for the effort, and actual steps taken to eliminate disparities and move toward parity. One of the key elements to make this happen is better health data. Again, that's something that's been

improving. We also need more data on disparities themselves, the causes of disparities and how to eliminate disparities. But data needs to go beyond just being collected—it has to be used to guide program development and policy implementation.

### *Anything you want to add?*

One other thing is the importance of history. We need to recognize the history of our communities, how we've gotten where we are, and the people who've been involved in that. The Asian-American community has had a tremendously diverse history. It's important to note who helped us achieve what we have so far around health and community issues. We also need to recognize those in the Civil Rights Movement of the sixties and seventies. That movement helped us learn to respond more politically. A large debt of gratitude goes to leaders and communities such as the African-American and Latino communities who have helped to pave the way. We are building upon what has come before.

Another thing is to recognize the importance of integrating international health and other issues into the health disparities work that we do with Asian Americans. Since a large percentage of Asian Americans are born in Asia, already there is a strong connection with other parts of the world. We are becoming a global community that sometimes requires local action but at other times requires international collaboration and global action. Again, tobacco is a prime example of a health-disparity issue for Asian Americans that must also be addressed globally.

One last thing is that we can talk about eliminating disparities and achieving parity for a long time. But until we actually operationalize the plan and take concrete steps toward making parity a reality, it will just be talk. There are some hard decisions, difficult choices and courageous actions that leaders in policy positions and in our community must make and take before we will see fruition, the end result of community empowerment and social change. I think of what Mahatma Gandhi said—"Be the change you want to see."

*Data needs to go beyond just being collected—it has to be used to guide program development and policy implementation.*

# Translating Tradition & Experience into Health

THOA NGUYEN



**THOA NGUYEN** is project director of the “Health Is Gold” Vietnamese Community Health Promotion Project at the University of California, San Francisco; coordinator of the project “REACHing Vietnamese Women: A Community Model for Promoting Cervical Cancer Screening”; and regional community director of the Asian American Network for Cancer Awareness, Research and Training (AANCART). She has over 30 years experience in the health field.

Throughout her career, she has promoted issues of access, service and equity to health care. She serves on the boards of directors and advisors of various organizations such as the American Cancer Society, Association of Asian Pacific Community Health Organizations, Asian Health Services, National Asian American and Pacific Islander Cancer Survivors and Advocacy Network, Asian Cancer Coalition, Vanguard Foundation, Komen Foundation, the Breast Cancer Early Detection Program for the State of California Department of Health Services, and Asian Immigrant Women Advocate.

She has received national and local awards for her work in the community. In 2000, she received a “New Horizons” award as one of 25 Vietnamese Americans from 1975 to 2000 who have made significant contributions to the San Francisco community.





*What are some of the most important issues for Asian Americans, and specifically Vietnamese Americans?*

I think the most important issue is for people to have language access. The government says translators must be provided, but so far, in reality, this isn't what happens. The great majority of Vietnamese families in the United States came around 1975—we are the first generation of Vietnamese here. And access to health is really a very big need in our community.

*I think the most important issue is for people to have language access.*

Preventive care is a new concept in our community, too. Growing up in Vietnam, we didn't go to the doctor unless we were really sick. If we had a stomach ache, our mom gave us some herbal medicine—maybe some ginger. We never went to a doctor when we weren't sick. When I was completely grown, I had still never been to a doctor. In Vietnam, the conditions in hospitals were poor. To go to the hospital was very serious. The hospital culture there is different. If you stay in the hospital, you have to have your family go too, to take care of you.

So, here in the United States, even if people have a cold or flu they still have a sense that this is a serious undertaking. They expect the doctor to give them something to cure their illness, a strong medication such as an antibiotic.

In Vietnam, the older generation really loves to use antibiotics when they're sick. They take the antibiotic until they feel better, and then they stop the medication. They might take only one or two pills. The belief is that if the medicine is strong enough, it makes you better quickly, so you stop. Western medicine is also considered a "hot" medicine, which is a very powerful way to treat an illness, and people only take it when they have to. If their illness is less serious, they might see a traditional healer and take a colder medicine—some of the traditional herbal medicines, for example. They do not want to overdo a hot treatment.

So you can see how the traditions and experiences Vietnamese families have about illness can make it difficult for them to understand treatment here, where they might get no medicine at all from the doctor, or be told to take all of their antibiotics even after they feel better.

In our work, we try to explain to the people why they need to make an appointment with the doctor for a physical examination, even when they aren't sick. We describe the tests they should ask about—blood pressure screening, screening their blood, having a mammogram, that kind of thing. That's our work—health education work. This is harder than it might sound. In our culture, patients don't ask the doctor to do things. The doctor makes all the decisions, and the patients just say, "Yes." In our

*We work with both the doctor and patient—so patients know they can and should ask for preventive screenings, and doctors understand how hard this can be for Vietnamese patients.*

work, we tell patients, "You must ask the doctor about a Pap test or a mammogram." This is quite difficult, especially for women patients to talk to a male doctor about a breast exam or Pap test. We work with both the doctor and patient—so patients know they can and should ask for preventive screenings, and doctors understand how hard this can be for Vietnamese patients.

I remember in the late 1970s when I first came from Vietnam, I experienced a lot of fatigue. I went to a doctor. The first thing the doctor did was give me a TB skin test. It was positive.

The doctor explained to me that I had to take medication, one pill a day, for a whole year, and I would have to have my liver checked regularly for side effects. I had never taken any medication in my life! I said, "I'm not sick. Why do I have to take this medication?"

So my husband and I went to another doctor. The doctor talked to me for a while. Then he spoke to my husband. He kept asking my husband, "Do you spend enough time with your wife?" We wondered why he asked this question.

The doctor recommended we see a marriage counselor. This puzzled both of us, and it didn't seem to have much to do with the medication issue. Later, I took psychology

courses here and realized the second doctor believed I wasn't taking the medicines because I wanted my husband's attention. He completely missed the cultural issues—that, from my perspective, taking a strong medicine for a year when I didn't feel sick didn't make any sense.

As it turned out, I had a positive skin test because when I was in Vietnam I had BCG vaccine. They use this vaccine in many countries outside the United States to prevent TB or limit its severity. People who have had BCG vaccine will usually have a positive TB skin test but this doesn't necessarily mean they have TB. Most of the people who came from Vietnam have had BCG, and they'll have a positive TB skin test.

I just worked with a woman who was diagnosed with breast cancer. She relied on her daughter to make appointments because she cannot speak English. But her daughter has a job and a family. She's very busy, and didn't understand that her mother's illness was serious. It took a long time for her to make an appointment. Usually, a woman with breast cancer meets with an oncology specialist first to find out what her treatment choices are. But the daughter was too busy and had a hard time getting the appointment, so she skipped the oncology consult and her mother went straight to a surgeon to have a mastectomy. So the mother had no choice about her treatment.

For the families I work with, the doctors often say, "If you don't speak English, bring your translator with you." This is usually someone in the family, which creates all kinds of problems. Once I volunteered to translate for a person who had hepatitis C. The doctor, a specialist on the liver, talked so fast and used such complex language, even for me. For the non-medical people who have never translated for a doctor, this can be overwhelming. They are shy about speaking up. They don't stop the doctor because he or she seems very busy and rushed. People are embarrassed about not understanding the complicated words and new concepts. The translation is not effective. It's a difficult thing.

Often, when patients request a translator, it's a phone translator. I always request a face-to-face translator for the first meeting, especially when the diagnosis is breast

cancer, cervical cancer or something that might require serious treatments. If you use a telephone translator, you don't know who you get. You might get a person who speaks Vietnamese very well, or someone who doesn't. Patients don't want to bother the doctor about a poor translator, so they may end up understanding very little about their visit.

*What have your life experiences—the people who have inspired you, the things that have happened to you—allowed you to accomplish?*

I learn from many different people, from many walks of life. I really admire the women I've worked with who come from Vietnam. When they come here, their life is turned upside down. They come as refugees, then their lifestyles really change. It can be quite a struggle. Typically, the husband loses status and becomes disillusioned and depressed. The wife must make the effort to take care of the family and keep everyone together. There is so much cultural adjustment. In Vietnam, children cannot talk back to parents. Here it is different. The culture is different. The parent has to adjust. It's difficult for children too. I respect these women. They are uneducated but they are very strong. Many of their children become very successful people.

I went through adjustments and changes, too. When I came as an adult, I went to college. I was very quiet in my classes. In Vietnam, the women are not supposed to talk. Now, I talk much more, and I know that women have a lot to say.

I've had an opportunity to be part of an organization called Women's Health Leadership. They do leadership development with women from a variety of underserved communities, especially immigrant and low-income communities.

When I worked with Women's Health Leadership, I learned a lot from women of different cultures. It was through WHL, I think, that I saw the ways all women come together. We all basically have the same kind of struggle. I'm in awe of their experiences—for example, cancer survivors.

It's difficult when Vietnamese are diagnosed with cancer. Sometimes, Vietnamese believe the diagnosis means a person is bad, or that perhaps in the last life he or she wasn't good. Because of these beliefs, people don't want to reveal their diagnosis to others.

But here is an amazing thing. I can contact one of these women—a cancer survivor—and say, "There is another woman in our community who has just been diagnosed with cancer. Would you be willing to talk to her, help her, give her support?"

She will say yes. She will tell the other woman about her own diagnosis, and help her get through the experience.

I respect these people. They've been through a lot. They say, "If you've been through a hard life, you become a stronger person."

*"If you've been through a hard life, you become a stronger person."*

*What are some of the things that should be done on a front-line community level, where you are, that would help resolve the health disparities faced by Vietnamese Americans?*

The policy people never hear much from the common people about the needs in their community. When I worked with Asian Health Services, we educated people and encouraged them to testify at hearings about what is needed.

If Vietnamese Americans could talk with policy makers they would want them to know that everybody should have equal access to health care. It doesn't matter if someone is poor or rich, you're insured or not insured. The thing we see is that health care is unequal.

*Your work with the Vietnamese Language School reflects an interest in keeping young Vietnamese people and their parents connected to their culture.*

Yes. I've known and worked with many families. I've discovered that when people know who they are culturally, they are happier and they do well.

In the Huong Viet Community Center, we work with young people at the Vietnamese language school every Saturday. All of the teachers are volunteers. We do this work because we want the kids to know where they come from, where their roots are, and to feel proud about that.

We also want them to learn about the best things in this country too. They must keep their roots, but they are Vietnamese Americans. They need to understand that—the unique experiences and opportunities because of this blending of cultures.

The kids will be a link between the older and younger generations. I started working in the language school in 1987, with others in the older generation who originally taught at the school. Now younger people are teaching there, including some who were born in this country. We are happy about their involvement, about the contributions they are making to help younger kids understand their roots, their culture.

*Trust is very important to Vietnamese people. When you work with them, you must show you care and want to learn.*

*Based on the challenges and opportunities in your own life, what lessons do you have to share with others?*

Trust is very important to Vietnamese people. When you work with them, you must show you care and want to learn. Even if you are yourself Vietnamese, working with other Vietnamese, you probably have a lot to learn. We must all learn how to respect each person's culture.

For example, one day I got a call from a hospital. A Vietnamese man, a patient, was dying. His family came with a video camera and wanted to take pictures. The nurse came in and was horrified that they wanted to take a video of this man dying. She asked me, "What should we do?" I said, "Let the family take the pictures." You see, some members of the family were not there. It was important to include them. The video was a way to do this, and it was a positive thing for this family. That is our culture—the older generation of Vietnamese.

*What kind of leadership is important at a community level to help address the problems in health care?*

It is important to be sympathetic to the needs of the Vietnamese community. War has divided us so much. The old ideologies have divided us from each other, from friends. Americans and Vietnamese have been divided.

This comes back to the issue of trust. If you come into the community looking like you have your own individual interests, people don't trust you. Then it is very difficult to get anything done. If, instead, you remain open minded, are willing to try things and take risks, willing to listen and learn, you can help people. You can be an inspiration to them.

For example, when I first came to work in the Vietnamese community, I did a lot of volunteer work. The people didn't know me. They said, "Oh, maybe she has her own intentions and interests. Maybe she is going to use the community to promote political ideas or sell things." I just kept working, and working, and working. I didn't promote anything except my interest in the people's well-being. After a long time, they came to trust me.

*If you remain open minded, are willing to try things and take risks, willing to listen and learn, you can help people. You can be an inspiration to them.*

Our community is deeply divided because of political issues. We went through a war, we were refugees. This has gone on for generations. It was in 1954 that the French divided us into the North and South sectors. Then the United States went into

Vietnam in the 1960s and maintained the divisions between North and South. The people of the North became enemies of the people of the South. When Vietnamese people came here, to the United States, they continued to have these different ideologies. The people from the South had lost everything. They were so depressed. It was very difficult.

Our local newspaper recently had an article about a teacher in Hawai'i. She had a group of young students who came from Vietnam to learn about Hawai'i and the United States. She tried to get a local Vietnamese newspaper to write an article about the students and the program. The paper refused because they didn't want to support Vietnamese communists.

Other groups and individuals refused to talk to these students because of all the controversy about Vietnam. It was sad. The students were young. They were born after 1975. They didn't even know about the war.

These kinds of issues continue to affect the Vietnamese community in this country. This is why it is sometimes so difficult to build trust—and so important to do so.

### *What is your vision and hope for the future?*

*I have always had the dream that everybody could have equal access to quality health care.*

I have always had the dream that everybody could have equal access to quality health care.

If we want this, all of us have to be aware, to reflect, to struggle, to advocate for the issues that we really believe in. We also have to vote. I talk to people in our community to tell them to vote. I tell them this is a way they can make a difference.

It will take a long time—it won't come tomorrow. This is a struggle that will go on for many years, maybe for many generations. But we must continue to be advocates. Dr. Martin Luther King, Jr., is a good model for us. Like him, we have to keep going forward.



# 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 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 Asian Americans.

\*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](http://www.omhrc.gov/CLAS); and *Healthy People 2010*, 2d ed., U.S. Department of Health and Human Services, Washington, DC.

### *General Recommendations*

- ✘ Think of health disparities in terms of root causes, instead of solely in terms of incidence of disease. This invites exploration of factors such as economic status, education, housing, civil rights, social justice and racism.
- ✘ Better health data about Asian Americans is key. Effective data must be collected in multiple languages from sufficiently large sample sizes.
- ✘ Data needs to be gathered in a way that allows examination of distinct groups within the Asian-American population. Aggregated data tends to render invisible those groups that are most likely to face severe disparities (e.g., new immigrants).
- ✘ Use Participatory Action Research models in which the community is actively involved as a partner in developing research design and conducting research studies.
- ✘ Develop effective strategies to address obstacles to health care, including language and cultural barriers and lack of health insurance.
- ✘ Consider immigration issues when addressing the problems of the uninsured. Laws that restrict the ability of immigrants to obtain health care are not effective from a public health perspective. These laws need to be evaluated and changed.
- ✘ Take into account the great diversity of Asian-American populations, including such things as immigration status, length of time in the United States, ethnicity and access to health information.
- ✘ Dispel the “model minority” myth. Misunderstandings about the success of Asian Americans have tended to obscure health problems faced by different groups.
- ✘ Effective leadership development efforts emerge from a collaborative perspective that considers the many different ways individuals can express leadership.
- ✘ Good mentor relationships are inspirational. It’s important for established providers to offer opportunities, and for students and young professionals to take initiative in establishing and maintaining such relationships.
- ✘ Work collaboratively with different organizations and individuals within a particular community, as well as across different ethnic groups. This enhances and expands each group’s political power and increases the chance of achieving our collective and individual missions.
- ✘ Take a strategic and analytic approach. Keep a long-range perspective and sustain efforts over time.

### *Butch de Castro*

- ✘ Recognize that as a public health student, worker or advocate, you are part of a movement addressing risk factors for marginalized or vulnerable populations, with an attention to issues of social justice.

### *Mohammed N. Akhter*

- ✘ Health is the responsibility of many parties. The faith community can play a critical role in health promotion, and can collaborate with the public health community to achieve essential goals.
- ✘ The United States has the most diverse population in the world. Because the strength of the nation depends on having people who are healthy and well-educated, the United States has the responsibility to act as a model to the rest of the world to address health disparities and provide a roadmap for others.
- ✘ We must ensure that the children of this nation, whatever their background, receive the best health care possible when they are young, before health disparities begin to take shape.

### *Tessie Guillermo*

- ✘ Organizations at every level—local, state, national—need to apportion some of their energy and efforts toward policy and advocacy. This is a task for everyone, not just for those who have established themselves as the advocacy community.
- ✘ It's important to take steps to maintain Asian-American participation in conversations about health disparities and health policy—to ensure a “place at the table.” Good data and research help support this effort by legitimizing Asian Americans as a population that belongs in that mix.
- ✘ Continue to explore ways technology can be used in coalition building, collaboration and providing service.

*Kaying Hang*

- ✘ True compassion and commitment make it easier to tackle any challenge, and can serve as a great entry to opportunities.
- ✘ Providers must be willing to listen and learn from members of the refugee community, see them as equal partners, and give refugee patients an opportunity to participate as equals and contribute solutions for their health care issues.
- ✘ Leadership development for young people is enormously important. Youth are valuable assets to the community, and the more we can increase their capacity, the better things will be.

*Sherry M. Hirota*

- ✘ Instead of only focusing on problems and disparities, identify positive health status indicators in newer immigrant populations. Track these over time to see whether they change and, if so, determine causes of the change.
- ✘ Allow young people coming into the health care field to train at community health centers, where they can learn about their ability to have a profound impact on a community, and gain a sense of movement for social change.
- ✘ Create better mechanisms for mentorship, helping front-line professionals as well as seasoned leaders synthesize and share their lessons more efficiently. Too often, when people move into new roles their lessons are lost, instead of being transferred to the next generation.

*Marjorie Kagawa-Singer*

- ✘ Address ethnic differences in social science research, and do so from a competency perspective rather than a deficit model. Help researchers and providers understand the cultural framework in which people's responses to health issues are expressed.
- ✘ Recognize that there are many "right" ways of coping with disease and illness. Broaden perspectives on successful coping.
- ✘ Apply the same kinds of principles of advocacy and leadership used in community settings to academia, particularly in terms of developing research that is directly relevant to communities.

### *Howard K. Koh*

- ❏ Address cigarette smoking specifically as an element of Asian male culture, and work to change norms about tobacco use in that culture in the United States and internationally.
- ❏ Bring attention to the education of the next generation of public health professionals. Ensure that all of them have the issues of diversity and disparities as top priorities.
- ❏ Use allies who operate beyond the traditional boundaries of public health. Some of the best and most effective public health practitioners include fundraisers, advocates and other people who know how the government, media and political system work.

### *Rod Lew*

- ❏ The exploration of health disparities should bring attention to the issue of parity as well—ensuring that people have equal access to care and resources, and focusing on a common, positive vision for the future.
- ❏ Progress in eliminating health disparities will depend significantly on the building of relationships and the establishment of trust within populations experiencing disparities.
- ❏ Recognize the importance of history—of our own communities, of individuals who have helped us make progress, and of the ways other communities have helped us.

### *Thoa Nguyen*

- ❏ Recognize that many Vietnamese patients will not ask a doctor questions. Provide culturally meaningful support and education that helps them learn about and become involved in their health care.
- ❏ Support people in staying connected to their culture of origin, especially children and youth. When people know who they are culturally, they are happier and do better.
- ❏ Recognize that trust is particularly vital to Vietnamese people. Avoid the appearance of self-promotion or self-interest. Don't promote products or political agendas.

# Resources

## *National Asian-American Community Health Organizations*

- ✘ Asian American Health  
National Library of Medicine, National Institutes of Health  
<http://asianamericanhealth.nlm.nih.gov>
- ✘ Asian American Network for Cancer Awareness, Research and Training  
[www.aancart.org](http://www.aancart.org)
- ✘ Asian Pacific Environmental Network (APEN)  
[www.apen4ej.org](http://www.apen4ej.org)
- ✘ Asian and Pacific Islander American Health Forum (APIAHF)  
[www.apiahf.org](http://www.apiahf.org)
- ✘ Asian Pacific Partners for Empowerment and Leadership (APPEAL)  
[www.appealforcommunities.org](http://www.appealforcommunities.org)
- ✘ Association of Asian Pacific Community Health Organizations (AAPCHO)  
[www.aapcho.org](http://www.aapcho.org)
- ✘ National Asian American Pacific Islander Mental Health Association (NAAPIMHA)  
[www.naapimha.org](http://www.naapimha.org)
- ✘ National Asian Pacific American Families Against Substance Abuse (NAPAFASA)  
[www.napafasa.org](http://www.napafasa.org)
- ✘ National Asian Women's Health Organization (NAWHO)  
[www.nawho.org](http://www.nawho.org)
- ✘ National Coalition for Asian Pacific American Community Development (National CAPACD)  
[www.nationalcapacd.org](http://www.nationalcapacd.org)

## *Government Resources*

- ✘ Centers for Disease Control and Prevention  
[www.cdc.gov](http://www.cdc.gov)

## RESOURCES

- ✘ Healthfinder®  
Office of Disease Prevention and Health Promotion  
U.S. Department of Health and Human Services  
[www.healthfinder.gov/justforyou](http://www.healthfinder.gov/justforyou)
- ✘ National Center for Health Statistics  
[www.cdc.gov/nchs](http://www.cdc.gov/nchs)
- ✘ Office of Minority Health  
[www.omhrc.gov](http://www.omhrc.gov)
- ✘ U.S. Census Bureau  
[www.census.gov](http://www.census.gov)

### *Selected Publications*

- ✘ LeVeist, T., ed. 2002. *Race, Ethnicity, and Health: A Public Health Reader*. San Francisco: Jossey-Bass.
- ✘ National Institutes of Health. 2000. *Addressing Cardiovascular Health in Asian Americans and Pacific Islanders: A Background Report*. National Institutes of Health, National Heart, Lung and Blood Institute. (NIH Publication No. 00-3647.) Available at [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov).
- ✘ Smedley, B. D., A. Y. Stith, and A. R. Nelson, eds. 2002. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy. Washington, DC: National Academy Press. Available at [www.nap.edu](http://www.nap.edu).
- ✘ Task Force for Advancing Parity and Leadership for Priority Populations. 2002. *Moving Toward Health: Achieving Parity through Tobacco Control for All Communities*. Available at [www.appealforcommunities.org](http://www.appealforcommunities.org).
- ✘ U.S. Department of Health and Human Services. 2001. *Mental Health: Culture, Race and Ethnicity*. A supplement to *Mental Health: A Report of the Surgeon General*. Rockville, MD.
- ✘ U.S. Department of Health and Human Services. 2000. *Healthy People 2010: Understanding and Improving Health*. 2d ed. Washington, DC.
- ✘ Zane, N., D. Takeuchi and K. N. J. Young, eds. 1994. *Confronting Critical Health Issues of Asian and Pacific Islander Americans*. Thousand Oaks, CA : Sage Publications.

## *Eliminating Health Disparities* *Conversations with Asian Americans*

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
- ✕ Funders