f you had asked Lia Lee’s parents what caused their daughter’s epilepsy, they might have told you, through an interpreter, about her soul wandering from her body. They might have said, too, that the medications her Western doctors prescribed were frequently changed, difficult to administer and caused side effects—and so they failed to follow the prescriptions. They might even have suggested things could have turned out differently had Lia been born in the Lees’ native Laos. But her birth was at a hospital in Merced, Calif., and at three months of age, the girl suffered her first epileptic seizure. Others followed quickly, becoming increasingly severe, and despite compassionate, often heroic care from physicians and nurses during 17 hospitalizations, Lia sustained irreparable brain damage.

In the Hmong language, epilepsy is known as *qaug dab peg*, literally “the spirit catches you and you fall down”—the title of the highly regarded book by Anne Fadiman, which recounts Lia’s failed journey through the American health system in the early 1980s, a passage beset by language barriers and a clash of cultures. Lia’s doctors put their faith in a regimen of antiepilepsy...
drugs, while her family, blaming malevolent spirits, wanted to appease them with animal sacrifices and other traditional healing techniques. Lia, caught in the middle, did not get well.

Fadiman’s account mirrors the experiences of legions of immigrants and their American health care providers. Those new to this country, particularly when they come from non-Western cultures, face many hurdles in receiving care, and similar problems plague native-born minority populations. Moreover, to varying degrees, these issues affect all Americans as they set out to navigate the medical culture. In the case of immigrants, not speaking the language is often only the beginning; they may also wait longer before going to the doctor—in some cases, until treatable conditions have become dangerous—or have different expectations about their care. And their beliefs, often unfamiliar to their new doctors and nurses, can influence whether they comply with a treatment plan.

It’s a problem most health care organizations recognize with a growing sense of urgency. “Hospitals only have to look outside their doors to see increasingly diverse populations,” says Rick Wade of the American Hospital Association. In response, Wade estimates, some three-quarters of the 5,000 hospitals in the United States have embarked on “cultural competence” programs, an array of patient education, prevention and intervention strategies related to ethnicity, religion and language. Moreover, there’s a growing emphasis on formulating standard policies and practices to address cultural issues of care. But it’s far from clear what those standards should be. “Right now, people are struggling with defining cultural competence and how to achieve it,” says Anne Beal, a physician and senior program officer with the Commonwealth Fund, a New York City foundation focused on health care issues.

That uncertainty doesn’t stem from lack of attention. Reducing disparities in health care has received serious attention since the mid-1980s after a government study painted a bleak picture of care afforded to African Americans and other minorities. Since then, an array of government and private-sector offices and programs have been launched, including the Office of Minority Health (OMH) in the U.S. Department of Health & Human Services. Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care, a 2002 report by the Institute of Medicine (IOM), added to the sense of crisis, documenting lower-quality care for minorities even when insurance status, income, age and severity of illness were taken out of the equation. The IOM’s findings, says Beal, “turned the lens on the medical system itself,” ratcheting up the pressure for fundamental changes.

Many recommendations in the IOM report overlapped with the first set of national standards for cultural competence, issued a year earlier by the OMH. Some of the 14 guidelines which were in those Culturally and Linguistically Appropriate Services (CLAS) standards have been incorporated into federal mandates. For example, any medical facility that receives federal dollars must provide language assistance to patients who have limited English proficiency. Other initiatives, recommended though not yet required, include recruiting a diverse staff that mirrors the local population, and developing strategic plans for providing culturally and linguistically appropriate services. Beal terms the CLAS standards “a good starting point,” but thinks they are too vague—for example, one standard recommends that health care staffs undergo cultural competence training but does not provide specific advice about the content.

Meanwhile, racial and ethnic disparities in health care remain, and threaten to mushroom. U.S. minorities, who now
Constitute 33% of the population, could grow to account for more than 50% by 2050. Already, roughly 20% of the U.S. population speaks a language other than English at home, and a growing number has limited proficiency in English. Against this backdrop, implementing comprehensive cultural competence strategies is a mammoth task. “People are just beginning to understand that this is about more than addressing language barriers,” says Joseph Betancourt, director of the Disparities Solutions Center in the Institute for Health Policy and director of multicultural education at the Massachusetts General Hospital (MGH). “Cultural competence has moved from the margins to the mainstream, but we’re still in a learning mode.”

Much of that learning, as well as many answers to questions about cultural competence, is being formulated hospital by hospital, with solutions designed to address local conditions. In Dearborn, Mich., Oakwood Hospital & Medical Center serves an area in which people of Middle Eastern ancestry, including many recent immigrants, make up more than 40% of the population. To serve them, Oakwood has built a stable of medical interpreters conversant in Arab dialects and trains its practitioners to recognize issues that may arise in treating patients unfamiliar with American medical practices. The hospital, which is hiring an increasing number of doctors and nurses of Arabic descent, holds health
Khalifa, a nurse and practicing Muslim who is fluent in Arabic, may be called in to help, for example, when a Muslim woman in labor refuses to be examined by a male physician. In these and other situations in which language, religion and cultural beliefs erect barriers, she can sometimes influence a patient’s care. “There’s an inherent comfort zone when these patients see I’m from their community,” she says.

Often, immigrants arrive with significant health issues and are thrust into a medical system they don’t understand. “They may come from a third-world country with a serious lack of health education, poor diets, no exercise and heavy smoking—all major health risks,” says Bruce Nelson, director of community services at Glendale Adventist Medical Center, which serves an area in Southern California in which people of Armenian descent comprise almost a third of the population.

With increasing numbers of immigrants showing up at the hospital with advanced diseases that are difficult and expensive to treat, a priority at Glendale Adventist has been to encourage better health habits by staging educational outreach programs. After a poor response to early efforts, the hospital began recruiting volunteer health educators from the Armenian community. Many are housewives, who typically hold events in their own homes or with friends and relatives. In these relaxed settings, the volunteers provide information about diabetes, cardiovascular disease and other health conditions. “Women in the Armenian community are responsible for the family's nutrition and lifestyle activities. So it's important for them to play the major role,” says Nelson. These trained volunteers have reached thousands of people, he says, and the numbers who show up for health screenings have grown steadily.

This kind of immersion in the community can sometimes head off cross-cultural misunderstandings. For example, at many hospitals, a patient who arrives covered with welts would prompt an immediate call to authorities to report suspected abuse. But at Kaiser Permanente Medical Center in San Francisco, where an entire wing is devoted to caring for a large Asian immigrant population, the staff recognizes the red marks as a likely consequence of “coining,” a traditional healing ritual that involves vigorously rubbing the body with the edge of a hot coin or spoon to draw out illness.

“Our internists are trained in Western medicine, but many of us speak Chinese, have been brought up in the Chinese culture and understand that patients have tried all kinds of traditional remedies before coming in, so they can talk to us without reservation,” says Anne Tang, chief of the center's Bilingual Chinese outreach programs in local mosques and other community centers and serves such Middle Eastern foods as hummus and halal meats prepared according to Islamic law.

“Many of our patients come from a non-Western mentality,” says Rose Khalifa, clinical educator in transcultural services at Oakwood. “They don’t know how medicine is practiced here, so a lot of education must go on.” Learning happens on both sides of the bed as staff seek to understand and accommodate patient requests—for example, moving the bed of a dying man to face Mecca so that his soul will exit in the direction of the Muslim Holy Land, and discussing the man’s end-of-life options with his eldest son, who is responsible for making his father’s medical decisions, a common practice in Arab culture.
One interpreter mistranslated the nurse’s directions to the mother of a young girl. The mother thought she was supposed to put oral antibiotics in the girl’s ear.

Module. Tang herself grew up in San Francisco’s Chinatown after immigrating to the United States from Hong Kong. “When patients receive advice from a physician of similar ethnic background who speaks their language, they tend to comply more readily with our recommendations,” she says.

Cultural competence, in the vision of its many advocates, would be embodied in a health care system that delivers high-quality treatment to every patient regardless of culture, race or language. Still, many harsh realities stand in the way of achieving those goals. For one, while many cultural competence strategies are funded by private donations, state and federal support, and nonprofit grants, Nelson says money is always an issue. “Cultural competence is so complex no one wants to look at it,” he says. “Often, institutions are afraid to address it, because they think they won’t be able to afford it.”

The cost of a medical interpreter, for example, according to a survey by the American Medical Association, ranges from $30 to $400 an hour, depending on the interpreter’s language and skill level. In many cases, that expense keeps health organizations from complying with federal rules requiring them to provide adequate access to language services, says Glenn Flores, a professor at the Medical College of Wisconsin in Milwaukee and an expert on language barriers in health care. He cites one study showing that in almost half of emergency department cases involving patients with limited English proficiency, no interpreter was provided. Instead, Flores says, many hospitals call on family members or untrained staff members.

Even when there is someone to interpret, inadequate training can cause problems. Flores tells of one interpreter who mistranslated the directions given by a nurse practitioner to the mother of a seven-year-old girl—causing the mother to think she was supposed to put the oral antibiotics in the girl’s ear. Only one in four hospitals provides training for staff who work with interpreters, Flores says, and very few states have interpreter certification programs.

But the challenges go far beyond funding. Training is a major problem, and while there are standards for training in medical schools, there’s a movement toward establishing mandatory requirements for cultural competence training, including as part of continuing professional education. Yet defining what skills are necessary and how they should be integrated into the curriculum remains an open question. Educational initiatives vary widely, says the MGH’s Betancourt, who is working to devise a more intensive cultural competence curriculum at the Harvard Medical School, where he is an assistant professor of medicine. Most cultural competence training amounts to brief sessions ranging from a few hours to a day—far too short, Betancourt says, to affect how health care is delivered. “Cultural competence should be embedded in our teaching, rather than addressed in a single, separate course,” he explains.

Another concern is that cultural competence efforts, designed to integrate diverse ethnic and racial groups into the health care system, could end up reinforcing stereotypes and isolating minority populations. But Garth Graham, deputy assistant secretary for the OMH, thinks the risk of doing too little outweighs the risk of doing too much. “Cultural competence should be about understanding,” he says. “It’s about learning more, not less, and integrating what you know about your patient and your patient’s background into clinical care.”

DOSSIER

1. The Spirit Catches You and You Fall Down, by Anne Fadiman [Farrar, Straus and Giroux, 1997]. This account, of a child lost between two ways of healing despite heroic efforts by everyone involved, has become an icon of the cultural competence movement.
4. “Cultural Competence and Health Care Disparities: Key Perspectives and Trends,” by Joseph R. Betancourt et al., Health Affairs, March/April 2005. Discusses how cultural competence is emerging as an important strategy to address health care disparities in managed care, government and academia.