

Overcoming Language Barriers to Health Care



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Foreword

With this publication, The California Endowment is pleased to issue our third public policy case study, *Overcoming Language Barriers to Health Care*. As a foundation committed to policy change, we began this publication series with the release in October 2006, of “Banning Junk Food and Soda Sales in the State’s Public Schools,” in order to better document how philanthropy can help shape public policy.

As political scientists and observers of the policymaking process well know, policy change is not a straightforward endeavor. It is complex, messy and nonlinear. Sometimes, you celebrate one step forward only to then have to take two steps back. That, coupled with a certain degree of risk, makes policy change work challenging for philanthropy. But it is possible. In fact, it is essential, if foundations seek to create real and lasting change from their investments.

This first case study described how The California Endowment helped inform the public policy debate, which ultimately led to the enactment of groundbreaking legislation banning the sale of junk food and soft drinks in schools. The soda ban case study showed the many twists and turns that the policymaking process takes and identified how and where The Endowment was able to contribute to the ultimate outcome through the strategic support of research and analysis, advocacy, government partnerships, and media activities, among other things. We subsequently published a second case study in November 2006 called “The Designation of Rural Areas in California.” This case study drew from an evaluation of a particular grant-making strategy, as well as other activities, and describes a multiyear advocacy effort to convince the federal government to change its methodology concerning the designation of rural areas in the state. The effort succeeded, which enabled many more communities in California to be formally considered rural, making them eligible for various programs.

This publication describes policy efforts at the state and federal levels to overcome language barriers to health care faced by non-English speaking patients. Importantly, this case study demonstrates the critical role that the administrative and regulatory process plays in establishing and implementing public policy. It also describes the inter-relationship between state and federal policy. As with the prior case studies, this report seeks to identify ways in which The Endowment—primarily through its support of advocacy and convening—helped raise the visibility of this issue, bring critical stakeholders together, and achieve meaningful progress.

We wish to thank all of the individuals who so graciously shared their insights and reflections for this report. They are among the many, many committed advocates who work every day to make change happen, and we are grateful to be able to learn from them how philanthropy can best support their efforts.



Barbara Masters
Public Policy Director

As much as I asked for someone that spoke Spanish... they never gave me any help or an interpreter. That is why they were not able to detect the cancer.

Overcoming Language Barriers to Health Care

“My name is Edna, and I am a cancer survivor,” the woman bravely declared into the microphone. “I would like to share my experience with you.”

Speaking through an interpreter, Edna was one of many witnesses at a February 2006 public hearing in Los Angeles before California’s Department of Managed Health Care who spoke little or no English. “In the year 2000, cancer was detected at a clinic in East Los Angeles,” she continued. “They transferred me to a hospital in North Hollywood. I don’t speak English. I started having problems with the lack of communication...

“The day that they were going to perform the biopsy, they were getting ready to do it on the breast that was not the right breast. It was logic that they were not going to find anything. As much as I asked for someone that spoke Spanish... they never gave me any help or an interpreter. That is why they were not able to detect the cancer.

“In the year 2004, when I went back, it was because the cancer had advanced quite a lot... I took my children with me as interpreters. My daughter knows English very well... She was understanding, but she was not able to tell me in Spanish. She would cry and cry, and she would say, ‘Nothing’s going to happen. Everything is fine.’ So I thought of calling my brother from my cell phone.

My brother drives the trucks. He helped me interpret to the doctor. But I didn't realize the harm that I was doing my brother, because he was driving long distances and he would get very nervous whenever my diagnosis would be... told to him.

“So in 2004, like I said, the cancer was quite advanced. They didn't give me a lot of possibilities of being successful, because the cancer had quite advanced. They did all the treatment for the cancer, the surgery. I lost my breast. I took chemotherapy, radiation, everything. I always experienced a lack of communication.”

As the hearing continued, it became apparent that the lack of communication that Edna had experienced in her dealings with the health care system was hardly unique. Witness after witness testified—in Spanish, Korean, Chinese, Thai—about the numerous problems they had encountered in California's health care system as the result of language barriers, including one mother's harrowing account of how she had first learned that her young daughter was terminally ill.

“A few years ago,” she said, speaking through an interpreter, “one of my daughters had a shock. There were convulsions. Well, she was hospitalized. About two days after she was hospitalized, they gave me the diagnosis. In order to be able to understand each other, they would use my son, who was 13 years old at the time. Unfortunately, the day that I was given my daughter's diagnosis, my son was not

with me. [So] they asked the mother of one of the children that was there from the pediatric department. The diagnosis was terminal. The doctor sentenced my daughter to death, as he told me, ‘When she reaches five years of age, she's going to die.’

“It's a situation that affected me in all aspects—in the family aspect, and psychological aspect as well. I felt frustrated. I [didn't] know how to explain everything that I felt in my own self... And I wasn't able to understand any longer, because the person who was starting to interpret for me, she stopped—and she left. And not to be able to ask why, why... the reason to all these things... why the doctor dared to sentence my daughter to death...”

As these accounts from the Los Angeles hearings illustrate, language barriers can—and often do—profoundly compromise the quality, accessibility and appropriateness of health care services for individuals with **Limited English Proficiency** (LEP—a designation used by the United States Census Bureau that refers to people age 5 and above who report speaking English less than “very well.”)

The evidence is not just anecdotal. The Institute of Medicine, in its landmark 2002 report summarizing the results of numerous empirical studies of the impact of racial and ethnic disparities in health care, found that: “Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural

information, misunderstanding of physician instruction, poor shared decision-making, or ethical compromises (e.g., difficulty obtaining informed consent). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance, and decreased satisfaction with services.”¹

A 2006 report from the National Health Law Program and the National Council on Interpreting in Health Care put the matter even more bluntly: “Indeed, language barriers have been found to be as significant as the lack of insurance in predicting use of health services.”²

“Smack Dab in the Middle of Our Mission”

The witnesses at the Los Angeles hearing described the experiences of many LEP patients who interact every day with California’s health care system. In numeric terms, the 2000 Census reported that roughly 6.8 million Californians are LEP. In addition, California’s LEP population has phenomenal linguistic diversity. According to the Census Bureau, more than 40 different languages are spoken in Alameda County alone, while Los Angeles County, one of the nation’s major ports of entry, is home to more than 80 different languages from around the world.

Yet despite California’s staggering ethnic diversity, it wasn’t until the 1990’s—as its already vast LEP population continued its rapid growth and as the evidence documenting the serious adverse consequences that could

result from poor communication between health care providers and their LEP patients continued to accumulate—that the problem of language barriers in health care truly started to attract the attention of California’s health advocates and public officials. In particular, it was becoming increasingly clear that many of the state’s doctors and other health care professionals were not able to communicate effectively with their LEP patients. LEP patients were often forced to have their children or other family members serve as interpreters, a far from optimal arrangement that all too often resulted in significant misunderstandings on both sides.

Among the state’s major organizations that took the issue of language access in health care very seriously was The California Endowment, a newly established private, statewide health foundation with the mission of expanding access to affordable, quality health care for underserved individuals and communities, and promoting fundamental improvements in the health status of all Californians. As Robert K. Ross, M.D., The Endowment’s current president and chief executive officer, put it, “Smack dab in the middle of our mission is access to quality health services for underserved populations—and immigrants are a very big part of that.”

As part of The Endowment’s exploration of the language access issue, then Senior Program Officer Jai Lee Wong convened a meeting of medical interpreters, advocates,

¹ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academy Press, 2002).

² National Health Law Program and National Council on Interpreting in Health Care, *Language Services Resource Guide for Health Care Providers*, 2006.

researchers and health care providers whom she thought would be knowledgeable about what was happening in California. The meeting, held in October 1999, covered a lot of ground, and although there was some discussion of the need to increase the number of bilingual and bicultural providers, the primary focus was on the need to increase the availability of high quality health interpreter services, probably through a combination of training, research, and advocacy.

In addition, there was considerable discussion at the meeting of what it would take to motivate the state's health care providers—including health plans, hospitals, and health care professionals—to implement interpreter and other language access services. Perhaps they could be persuaded by economic arguments, such as the potential for increased market share or reduced malpractice costs. Perhaps the case could be made on quality-of-care grounds, especially if some of the major health care accreditation organizations could be persuaded to incorporate language access measures into their assessment instruments. Or perhaps it would come down to compliance with the relevant state and federal statutes, regulations and contract provisions. Probably, it was agreed, it would take some combination of all of these approaches, as well as perhaps educating and encouraging LEP patients to become more assertive in requesting that their providers offer languages access services.

Not long afterwards, Wong invited some of the participants from this initial meeting to a smaller dinner meeting where she told them that The Endowment was ready to begin making grants within the next 30 days to implement some of the ideas that they had discussed about improving language access in California, and invited them to submit proposals.

Among those at the dinner meeting was Ignatius Bau, an experienced civil rights lawyer who at that time was the policy director of the Asian and Pacific Islander American Health Forum, a national advocacy organization based in San Francisco.

The Health Forum was already receiving funding from The Endowment to strengthen the advocacy voice of community-based Asian and Pacific Islander American health organizations in California (as well as its own internal capacity) on issues related to welfare reform, immigration, Medicaid managed care and the State Children's Health Insurance Program (SCHIP), so Bau readily agreed to go ahead and submit a proposal for a new project focused on language access.

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He felt strongly that in order to be successful, the project would need to involve a coalition of organizations representing a range of key ethnic and professional constituencies and perspectives, rather than just the Asian and Pacific Islander American Health Forum acting on its own. Consequently, the Health Forum's proposal, submitted in December 1999, shortly after the dinner meeting, included funding for subcontracts to four additional organizations: the Latino Coalition for a Healthy California, the California Primary Care Association, the National Health Law Program, and the California Pan-Ethnic Health Network.

The new grant to the Asian and Pacific Islander American Health Forum was by no means the only language access grant made by The California Endowment at that time—The Endowment also began awarding a number of sizeable grants in support of health interpreter training, the development of standards for health interpreters, consumer education and the placement of immigrant health care providers in ethnically diverse regions of the state—but it was the only one of The Endowment's initial language access grants that was focused squarely on a strategy of policy advocacy.

The Health Forum was well-positioned to lead the charge. Although this was its first grant from The Endowment to deal explicitly with language access, the Health Forum, under an earlier capacity-building grant, had in fact already been involved with language access

issues for some time. At the state level, for example, the Health Forum had been working closely with the California Pan-Ethnic Health Network and other health advocacy organizations to push for the adoption of the same cultural and linguistic standards in Healthy Families, California's new child health insurance program, which the state had several years earlier incorporated into its Medi-Cal (California Medicaid) managed care program. What's more, the Health Forum was one of the four founding members of the California Pan-Ethnic Health Network, a multiethnic health advocacy organization that had been instrumental in advocating for those original Medi-Cal managed care cultural and linguistic standards in the first place.

Meanwhile, at the national level, the Health Forum, in collaboration with the the National Health Law Program, Mexican American Legal Defense and Education Fund and others, had been actively urging the Office for Civil Rights of the federal Department of Health and Human Services to strengthen the guidance that it had issued early in 1998 to clarify the language access requirements under Title VI of the 1964 Civil Rights Act—an effort that was soon to pay off in unexpected ways.

“This Was the Proverbial Policy Window”

Title VI of the landmark 1964 Civil Rights Act flatly declares that: “No person in the United States shall, on the ground of race, color, or national origin, be excluded from

participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” While the legal and moral significance of this provision was apparent from the outset, its relevance to the health care system was underscored in the years immediately following its enactment with the launching of Medicare and Medicaid, the two huge new federal health care financing programs that soon became a principal funding source for the health care system in the United States, including many of the nation’s hospitals, doctors and other health care providers. Now that they were receiving substantial federal funds, these providers would have to pay serious attention to the provisions of Title VI.

Yet for many years, most health care providers did not see language access as part of their responsibility under Title VI. In fact, it wasn’t until 36 years after the passage of the Civil Rights Act that the president of the United States finally issued a pivotal executive order making it clear that, in prohibiting discrimination on the basis of national origin, Title VI did in fact apply to persons with Limited English Proficiency. On Aug. 11, 2000, with the end of his administration only months away, President Bill Clinton signed Executive Order 13166 directing that: “Each federal agency shall prepare a plan to improve access to its federally conducted programs and activities by eligible LEP persons.” The executive order, entitled *Improving Access to Services for Persons with Limited English*

Proficiency, noted that the Department of Justice was, that same day, issuing a general guidance document for all federal agencies “which sets forth the compliance standards that recipients [of federal funds] must follow to ensure that the programs and activities they normally provide in English are accessible to LEP persons and therefore do not discriminate on the basis of national origin in violation of the Civil Rights Act of 1964, as amended, and its implementing regulations.”

It was intended as a wake-up call to the providers of federally funded services, and it certainly did get the attention of the health care establishment. The American Medical Association, in particular, protested vigorously, charging that the executive order amounted to nothing more than another “unfunded mandate,” and even sought to have the order rescinded when the Bush Administration took office in 2001.

But although the Bush Administration softened some of the terms of the Department of Health and Human Services guidance explicating the executive order, the executive order itself ultimately remained intact—and still does to this day, in contrast to what have been regarded as some of the Clinton administration’s other achievements. Maria Echaveste, a California-based lawyer who served as deputy chief of staff in the Clinton White House from 1998 to 2000 and who played a key role in the genesis of the executive order, is pleased with its durability. “One of the things that I’m most proud of,”

she says, “is that, OK, fast forward [from the end of the Clinton administration] to 2003, 2004: that Social Security surplus, that economic policy—gone. But our executive order, it got reviewed, but it’s still law. And it has huge consequences that really affect people in a daily way.”

Echaveste traces the origins of the executive order back to President Clinton’s initiative on race, and, more specifically, to a commencement address that Clinton gave on June 13, 1998, at Portland State University in Portland, Oregon, in which he zeroed in on what he saw as the benefits and challenges of immigration. While stressing the responsibilities of new immigrants to become a part of American society, Clinton insisted that, “We must protect immigrants’ rights and ensure their access to education, health care, and housing and help them to become productive citizens.” Echaveste maintains that while the speech did not specifically address language access, “It was within this framework that we worked on the executive order.”

Specifically, as deputy chief of staff, Echaveste was looking for a “legacy initiative” in the area of civil rights and immigration that could still be carried out in the waning years of the administration and potentially have a lasting positive impact. In her search for ideas, she convened a meeting in the Roosevelt Room of the White House of the directors of the civil rights offices of the various federal agencies, and asked them whether there were any new regulations or executive

orders that they believed could advance President Clinton’s civil rights agenda.

One of the participants who spoke up was Tom Perez, who headed up the Office for Civil Rights for the Department of Health and Human Services. Perez indicated that he had been working on a formal departmental guidance that would explain to health care providers who received federal funding what their responsibilities were under Title VI for making language access services available for their LEP patients. The idea of doing this as an executive order rather than simply as a Health and Human Services guidance was attractive, Echaveste recalls, because an executive order would extend to all federal agencies, not just Health and Human Services—thereby greatly enhancing its impact, while at the same time avoiding the appearance that the administration was singling out health care providers for language access compliance.

For Perez, the meeting was “the proverbial policy window to push something we had been working on. We were trying to do things internally at the Department, and this meeting gave us the external impetus to move forward.” Moreover, Perez was convinced that an executive order on language access would be sustained regardless of who won the next election. “It’s hard to quibble with the need to communicate with your doctor,” he contends. “The failure to do so has life or death consequences. And so it just didn’t feel like a Republican or Democratic issue. It was really an issue of health care quality.

And so we thought it would be the perfect time to elevate the issue across the entire federal government.”

“That’s Where the Action Was”

Not only had a policy window opened up, but, as Perez learned soon after taking office as director in early 1999, there was now a real demand that the federal government do something serious about language access—especially in California, where the problem had escalated dramatically since the early 1990’s. “As director, I was in California regularly,” Perez recalls, “because that’s where the action was, and where I thought we could get things done. The nonprofit advocacy network in California was so far ahead of virtually everyone else.”

The California advocates, in fact, gave Perez an earful, especially about language access and Title VI. As it happened, Perez’s predecessor had issued an unpublished “internal guidance” on language access to the regional civil rights offices of the Department of Health and Human Services a year earlier, in January 1998, but the advocates felt strongly that the guidance didn’t go far enough.

Among the most vociferous was Deena Jang, a seasoned civil rights lawyer who was working with Ignatius Bau at the Asian and Pacific Islander American Health Forum under the initial welfare and immigration policy grant from The Endowment. “When Tom [Perez] first came to meet with us,” Jang recalls, “everybody told him, ‘There are problems.

The guidance isn’t strong enough, especially about using kids as interpreters. And providers aren’t complying.’ Tom got it right away. He said, ‘You need a regulation.’ And we said, ‘Yes, that’s exactly right.’ So Tom immediately said to me, ‘Well, send me whatever you have. Take the 1998 [internal] guidance, use that as a base, change it how you want to see it changed, and then send it to me.’”

Jang took Perez at his word, and through the Health Forum quickly convened a group of fellow advocacy organizations to pull all their comments together so that they could be shared with Perez. “We had conference calls, and people took different pieces of it,” Jang says. “There was Chris Ho and Jodie Berger at the Employment Law Center, and Luz Buitrago from the Law Center for Families, and of course all the people from the National Health Law Program, the Asian Pacific American Legal Center, and the California Pan-Ethnic Health Network.”

... there was now a real demand that the federal government do something serious about language access—especially in California, where the problem had escalated dramatically since the early 1990’s.

There was, however, one fly in the ointment. Although Perez had initially wanted to go the regulatory route, it became soon apparent that the clock would probably run out on the Clinton Administration before he could clear the many bureaucratic hurdles required to promulgate a new regulation. And so he decided instead to produce a revised policy guidance—except that this time, in contrast to the 1998 internal guidance, the new revised policy guidance would actually be published in the Federal Register. “That way, it would kind of *seem* like a regulation,” says Jang.

With the collective input from the California advocates in hand, Perez’s work on the new and improved language access guidance was well under way by the time Maria Echaveste convened her brainstorming meeting in the Roosevelt Room. And so, Perez recalls, when Echaveste asked the assembled participants to think about what new civil rights initiatives could be enacted that would make a difference and be sustainable, he was ready. “Our answer was language access,” he says. “Let’s really move the language access ball forward.”

As with most things in government, it took some doing. “The process is such,” Echaveste explains, “that you try to reach consensus. You have to take the time to hear people’s objections and to have them raise their hypotheticals. The White House counsel’s office was involved, as well as the legal offices of the various agencies. So it was about a year-long process—which is actually pretty fast for something like this.” In the meantime,

Perez had to delay the publication of his new Health and Human Services guidance, since it could not be released until after the Executive Order—and the accompanying general guidance from the Department of Justice—had been issued.

Throughout this process, the Asian and Pacific Islander American Health Forum and its fellow advocacy organizations kept up the pressure, not only providing feedback to Perez but also signaling that *the* issue of language access was a high priority for the various constituencies that they represented. They also, at times, provided valuable ammunition to Perez and his staff on the thorny issues of feasibility and cost. “Some of these advocacy organizations were Exhibit A when you wanted to talk about what you could accomplish,” Perez recalls. “I remember speaking at the annual patient meeting of Asian Health Services in Oakland, and they had simultaneous interpretation in six or seven languages... And of course, these guys are operating on a shoe-string budget—which really belies the notion that this is unduly burdensome.”

Yet, as important as it turned out to be, all of this effort by the California advocates to help shape what ultimately culminated in a watershed presidential executive order on language access had not been planned or foreseen as part of advocacy strategy. The idea of an Executive Order had not been raised at the first dinner meeting, nor was it mentioned in the Health Forum’s language access proposal to The Endowment.

Rather, as Ignatius Bau notes, the Health Forum and its fellow advocates were being opportunistic: responding to serendipitous “windows of opportunity” as they opened—including Tom Perez’s request for input on the new language access guidance, and especially Maria Echaveste’s subsequent decision to pursue an executive order on language access. “When we first got the grant [from The Endowment] in early 2000,” Bau recalls, “the opportunity immediately presented itself—and not by our design.” However, what Bau and his colleagues understood was that, even though all of this activity at the federal level was occurring almost 3,000 miles from their base in California and even though its impact would extend to all 50 states, its potential impact on the millions of LEP residents living in California could—if all went well—be profound.

“We Were Providing a Roadmap”

But whether or not all *would* in fact go well was not immediately clear. On August 30, 2000, shortly after President Clinton signed Executive Order 13166, the new Department of Health and Human Services guidance on language access was published in the Federal Register, as planned, spelling out for providers what they needed to do in order to be in compliance with Title VI and the new executive order—steps that included conducting “a thorough assessment of the language needs of the population to be served;” development and implementation of “a comprehensive written policy that

will ensure meaningful communication;” providing the training necessary “to ensure that staff understands the policy and is capable of carrying it out;” and, finally, conducting “regular oversight of the language assistance program to ensure that LEP persons meaningfully access the program.” As evidence of the vital role that California advocates had played in the process, the regional Department of Health and Human Services Office in California held a joint press conference with the advocates announcing the guidance.

By October, just weeks after its publication, the AMA fired off a blistering letter to the Department’s Office for Civil Rights (OCR) that, according to an internal AMA memorandum, “vigorously detailed our unified views and firm opposition” to the new guidance. This initial salvo was soon followed by a joint letter from the AMA and a long list of specialty associations, together with many state medical societies, reiterating “our strong opposition to the unreasonable burden the OCR standards place on physician practices.”

Tom Perez’s response, during his few remaining months as director of the Office for Civil Rights, was to get out on the road and to explain the guidance face to face with health care providers across the country. “The American Medical Association hated the executive order,” he recalls, “but they were an outlier. On balance it was well received. A lot of providers were saying, ‘I don’t want

to break the law, but you've got to tell me what to do.' So we were providing a roadmap. And I believe a big part of our success was because of the dissemination effort."

During the comment period following the publication of the guidance, representatives from the AMA took the opportunity to come in and meet with Perez. He offered to speak to their membership about the guidance "any place, any time," but that was not what they wanted. "They wanted it gone," Deena Jang recalls. Jang, who had been the Asian and Pacific Islander American Health Forum's point person on language access, was hired by Perez in October 2000, and wound up staying in the Office for Civil Rights for the next four-and-a-half years, long after Perez's departure. "I stayed there because I felt obligated to make sure that the guidance stayed as good as it could get," she says.

And as soon as President George W. Bush took office in January 2001, the AMA went into high gear, launching what an internal memo described as "extensive and ongoing discussions" with the new administration and requesting that "the Administration immediately rescind the OCR LEP regulations [sic] and reconsider other approaches that would not impose new, unfunded mandates on physicians." In addition, the AMA actively supported a new bill proposed in March by Congressman Bob Stump of Arizona that sought to prohibit the use of federal funds for the promulgation or enforcement of any executive order that created an entitlement to services for LEP individuals.

While the AMA was seeking to have the new language access guidance rescinded, the advocates were mobilizing to have it strengthened. "We certainly thought it was good," recalls Mara Youdelman, then a new staff attorney at the National Health Law Program in Washington, D.C. "But it wasn't everything we wanted—and we made that clear to the Office for Civil Rights."

The National Health Law Program, a national public interest law firm that had been established in the early 1970s to improve health care for low-income populations, was one of the four subcontractors under the Asian and Pacific Islander American Health Forum's language access grant from The Endowment. Following the departure of the Clinton Administration, staff members from the National Health Law Program—together with fellow advocates from the Mexican American Legal Defense and Educational Fund, the National Council of La Raza, the National Asian Pacific American Legal Consortium (now the Asian American Justice Center), the National Immigration Law Center, and the Asian and Pacific Islander American Health Forum—met with officials in the new Bush Administration to continue to make their case in support of the executive order and the language access guidance. "From the advocacy side, the six of us were probably the most active in collaborating together, coordinating our efforts and really pushing to make sure that the executive order was reaffirmed, that the guidance was maintained, and that there wasn't any weakening by the Bush Administration," Youdelman says.

“We Were Very, Very Nervous”

It proved to be an uphill battle—and a steep hill. Not only was the AMA continuing to use its considerable influence with the new administration and throwing its support behind the Stump bill to withhold federal implementation funding for the executive order, but in April 2001, the United States Supreme Court entered the fray with its ruling on the case of *Alexander v. Sandoval*, which held, by a 5-4 majority, that individuals did not have the right to sue for “disparate impact discrimination” under Title VI. They could only sue for “intentional discrimination,” a considerably higher threshold. The upshot, says Deena Jang, who watched all this unfold from her position at the Office for Civil Rights, was that “it called into question the basis for the guidance, which was the Title VI regulations—the disparate impact piece. So [opponents] used this as another way of attacking the guidance.”

And then another Congressman weighed in against the executive order: Ernest Istook of Oklahoma, a powerful member of the subcommittee that handled appropriations for the Department Health and Human Services. He wrote an anguished letter to his colleagues asserting that under the new executive order, “Common sense is abandoned. Relatives and friends are not even *permitted* to help translate; professionals must be hired... Join me in opposing E.O. 13166.” Istook then proceeded to include language in the Treasury-Postal Appropriations Bill for 2002 requiring the Office of Management and Budget to conduct

an assessment of the costs and benefits of implementing Executive Order 13166, with a full report due back to the House Appropriations Committee “no later than 120 days after the enactment of this act.”

“We were very, very nervous about what it would say,” recalls Ignatius Bau. The Health Forum, together with nine other health advocacy groups, submitted detailed comments to the Office of Management and Budget, urging, among other things, that the cost-benefit analysis take into account the societal costs of *not* providing language access to LEP individuals.

When the Office of Management and Budget study was released in March 2002, there was a collective sigh of relief within the advocacy community.

Although the estimated cost to health care providers of complying with Executive Order 13166 came out to a big number—up to \$268 million per year—this turned out to be only a small fraction of total health care expenditures. At just over \$4.00 per visit, it amounted to only 0.5 percent of the \$865 cost of the average health care visit (including all inpatient hospital, outpatient physician, emergency

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room and dental visits)—hardly the crushing burden that opponents of the executive order had been claiming.

In the meantime, there had been another unexpectedly encouraging development within the Bush Administration. On October 26, 2001, Ralph F. Boyd, Jr., assistant attorney general for civil rights at the Justice Department, had issued a memorandum to all federal departments and agencies reaffirming Executive Order 13166. Boyd focused specifically on the implications of the Supreme Court's ruling on *Alexander v. Sandoval*: "Some have interpreted *Sandoval* as impliedly striking down Title VI's disparate impact regulations and thus that part of Executive Order 13166 that applies to federally assisted programs and activities. The Department of Justice disagrees... It is the position of the Department of Justice that the Executive Order remains in force." Boyd's memorandum even went so far as to add that, "While Executive Order 13166 requires only that Federal Agencies take steps to eliminate recipient discrimination based on national origin prohibited by Title VI, each Federal Agency is encouraged to explore whether, as a matter of policy, additional affirmative outreach to LEP individuals is appropriate."

The fact that the executive order had been reaffirmed was especially gratifying because the new administration had recently pulled back some new Medicaid regulations that had been initiated during the Clinton

Administration, but not finalized. The decision to uphold the executive order, despite considerable pressure from some powerful opponents, appeared to vindicate Tom Perez's earlier decision to issue a new guidance immediately on the heels of the Executive Order rather than to go through the slow process of issuing a new regulation that, with the change in administrations, might never have seen the light of day.

Boyd's memorandum did, however, include one provision that worried the advocates: the language access guidances that had been published during the Clinton Administration by all the federal agencies would have to be reopened to a new round of public comment. This, the advocates feared, would give opponents of the existing Health and Human Services guidance a second chance to voice their concerns—presumably to a more receptive audience this time. And in fact, says Mara Youdelman of the National Health Law Program, "The guidance did get weaker. If the initial guidance was four steps forward, this was probably two steps back." In particular, the newly revised guidance no longer required the same degree of compliance by all providers. "It slipped by moving from an absolute to, essentially, a sliding scale approach," says Ignatius Bau.

Moreover, it appeared to the advocates that, in addition to a weakening of the guidance, there was not much interest in enforcement. "We feel that the Administration has been weak on enforcement—that the Office for

Civil Rights has been understaffed and that it has not been a priority,” says Youdelman. “People do still file complaints, but it can be years before the Office for Civil Rights takes any action, if at all.” A regional federal official with responsibility for monitoring health plans’ compliance with the language access guidance agrees. “We get the sense from D.C. that HMO’s are our friends,” he says.

“Isn’t This About Quality of Care?”

As these events were playing themselves out, The Endowment decided that it was time to convene a national meeting in Washington, D.C., that would bring language access advocates from California and Washington together to take stock of where things stood and what could be done next to advance the language access agenda at the national level—mindful once again that what happened in Washington had very real ramifications for what happened in California.

Held in July 2002—practically on the heels of the Institute of Medicine’s pivotal March 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which had brought to national attention the great difficulty that non-English speakers often had in accessing needed health services—the meeting included not only staff from The Endowment and a who’s who of language access advocates, but also current insiders like Deeana Jang from the Office for Civil Rights, and former insiders like Tom Perez and Maria Echaveste. Among the numerous recommendations to come

out of the meeting, three topped the list: the formation of a national coalition on language access; better data collection; and—not surprisingly, given the list of participants—continued support for federal, state and local advocacy.

Once again, as it had following its initial language access meeting back in 1999, The Endowment was prepared to financially support these recommendations. In keeping with the coordinated approach that it had used in funding its earlier language access grant to the Asian and Pacific Islander American Health Forum, The Endowment again funded a single lead grantee, with multiple subcontracts. In this case, the National Health Law Program took the lead, with subcontracts to four additional organizations that would play key roles in getting the work done: the National Immigration Law Center, the National Council of La Raza, the National Asian Pacific American Legal Consortium (now the Asian American Justice Center), and the Asian and Pacific Islander American Health Forum, which had previously subcontracted work to the National Health Law Program under its California-focused language access grant.

These five organizations, together with the Mexican American Legal Defense and Educational Fund (which was receiving separate funding from The Endowment), formed the steering committee and the nucleus of what was eventually to become a much broader national language access coalition—

although, as Mara Youdelman of the National Health Law Program, who chairs the coalition, is quick to point out, “We didn’t want to be known as the language access coalition. We don’t have a name. That was very explicit.” Keeping the coalition nameless would make it easier for a very diverse group of organizations to sign on. “If the coalition has a name and a list of members, and then the coalition says *x*, it implies that all members say *x*,” Youdelman explains. “Without a name, organizations get the opportunity to sign on to letters or projects one by one without any long-term commitments or implied support of broader issues.”

The true significance of this new nameless national coalition only began to emerge in early 2004, about six months after the grant had been awarded. In preparation for the first meeting of the coalition, which was held in February 2004, the steering committee had put together a long list of organizations to be invited to participate in the coalition, including both advocates and providers. More than 75 of these organizations said that they were interested, and were included in the coalition’s listserv. So far, so good.

But the real surprise, given its continuing opposition to Executive Order 13166, was the AMA. As the National Health Law Program later reported to The Endowment, “Prior to the initial coalition meeting, the Steering Committee met with staff from the American Medical Association to discuss the coalition and how we could work with the AMA on mutual goals. Many areas of agreement were

discussed, including issues of funding, quality of care, competency and identifying resources. The AMA agreed to participate in the coalition.”

The AMA’s participation had not come easily. “There was a lot of tension between the advocacy community and the provider community at that time,” Youdelman recalls. “People were just sort of butting heads as opposed to working together... We tried to find areas of consensus. We took Title VI off the table from the outset, because we knew we could never get consensus on issues related to enforcement. Instead, we focused on funding and other areas where consensus arose. We knew that if we could address funding, it would be a lot harder for the providers to say that they couldn’t provide language access services.”

But, Youdelman says, the true watershed moment that changed the dynamics of the coalition from active confrontation to constructive engagement occurred one day when one of the provider representatives put a simple question to the group. “What turned the process around was when one of the provider groups said, ‘Isn’t this about quality of care?’ And everybody said, ‘Yeah.’ So that’s what framed it. And by framing it as quality of care, that erased a lot of the other issues and concerns and problems.”

As the coalition took shape, its focus became the development of 11 guiding principles that “represent a consensus for a framework to ensure that language access barriers do not affect health outcomes.” As of 2007, some 80

organizations—ranging from the American Medical Association and the American Hospital Association to La Clinica Del Pueblo, a free clinic for low-income Latinos in Washington, D.C.—had endorsed the coalition’s Statement of Principles, which covers the issues of access to language services, funding, quality and accountability. It was not an easy process. It took three years of continual give and take before the AMA finally became a signatory in mid-2007, and even then, there were others who were still on the fence. But the process demonstrated that there were areas of common ground, and that is beginning to pay off in ways that go beyond the principles themselves. Simply put, says Mara Youdelman, “The provider groups have brought openings and brought the ability to converse with [legislative] offices that we [as advocates] don’t have.”

“A Deliberate Strategy of Engagement”

The national coalition’s strategy of engagement was not accidental. The Endowment President & CEO Robert K. Ross, M.D., recalls that, before the grant supporting the national coalition was made, there was considerable internal debate within The Endowment about which path to pursue in its effort to improve language access. Generally, Ross says, foundations try to leverage local demonstration projects that they have supported into new policies at the state or federal levels. “But in this case the policy was already on the books in the form of Title VI—and the Clinton Administration had

affirmed it [with Executive Order 13166]. So should we just fund legal advocacy organizations and use a litigation strategy, or should we pursue a more deliberate strategy of engagement with providers? Our grant-making resources are an obvious resource, but it is our *non*-grant-making resources that are the hidden gem—our relationships with clinical providers as well as with the advocacy organizations. We found that the physician groups and other providers wanted to do the right thing, but that there were lots of barriers—like financing.”

The Endowment also began to make grants directly to health provider groups and develop ways to engage them directly. One innovative approach began in 2002, with a convening of the Medical Leadership Council on Language Access, comprised of the lead staff person and a board member from the California Medical Association, dozens of local county medical societies, physician specialty associations, ethnic physician organizations and other health care provider stakeholders. This was an explicit strategy to build support

As of 2007, some 80 organizations... endorsed the coalition’s Statement of Principles, which covers the issues of access to language services, funding, quality, and accountability.

for language access among California physicians. The California Academy of Family Physicians took the lead in organizing its peers to meet twice a year. Through the Medical Leadership Council, these California physician associations took public positions in support of language access. This process, in turn, helped reverse the positions of their national counterparts, who had opposed the Executive Order and DHHS guidelines. As noted above, even the AMA, which led that opposition in 2000, eventually signed onto the statement of principles in support of language access in 2007.

Looking back, Mara Youdelman believes that The Endowment's decision to promote a strategy of constructive engagement was pivotal. "If there had been no California Endowment, I don't think we'd be working with providers. And although we certainly would have worked on language access without The Endowment, it probably would have been on education and awareness with our like-minded advocacy partners, as opposed to having opportunities for real policy accomplishments."

Even with the support of provider organizations, however, progress at the federal level could be maddeningly slow. One minor but typically frustrating example, says Youdelman, has been the government's persistent refusal—despite repeated efforts by the American Hospital Association and others on the national coalition—to translate many of its Medicare forms for its LEP beneficiaries.

From the perspective of The Endowment, this apparent weakening of federal resolve upped the ante on efforts to strengthen California's state policies on language access. For while technically Executive Order 13166 did still apply to all health care providers and health plans in California that received federal funding—which meant just about everybody—the reality of the weakened guidance, coupled with anemic federal enforcement, meant that little was likely to change on the language access front unless the state itself did something fairly dramatic to reinforce the message.

But what? During the late 1990s, several health advocacy organizations, including the California Pan-Ethnic Health Organization, the Latino Coalition for a Healthy California, and the Asian and Pacific Islander American Health Forum, had successfully persuaded the state to incorporate provision of language access services as an explicit requirement in all of its Medi-Cal managed care contracts, as well as in its Healthy Families contracts. Increasingly, however, some of the advocates were beginning to worry that simply stipulating language access requirements in a contract might not be enough. Contracts, after all, were always open to renegotiation, and depending on who happened to be at the table, the language access requirements could easily become vulnerable. Adding to their anxiety was the Supreme Court's decision on *Alexander v. Sandoval*. Could the *Sandoval* ruling be a prelude to the Court overturning Title VI in its entirety? Because if that were to happen, California's language access

contract requirements—which were explicitly justified on the basis of Title VI—would go right out the window.

Faced with these alarming possibilities, the Asian and Pacific Islander American Health Forum and its partner organizations under The Endowment’s language access grant decided to try to get the language access provisions from the Medi-Cal and Healthy Families contracts codified into state law (although not with The Endowment’s funding). They tried twice, and both attempts failed. The first bill, AB 2739, made it through the Legislature, but was vetoed by Gov. Gray Davis in September 2002. The second bill, AB 154, stalled in committee the following May.

Meanwhile, however, one of the Health Forum’s partner organizations, the California Pan-Ethnic Health Network, with additional funding from another health foundation in California, had been working with several other advocacy organizations to advise and advocate for regulatory changes with the state’s new Department of Managed Health Care, established in July 2000 to oversee California’s huge 23 million member managed care market. “Cultural and linguistic competency was one of the priority issues we worked on,” recalls Ellen Wu, executive director of the California Pan-Ethnic Health Network. “We spent the first year and a half working directly with the Department of Managed Health Care to incorporate language access requirements into existing regulations, such as the grievance regulations, and also advocating for [the

Department] to develop ‘stand-alone’ cultural and linguistic regulations.”

But while the Department’s staff was generally supportive of these objectives, they eventually told Wu and her colleagues that, according to the Department’s legal counsel, they lacked the authority under existing state law to promulgate language access regulations. Undaunted, Wu suggested that, if the Department didn’t have the necessary statutory authority, perhaps the California Pan-Ethnic Health Network and its partners could approach the Legislature and cosponsor new legislation granting that authority to the Department. “Because we had a positive relationship with [the Department] and they had a positive relationship with the Governor’s office, we felt that our bill had a very good chance of getting through the Legislature and getting signed,” says Wu. And, sure enough, the bill, SB 853, was signed into law by Governor Davis on October 8, 2003—one day after he became the first governor in the state’s history to be recalled.

It was—like Executive Order 13166 at the federal level—a remarkable development. Just as the executive order had, in one fell swoop, elevated the implementation of bold new language access rules from just the Department of Health and Human Services to the entire federal government, SB 853 suddenly expanded the state’s authority to regulate language access to California’s entire managed care and preferred provider market—including the commercial plans and

insurers. It was all the more remarkable given that the two earlier efforts, which had limited their focus to Medi-Cal managed care and Healthy Families, had failed.

Attempting to explain this apparent anomaly, Martin Martinez, policy director at the California Pan-Ethnic Health Network, points out that, “SB 853 is indeed more expansive than the other bills, but it was also more clearly addressing a need or a gap. With the prior bills, we were trying to get stronger enforcement of requirements for public programs, whereas with SB 853 we were addressing the fact that there was no requirement for commercial insurers or health plans to provide cultural and linguistic services—other than the Title VI argument, which is complicated. So I think we were able to make a more compelling case that SB 853 was necessary.”

However necessary SB 853 may have been, the subsequent process of developing and issuing the language access regulations that it authorized proved to be an exceptionally long and arduous one, complicated by the fact there were two separate state agencies involved—the Department of Managed Health Care and the Department of Insurance. It took until December 2006—more than three years after SB 853 had been signed into law—before the managed care regulations were finally issued. The Department of Insurance regulations were not finalized until 2007.

Throughout this process, the advocates remained very much involved, providing input and feedback at every opportunity. (Among the opportunities for input were the public hearings in Los Angeles cited at the beginning of this report at which Edna and many other LEP individuals testified about the language barriers and consequent problems they had experienced in the state’s health care system.) Yet in the end, the managed care regulations that were implemented fell short of what the advocates had hoped for. Ellen Wu believes that the second draft of the regulations, which included much of the input from the advocacy community, was much stronger than the initial draft. “Unfortunately, though, the third draft was weaker,” she says. “And that’s what got implemented.”

“A Carrot and Stick”

In July 2000, at the same time that it established the new Department of Managed Health Care, California’s Legislature also created a new and independent Office of the Patient Advocate. While the Department of Managed Health Care was to use a regulatory approach to ride herd over the state’s booming managed care industry, the Office of the Patient Advocate was charged with “informing and educating consumers about their rights and responsibilities as HMO enrollees.” Among other activities, it was to produce an annual Web-based HMO Report Card on the quality of HMO services—and the advocates quickly seized on the report card as another golden opportunity to advance their language access agenda.

Despite some initial reluctance, eventually the staff of the Office of the Patient Advocate, with a great deal of input from the advocates, did come up with a methodology to collect data from the health plans about their language access services, and it was incorporated into the scoring for the HMO Report Card.

In a sense, the decision by the advocacy community to try to include language access measures in the HMO Report Card was consistent with The Endowment's internal decision to move towards greater engagement with providers. The report card represented a broadening of the advocates' strategy from what until then had largely been an adversarial "stick" approach—pushing for tougher federal and state regulatory measures that *required* plans and providers to provide language access—to a more balanced "carrot and stick" approach that included market incentives and that began to reframe language access as an issue of health care quality. Higher report card scores meant higher quality, and higher quality, presumably, would attract more enrollees.

The notion that language access was related to quality of care had actually surfaced as early as The Endowment's initial language access meeting back in October 1999. And it was reinforced by the Institute of Medicine's 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which stressed that health care should "not vary in quality because of personal characteristics such as gender, *ethnicity*, geographic location, and socioeconomic status."³ (emphasis added)

But it wasn't until 2003, when Bau moved from the Asian and Pacific Islander American Health Forum to join the program staff at The California Endowment, that The Endowment began to take the quality side of language access head-on, with grants to hospitals and health systems throughout California and then to national organizations such as the Joint Commission on Accreditation of Healthcare Organizations, the National Committee on Quality Assurance, and the National Quality Forum. With grants to public hospitals and five of the major nonprofit hospital systems operating in California (which included approximately a third of all the hospitals in California), The Endowment began to directly fund changes at the hospital and systems levels. Data about patient language services needs were collected, new interpreter and language services coordinator positions were established, assessments and training

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³ Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (National Academy Press, 2001)

programs for interpreters and clinicians were implemented, and innovative videoconference and other technologies were developed to facilitate language access.

And as their names suggest, the national organizations each play a role in assessing the quality of care provided by the nation's health care providers—including California's. The Endowment's initial grants supported research to enable these organizations to determine how well or how poorly language access was being addressed by hospitals and managed care plans at that time. But the longer-range goal—as with the California HMO Report Card—was for these organizations to begin including language access measures as an integral part of their accreditation and other quality assessment processes.

The logic behind these grants was plain enough. Endowment staff believed that what really moved behavior among health providers and health systems was accreditation. Since those grants were made, the Joint Commission has begun requiring the collection of data about language and communication needs from all patients as an accreditation requirement and, based on research at 60 hospitals nationwide, is reviewing its accreditation, patient safety, disease certification and other programs to incorporate language access issues. The National Committee for Quality Assurance has begun a recognition program for health plans demonstrating excellence in multicultural health and is planning

to propose new accreditation standards in 2009 which would promote culturally and linguistically appropriate services. And the National Quality Forum has convened a national expert panel to develop a framework and identify potential nationally adopted measures for advancing language access and cultural competency as essential for improving health care quality. Clearly, the “improving quality” framework has gained momentum in advancing language access.

“Who’s Going to Pay?”

Yet as important as the “carrots” of quality and market share might be in motivating providers and health plans, the “stick” of regulation remained a crucial part of the advocates' overall strategy. After the Department of Managed Health Care finally issued its language access regulations under SB 853 in December 2006, staff members from the California Pan-Ethnic Health Network and their fellow advocates continued to meet on a regular basis with the department on implementation issues. “We’ve worked with them on the auditing and the monitoring, and now they want to figure out the best way to inform consumers,” says Ellen Wu. “So it’s not over yet. It’s never over.”

The biggest remaining sticking point—as it has been from the start, when the AMA first rose up against Executive Order 13166 and the subsequent Health and Human Services guidance as an “unfunded mandate”—was money. These language access services were

all well and good, the providers said, but who was going to pay for them?

The federal government had given a partial answer to this question when the original guidance developed by Tom Perez and his team was issued back in August 2000, with a letter to state Medicaid directors clarifying that federal matching funds were available under Medicaid and SCHIP to pay for language access services. But the catch was that the states themselves would have to come up with the necessary matching funds.

For states with relatively small LEP populations, this state match requirement wasn't an especially high hurdle. Accordingly, by 2006, 11 states—ranging from Maine and Vermont to Utah and Montana—had come up with the necessary match and were paying their share for language access services for their Medicaid and SCHIP enrollees. But California, with the largest LEP population in the country, was no Vermont or Montana, and so the budgetary implications were likely to be of a different order of magnitude entirely.

In late 2006, in an effort to at least begin to grapple with this daunting financing challenge, the director of the state's Department of Health Services created the Medi-Cal Language Access Services Task Force and charged it with developing recommendations for "the economical and effective delivery and reimbursement of language services under Medi-Cal." Co-chaired by the directors of the

Department's Office of Multicultural Health and the Latino Coalition for Healthy California (one of the partner organizations under The Endowment's initial language access grant to the Asian and Pacific Islander American Health Forum), the task force was deliberately structured to include key provider organizations such as the California Hospital Association and the California Medical Association, as well as advocacy groups such as the California Pan-Ethnic Health Network, the Asian and Pacific Islander American Health Forum, and the National Health Law Program. As Lupe Alonzo-Diaz, executive director of the Latino Coalition for a Healthy California and co-chair of the Task Force, points out, "For the first time in a long time, you're seeing consumer advocates and provider groups working together towards the same goal."

As of January 2008, the Task Force had not yet completed its recommendations. And with economists increasingly predicting a relatively bleak outlook for the nation's and the state's economy in the coming year, Alonzo-Diaz believes that, in the short run, any progress on the financing front will be incremental at best. But even a small step, she says, would be a step in the right direction.

"A Central Tenet of Quality Health Care"

In March 2007, The Endowment hosted a two-day meeting in Los Angeles where it once again—as it had in its initial meeting in October 1999—brought together people

from around the state and elsewhere who were involved with and committed to promoting language access for California's LEP population. Only this time, instead of the handful of advocates, medical interpreters, researchers and health care providers who had attended the 1999 meeting, the meeting had more than 130 participants, including senior leaders from some of the state's largest hospitals and health care systems, state and federal officials, accrediting organizations, provider associations, and health advocacy organizations. Instead of heart-wrenching testimony from patients who experienced language access barriers, CEOs and vice presidents of hospitals and health systems spoke passionately about their personal and organizational commitments to improving language access and care for LEP and other diverse patient populations.

In part, the difference between the two meetings reflected The Endowment's conscious decision to be as inclusive as possible in its efforts to address language access. Now, in 2007, it appeared that this "big tent" strategy was beginning to pay off—not only because providers and advocates were sitting side by side on the various panels at the meeting, but because they were actually *working* side by side towards some of the same goals, both in Sacramento on the Medi-Cal task force, and in Washington, D.C., on Mara Youdelman's national coalition.

Another important difference between the two meetings was the seniority of many of the attendees. The fact that individuals from the highest levels of leadership from some of the state's largest health care organizations and systems were taking two days out of their very busy schedules to talk and learn more about language access spoke volumes about just how far the issue had come in less than a decade. "We're not in the end zone, but we're moving the ball up the field," says The Endowment's President & CEO, Robert K. Ross, M.D. "Ten years ago, cultural competency and language access was seen as a nice thing to do. Now it has become a central tenet of quality health care."

Conclusion

In looking back at The California Endowment's efforts to improve language access over the past decade, a number of useful lessons emerge, most of them with implications that extend well beyond language access alone.

One of the most important lessons has to do with the interplay between activity at the state and national levels, both in terms of the policy process and the work of the advocacy community. For example, the new federal guidance on language access—which helped to pave the way for the development of President Clinton's Executive Order 13166—was directly influenced by the input that Tom Perez received from the California advocates. The executive order in turn helped

to raise awareness among providers and state policy makers, creating a climate that eventually resulted in the enactment of California’s SB 853. This interaction between events at the state and national levels is continual rather than sequential, and underscores the need for advocates at the state and national levels to be constantly in touch with one another and to work together whenever it makes sense to do so.

Along similar lines, the language access story illustrates the extensive interplay that occurs between the legislative and administrative processes. The Executive Order and the new Health and Human Services guidance, which were administrative instruments designed to clarify the requirements under the 1964 Civil Rights Act, helped to trigger new legislation in California—SB 853—which in turn spawned new state regulations from the Department of Managed Health Care and the Department of Insurance. Eventually, additional legislation may be required to come up with the financing necessary for providers to fully implement language access services. This interactive dynamic between legislation and administration highlights the need for foundations, advocates and others seeking to bring about positive change to pay close attention to both aspects of the policy process. Not only are both ultimately necessary in order for real change to occur, but sometimes it may be easier to get initial traction in one arena than in the other.

Administrative advocacy has played an especially prominent role in The Endowment’s language access strategy, both at the federal level and in California. In advancing the language access issue, advocates have engaged closely with the White House, many divisions of the U.S. Department of Health and Human Services, the Department of Justice and the Office of Management and Budget at the federal level and with the California Department of Health Services, the Managed Risk Medical Insurance Board, the Department of Managed Health Care, the Department of Insurance, the Office of Patient Advocate and the Department of Consumer Affairs in California.

Barbara Masters, The Endowment’s public policy director, points out that while it is “not always as sexy” as legislative advocacy, administrative advocacy can be a powerful way to advance public policy. Moreover, because administrative advocacy by foundations is permissible under federal law, Masters views it as “a great avenue for

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foundations” that want to play a more direct role in funding and engaging in the policy process than they are able to on the legislative side. And indeed, at one point Endowment staff did submit written comments to the Department of Managed Health Care on its proposed language access regulations under SB 853.

Another key lesson from The Endowment’s experience with language access is that foundations need to be prepared—and, perhaps even more important, they need to prepare their grantees—to take full advantage of unexpected windows of opportunity that may suddenly open. The fact that The Endowment had provided capacity-building support to health advocacy organizations during the late 1990s meant that when Tom Perez came to California seeking feedback on the federal language access guidance, those organizations had both the staff and the flexibility to respond, thus helping to set the stage for Executive Order 13166. And once the executive order was issued, The Endowment itself had the flexibility to fund activity at the national level—such as the provider coalition spearheaded by the National Health Law Program—to sustain and build on the momentum created by the executive order. Often, as in this case, the greatest opportunities to break through on a policy issue seem to come out of the blue. Had The Endowment and its grantees not had the flexibility and the capacity to recognize and seize on the unexpected opportunities

that arose, many of the recent gains in language access might never have materialized—including the extension of language access requirements to all federal agencies and their funding recipients, and the extension of language access requirements to all commercial health plans in California.

In assessing The Endowment’s key decision points, a critical one occurred early on when it made a deliberate decision to pursue a strategy of engagement with providers, rather than confrontation: looking for and building on areas of common ground, whenever possible. While it is impossible to determine what the impact of a confrontational, litigious approach might have been, it appears that, both in Washington and in California, many of the leading institutions and organizations—including some that were originally quite hostile to the language access agenda—have now actively embraced the principles of language access, and are working hand in glove with the advocates to secure the necessary financing.

Finally, it’s important to note the collective and collaborative leadership that has developed among the advocates, and the role The Endowment’s ongoing support of both California and national coalitions played to help ensure a high level of collaboration and coordination. Moreover, two of the advocates took on new roles—one at The Endowment and one with the federal

government—bringing their considerable expertise and relationships to the language access work inside those entities to effect change.

Financing has been, and remains, the greatest challenge on the horizon. While some providers and health plans have already made language access services available on their own—either because most of their patients speak little or no English, or because they believe that it is in their long-term economic interest to gain a significant market-share in California’s vast LEP population—most of California’s health care system still has a long way to go. While Gov. Arnold Schwarzenegger’s ambitious health care reform proposal recently failed to make it through the senate because of concerns about affordability, perhaps a more modest proposal to improve access to care by financing the state’s share of language access costs for California’s Medi-Cal and Healthy Families population might just make it through on the rebound. Whatever the next window of opportunity turns out to be, success will no doubt once again depend on people’s readiness to respond rapidly, effectively and in collaboration with one another.



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