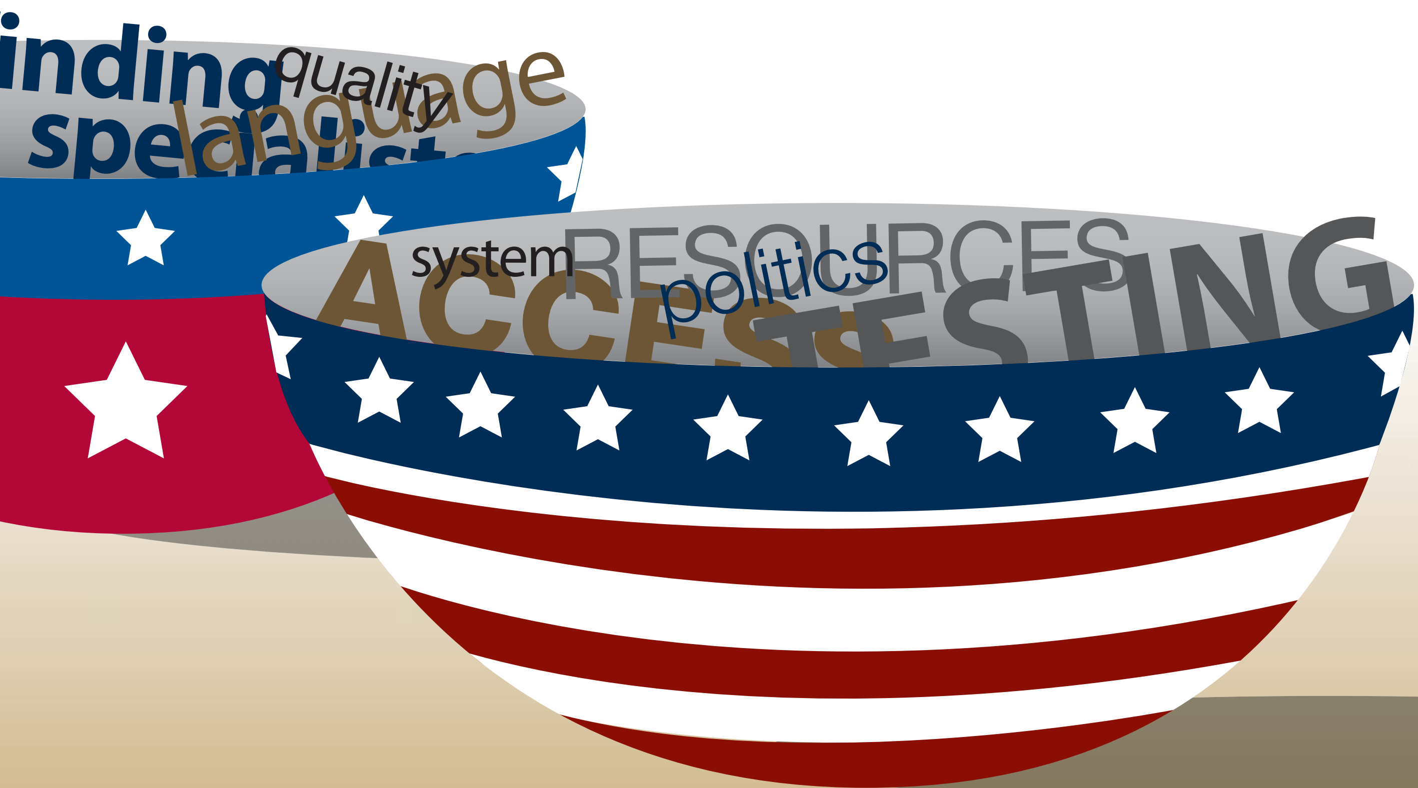
IN AMERICA'S SALAD BOWL, RESIDENTS FIND BARRIERS TO CARE

By Linda Anderberg



Even with excellent medical insurance, it can be difficult to access health care. Your doctor doesn't have an available appointment for weeks, you have trouble taking time away from your work, or your pharmacy closes at 6 P.M. but you have to pick up your child from daycare right after your five o'clock meeting.

But imagine if you don't have decent health insurance, and you're not even sure what coverage you do have or where to go to get help. And you're in a rural area where services are sparse, and you don't have a car—or even a driver's license—and you don't speak the same language as your doctor. Maybe you're not even a U.S. citizen. This combination of problems can turn even a simple doctor's visit into a pipe dream.

Fixing the health care system in California is not just about giving everyone the right to care. Beyond the debate over the cost of health insurance and the levels of uninsured lies the basic need of individuals to have the knowledge and ability required to access their right to care. Take, for example, Salinas Valley residents—the majority of whom are rural farm workers, many of them undocumented immigrants. Among them are women and children taking part in a research study by the **Center for the Health Assessment of Mothers and Children of Salinas** (CHAMACOS). The primary goal of the center's main cohort study is to assess the health effects of low-level, chronic pesticide exposure and other exposures in children living in an agricultural community. And yet—from seven years ago when the mothers were pregnant to today when their children are school age—center researchers have been addressing access to care issues.

Brenda Eskenazi, professor of maternal and child health and epidemiology and director of CHAMACOS, says that the center has often negotiated additional care for the children and their mothers, such as school or medical attention. The reason is often less that the women wouldn't normally get the services and more that they can't access the system. "I would say that a good portion of the women, either because they weren't that familiar with the United States or couldn't speak English, could not readily figure out what to do," says Eskenazi. "So there's access at the level of 'Would they have the right to have this if they knew how to get it?', and there's access at the level of 'They just don't know how to get it.' And there were numerous times when we helped them to get what they had the right to get."

A Scarcity of Specialists

The right to medical and mental health services can be difficult to take advantage of in Salinas Valley for a variety of reasons, including transportation problems, language barriers, and distance issues, but one major obstacle is the dearth of trained professionals. Salinas Valley, considered "America's salad bowl," is rich in agricultural resources and home to an incredibly diverse yield of crops, including lettuce, strawberries, broccoli, artichokes, carrots, cauliflower, celery, and wine grapes. Medical resources are in short supply, however. Although there are a series of clinics dedicated to serving the farm worker population with staff members who do speak Spanish, specialized medicine and mental health services are much harder to come by. For example, at the beginning of the cohort study, CHAMACOS researchers needed to take blood samples from the children, a process that should be routine because it's required by MediCal at 12 and 24 months. But the local hospital was facing a very low success rate; a lack of pediatric phlebotomists in combination with parents' uncertainties about services available to their children resulted in a great number of children missing standard blood screenings.

"In order for us to get the blood for our study, we had to hire somebody, train that person to become a pediatric phlebotomist, and send her down there," says Eskenazi. "There's nobody there."

Even with their phlebotomist in place, researchers struggled with special blood tests. "There was a courier that would go from the different clinics back to Salinas where they could do some of the processing of the blood," Eskenazi explains. "But that courier service only came once a day. And some of the blood couldn't stand there unfrozen, so we had to get dry ice, but there was only one dry ice vendor in the entire valley."

Katherine Kogut, a School of Public Health alumna and CHAMACOS study coordinator, oversees most of the neurodevelopmental testing of the children in the cohort study. She runs into access problems more often now that the children are school age. Her tests now include assessments of mental health symptoms such as early onset of depression, as well as cognitive tests and behavioral inventories. If any red flags go up during these tests, then CHAMACOS researchers can make a referral to the school system to make sure the child is plugged in with the right community resources he or she needs.

"It's pretty frequent that we are making a referral for a child in a case where a parent has had concerns about the child for a long time," Kogut says. "It's rare that we find something that is completely new and surprising to the parent. But the parents have never found a way to communicate that to the school system or haven't known that there was any source of help for them in the school system."

When members of the school system are made aware of a problem, they may still struggle to find the resources to help. Kogut recalls a time when she

spoke to the woman who runs the special education program at a local elementary school about a girl who was expressing suicidal tendencies at age seven. The child was already on her radar, but because the school did not have a psychologist or child counselor who spoke Spanish, they could not intervene. "So that's not going to be a help to this monolingual child. Or a comfort to this monolingual family," says Kogut.

Eskenazi and her colleagues tried to find bilingual specialists able to work with uninsured families on a private family counseling basis, but again faced a resource scarcity.

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Enlisting the Help of Faith-based and Cultural Organizations

Breast and cervical cancer screenings are considered "gold standard" by the U.S. Preventive Services Task Force, meaning that they have been shown to significantly reduce mortality; however, many women are not getting these vital services. Professor Joan Bloom is studying how culture and religion can serve as barriers to health services, and how community resources such as churches can be harnessed to improve access.

In California, breast and cervical cancer screenings are provided to women without health insurance at 200 percent of poverty line. Women can call 1-800-511-2300 to determine eligibility and enroll. Yet African American women are receiving these screenings at much lower rates than other state populations. Bloom—who is a member of the State of California Breast and Cervical Cancer Advisory Committee and serves on the Northern California Cancer Center's board of directors—surveyed clinics participating in the program and interviewed women to find out why. Her research indicates that secondary access issues—travel times, lack of outreach, and cultural insensitivity—play a large role. "For example," Bloom says, "when one African American woman called the 800 number, she was sent to a physician in Chinatown. So she got to the Chinatown clinic and of course, as she said, 'I stood out.'"

Bloom hopes to harness the resources of community churches to help women negotiate the system. She and colleagues are working with Glad Tidings, an evangelical church in Hayward, on a pilot project to provide outreach services, counseling, and even transportation to screenings from church. If successful, the program will be expanded throughout the Bay Area.

Bloom has also begun work on a breast health project with Afghan women in partnership with the Afghan Coalition—a nonprofit organization providing social services to Afghans in Northern California based in the Fremont area, where 60 percent of the U.S. Afghani population lives. Available data suggests that Afghan women may not use the medical care system even if they do have health insurance. While language and cultural issues play a role, Bloom believes religious barriers may be the greatest impediment. "Some of the religious taboos are actually in the Koran," she says, "and some of them, according to my informants, are interpretations in the Afghan culture. So we're trying to separate the cultural barriers from the religious barriers."

Bloom's team is training Afghan women as interviewers and will use the gathered information to develop and culturally adapt education programs to reduce barriers to health care. "There are a lot of issues in terms of moving to a new country with a different culture and losing roots with a religion that regulates family life," says Bloom, "so we're hoping to help."

Barriers to Care, continued

The Trouble with Testing

"It's not just that there are very few psychologists, but there are also few assessment tools that can be used to properly assess these kids," says Eskenazi. The trouble with testing goes beyond finding a good standardized test in Spanish, although that in itself has proved difficult. The real challenge is figuring out how to assess a child who is learning two languages at the same time. There is a paucity of information on assessment of bilingual children: when to know when their problems are really cognitive and not a result of uneven language acquisition, and when to intervene.

"You know, there's so little data on acquisition of cognitive ability and learning in two languages, it's amazing," Eskenazi says, "These kids might be getting lost because we can't assess them."

The language issue as it affects assessment and access to health care is only growing. According to the 2000 census, 39 percent of California residents speak non-English languages at home—a higher percentage than any other state in the nation. Twenty percent of California residents also reported that they don't speak English "very well."

To combat these challenges, Kogut came up with a method to assess their bilingual subjects using a fairly quick vocabulary test that is available in English and Spanish. It takes 10 minutes in each language, so researchers spend about 20 minutes at the beginning of each assessment figuring out the best language in which to proceed with each child. But they still have to take into account the language the child is using in school to learn reading and math. Kogut explains, "When we administer tests of achievement, even if they're stronger in Spanish, it's not going to work to ask them math equations in Spanish if they haven't heard 'plus' and 'minus' in that language."

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The Binder of Black Doom

Eskenazi and Kogut are hushed and somber when they talk about the "binder of black doom." And with good reason. Says Eskenazi, "Each one of these pieces of paper represents a specific case where we either found neglect, abuse, or some situation where the child was in danger, and we intervened outside of the research setting."

She can recall each case in vivid detail. In one instance, a woman came to them for help because she thought her husband was going to abuse her, and she didn't have a safe place to go with her child. The staff realized that it was an emergency situation. "It was not something where we could refer her to a social service and maybe a week down the road something would happen," says Eskenazi. "We did everything simultaneously. We figured out who to put her in touch with in the clinic, but at the same time we were on the phone calling every shelter we could find to see if any of them spoke Spanish and were willing to accept a child. And I think there was one—one of them. Most would accept the woman but not the child. They just didn't have the services or the capacity."

CHAMACOS is a research study and not a social service organization, and so its role in these situations is necessarily limited. "But some of these women don't feel comfortable or know how to access social services organizations," says Eskenazi. "So our staff members serve as an outreach to the community because they're known as being people to talk to, and at the same time are acculturated enough to know how to access the system."

They have combated the "binder of black doom" with a more cheerful binder chock-full of resources they have compiled over time to help serve the Salinas Valley population. The binder includes a list of bilingual social services in the county, including mental health counseling, child abuse and suicide hotlines, and domestic violence shelters.

Farm workers tend a carrot field in the Salinas Valley.

Outreach Can Improve Access

The CHAMACOS study has led to improvements in health care access for study participants, in part because of necessities for the research—as in the case of the phlebotomist and the bilingual assessment tests—and in part because center members engage in a lot of activities that are outside their role because they "have hearts," according to Eskenazi. In addition to collecting outside resources, CHAMACOS researchers are also beginning to provide some resources of their own, based on the findings in their research and their close experiences with the access problems in the community. They have produced an attractive and inviting suite of brochures in Spanish, addressing health issues like exposure to sun, allergies, and protecting children from pesticides. They've also recently launched a kiosk at their prenatal offices where women can access health information using a computer. The kiosk gives the women, most of whom are not computer savvy, a chance to train using a mouse and learn about computer navigation. "At first a lot of the women were reluctant to use it," says Kogut. "They felt like they couldn't learn to use the computer. But once they tried it, it empowered them."

CHAMACOS is also helping to train bilingual individuals and encouraging undergraduates from Salinas Valley to give back to their community. An intern this past summer worked with CHAMACOS conducting research on the accessibility and cost of fruits and vegetables for the farm worker population in the county—finding that there were few stores in the region that offer fresh produce to the farm workers who grow it. Another student plans to develop an education program for seven- to eight-year-old school children on environmental health.

Kogut says, "When I see a kid in our study who pops up with high scores—130 and 140 IQ scores—I'm always thinking 'we need to send that kid to college and we need to get that kid back in this community sharing those gifts.'"

In the long term, Eskenazi believes the solution to the Salinas Valley access problems lies with major policy change. "We have to do something about accepting that we have an immigrant population that's providing the infrastructure to put food on our table and feeding us," she says. "And we can't let them continue to live on fringe and provide medical care for them as if they're on the fringe, and then expect to have food on the table. We're going to have to deal with the bigger picture."