

Let's Work Together: Connecting Research and the Community

The “mountains” in northeastern Oklahoma were ideal for four-wheeling in the summer and sledding in the winter, and people came from miles around to enjoy such recreation. But there was one problem with those mountains: they were actually enormous piles of mine tailings containing lead, zinc, and other heavy metals. Although mining had ceased in the 1970s, its by-products were everywhere—the tailings had long been used as road-building material, foundations for buildings, and filler for children’s sandboxes. And blood lead concentrations in the community’s children were high.

Thanks in part to an NIEHS initiative called community-based participatory research (CBPR), many community members are now curbing their contact with the tailings. CBPR grants unite scientists and community members to conduct research on the effects of environmental health hazards and to educate local residents on how to avoid or mitigate their risk of exposure. Through the CBPR program, the community participates at various stages of the research and intervention effort, including design, implementation, and dissemination.

“The program has been very advantageous for both communities and researchers,” says Allen Deary, chief of the Chemical Exposures and Molecular Biology Branch of the NIEHS. “It really does increase understanding for all the groups involved. Although new to a lot of communities and scientists, in the long run the partnerships can make intervention a lot more sustainable, since the community can continue with it on its own. It also enhances the quality and quantity of the data collected because the community is much more willing to cooperate.”

Bringing scientists and community members together for research and intervention is a novel approach in the world of population-based biomedical research—research that is based on defining a certain population, such as children, Hispanic people, or residents of a particular town. Scientists had been finding themselves increasingly shut out of the communities they wanted to study; residents feared being treated like guinea pigs and then abandoned by those running the studies. Historically, many investigators had conducted their research with little regard for the needs of the communities in which this work was



Cultural exchange. As part of a CBPR-funded project in North Carolina, researchers developed an illustrated brochure on pesticide safety aimed at Mexican farmworkers. Titled “El Terror Invisible” (the invisible terror), the brochure stresses the idea that, even though workers may not see the pesticides, they are still there and can cause health problems if used improperly.

carried out. The findings did little to benefit the communities studied or were not useful in developing and implementing successful intervention strategies.

“You need to gain the trust of the community,” says Wilma Brakefield-Caldwell, a community representative for the Detroit, Michigan-based grassroots group Community Action Against Asthma. “A lot of the people in this community were saying that the problem was that scientists were coming in, doing their research, and leaving—they wrote their papers and never shared the information with the community or developed a resolution to the problem that the community could use. So people started wanting to know how research was going to add value; they started getting very picky about who could do research here. With this partnership, however, it works much better.”

Pockets of Partnership

CBPR grants currently involve projects focused on pesticide exposures, lead poisoning, and asthma in rural and urban areas throughout the United States. Regardless of location, however, the goal is always the same—to bring together the scientists who understand the hazards and the community members who know how to best reach those potentially affected.

Pesticides in North Carolina. In eastern North Carolina, many tobacco farmworkers are Mexican, speak little English, and often do not read Spanish. A CBPR-funded project there has spent three years developing and implementing an intervention program to help reduce farmworker exposure to pesticides in the fields. During the first year, researchers at Wake Forest University in Winston-Salem and community members met with hundreds of farmworkers, often visiting the camps where they lived, to develop educational materials that would be culturally appropriate and effective.

“Many farmworkers believed that if you couldn’t see a pesticide, taste or smell it, it wasn’t there,” says Thomas Arcury, an associate professor in the Department of Family and Community Medicine at the Wake Forest University School of Medicine. “The main thing we had to get across was the whole idea of pesticide residues—we call it the ‘invisible terror’—[that] even though you can’t see it, it’s still there. We wanted to make them aware of the problem and then discuss ways to reduce their risk, such as washing their hands, wearing protective clothing, and cleaning their work clothes separate from their regular clothes.”

But through conducting interviews and coming to understand cultural attitudes, the researchers could see that carrying out these

tactics would not be easy for the farmworkers. For example, water is not always available for washing hands in the fields. Sometimes the only water is ice-cold, and many Mexicans prefer not to put cold water on hot hands. Laundromats can also be difficult to get to on a regular basis, and the workers may lack the money to separate work clothes and regular clothes into different washing machines.

“We suggested that several workers pool their work clothes together in one machine,” says Arcury. “We also suggested filling plastic jugs of water and taking them out in the fields with them each morning. Another challenge was encouraging them to shower as soon as they return home from work—some workers prefer to wait until their bodies ‘cool down.’ And they often couldn’t tell their boss what they needed; most tobacco farmers don’t speak Spanish. So we had to help farmworkers understand how they can take action, how they can educate their employers.”

Lead in Oklahoma. Developing culturally appropriate messages was also a challenge in northeastern Oklahoma, home to eight small tribes of Native Americans. Seventy-five years of lead and zinc mining had left piles of mine tailings, known locally as “chat,” as well as contaminated flotation ponds, which were used in the mining process to separate the desired minerals from the tailings. The area, covering hundreds of acres of Indian-owned land in rural Ottawa County, was designated a Superfund site in 1984 in response to potential contamination of a regional aquifer; current Superfund efforts include excavating yard soil in the area. A population-based survey conducted door to door found a high prevalence of lead

poisoning in children ages one through six.

“Before EPA started cleaning it up, the chat was used in ballparks, playgrounds, roads, construction, many different areas,” says Michelle Kegler, an assistant professor in the Department of Behavioral Sciences and Health Education at Atlanta’s Emory University. Kegler was at the University of Oklahoma College of Public Health when it received a 1996 CBPR grant to work with the Native-American community on its environmental lead problem. “Years ago, kids swam in the flotation ponds,” says Kegler. “People didn’t know it caused health problems. And some residents felt it wasn’t significant—they felt the government was just coming in and making a big deal over nothing. We needed to make people realize that this really was a problem, and to overcome those antigovernment attitudes.”

The researchers and community members created the Tribal Efforts Against Lead (TEAL) project to develop and enact strategies for reaching out to the community. The project used a lay health advisor model because it builds on existing social networks within a community to prevent disease and promote health. Through a consensus-building exercise featuring brainstorming sessions, tribal members and representatives from local organizations developed an action plan with objectives for behavioral and policy change.

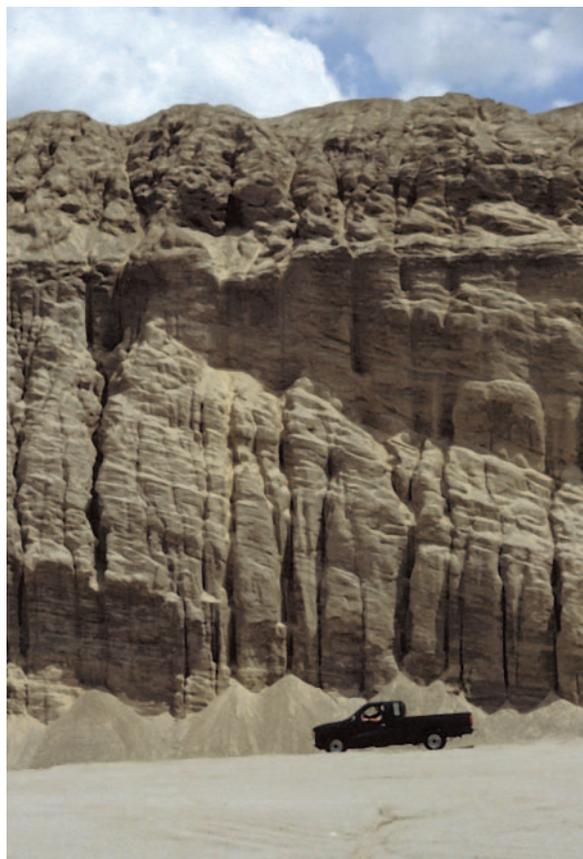
“To gear the program for the Indian community, we thought we should pattern it after the clan system and have a ‘clan mother,’” says Sally Whitecrow-Ollis, TEAL project coordinator. “The clan mother is very

wise and people go to seek her counsel if we have a problem, or to get her blessing. We asked for five volunteers from each of the eight tribes, and that’s how we got our core group of clan mothers and clan fathers. They each received two days of training on lead poisoning and prevention.”

The volunteers spent the next two years passing the information along to the rest of the community. They set up booths at county fairs, powwows, carnivals, and sidewalk sales. They handed out items such as pens, emery boards, and balloons that had been imprinted with simple messages on how to reduce exposure in the home—wet-mop regularly, wash children’s hands, eat foods high in calcium and iron, and avoid playing in the chat. Some clan mothers worked with the local Boys and Girls Club to bake Valentine’s Day cookies and slip lead-related messages into the boxes along with them.

“We also had stickers made,” says Whitecrow-Ollis, “that had our Terry Teal logo on them. One of our clan mothers is an artist and made drawings to go with the messages in a Terry Teal coloring book we handed out to the children with little packs of crayolas. But we also realize that you can’t just do something like this one time and expect that’s all you have to do—the problem is going to be here for a long time.”

A tale of tailings. Decades of lead and zinc mining in Oklahoma left mountains of tailings known locally as “chat,” which were used by the community for recreational purposes and provided a backdrop to settings such as the Little League field below. CBPR scientists worked with community volunteers to teach townspeople about the health concerns associated with chat.



Asthma in Michigan. In the economically disadvantaged neighborhoods of east-side and southwest Detroit, CBPR-funded scientists from the University of Michigan at Ann Arbor and community members have combined a more traditional epidemiologic research project, which assesses the effect of air quality on asthma, with a household and neighborhood intervention to reduce children's exposure to environmental triggers for asthma. Three Detroit children have died from asthma attacks in the past two years, according to Brakefield-Caldwell.

"This was a real learning experience for the community," says Brakefield-Caldwell. "The community had input as to how we thought we should carry out the research; we looked at different methods and decided how it should be done. The community environmental specialists have learned a lot about asthma, and they can share that information with their neighbors, relatives, and friends. . . . They teach participants how to keep the dust down in their homes and how putting plastic covers on mattresses and pillows helps [with] asthma." She continues, "The specialists have

the steps they took to conduct baseline population-based blood lead screening in the Ottawa County community in the summer and fall of 1997. They hired 14 community residents to visit more than 5,000 households to identify eligible families. Blood samples were then drawn from more than 300 children, a 60.2% overall response rate.

They conducted a second screening in the summer of 2000 to assess changes resulting from the intervention (those results are not yet available). Data collection involved in-person interviews with the primary caregivers



Fighting asthma in the Motor City. A CBPR project in Detroit is assessing the effect of air quality on asthma in children. Community members are also teaching their peers ways to protect their children against environmental triggers for asthma.

The first step was to identify children with mild persistent and moderate-to-severe asthma through the elementary schools in the intervention area. The schools agreed to send letters with a self-administered screening questionnaire to all parents. As an incentive, parents were offered discount store coupons if they completed the questionnaire, a strategy that yielded a good response, says Brakefield-Caldwell. The children were next skin-tested for allergens such as grass, cockroaches, cats, dogs, and dust mites.

For the air quality exposure research part of the project, the participating children are being asked to blow into a peak flow meter during two weeks every season for two years to evaluate the health effects of changes in air quality. The sampling is done at times when asthma symptoms have been statistically proven to be the highest, such as mid-July and late September/early October. A subsample of 20 children is involved in intensive indoor air sampling during these seasonal measurement periods. Air quality monitors are placed in their homes, and the children carry personal air quality monitors in special backpacks during their waking hours.

For the intervention research part of the project, four community environmental specialists, all residents of the community themselves, were trained to conduct home educational visits to participating families to teach them how to reduce indoor environmental triggers for asthma. In addition, community organizers will soon be hired to work with neighborhood groups on the reduction of environmental stressors.

seen quite a bit of impact; they say they've seen some changes in the homes they're working in. Because they live in the community, they feel like they can better help the community."

But Is It Science?

Involving residents in the research conducted in their neighborhoods can help scientists overcome community resistance to their work. CBPR introduces variables, however, that are not often considered in traditional research, such as the potential for community involvement to bias the results. The question is, how does this kind of research stand up to peer review?

"All applications go through NIEHS's customary rigorous peer-review process to be sure a project has all the usual standards of objectivity," says Deary. "Maybe some more traditional scientists might have a question in their minds about the objectivity of a CBPR project, but we really go through a number of steps to be sure they're valid."

"It's a fairly complicated process," adds Arcury, "because it's more behavioral science than lab science. Community partners may have their own agenda, but can you give me an example of anything in which there is not some bias? . . . You try to reduce the potential for bias as much as possible by, say, coding and double-checking the data, but this kind of research is by nature more complex than any research carried out in a laboratory."

Such measures are described in an article by Kegler and colleagues to be published in an upcoming issue of *Environmental Epidemiology and Toxicology*. They discuss

of the participating children and covered a wide variety of health-related information. The study protocol was reviewed by the Institutional Review Board of the University of Oklahoma Health Sciences Center.

The group also conducted environmental assessments of 245 residences in the area, including all residences with a child whose blood lead concentration was elevated, as well as a random sample of other participating residences. Soil samples from around the house including indoor and outdoor paint, dust samples from within the home, and kitchen tap water were assessed. The assessment team followed U.S. Department of Housing and Urban Development and U.S. Environmental Protection Agency protocols. Results from those assessments will be published in the near future.

Building on Success

So far, the clearest indicators for the program's success have been in intervention. Community members often know better how to reach their neighbors with key messages on reducing exposure to environmental health hazards. Based on their progress to date, a number of CBPR programs have been funded for the next phase in their research, allowing follow-up studies on possible health improvements in the communities as a result of intervention.

In the past, such access to community residents may have been limited or impossible. Today, however, by involving those whose needs were often overlooked in the past, everyone stands a chance at benefiting from the effort. —Rebecca Clay