

Community-Based Projects Help Scholars Build Public Support

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With backing from some federal agencies, more scientists look to local groups to help plan research agendas

CHICAGO

Cambodian refugees scarred by torture are among the 10,000 low-income elderly and disabled immigrants who live in three north-side neighborhoods here -- Uptown, Edgewater, and Rogers Park.

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The full text of the Loka Institute's new report: "Community-Based Research in the United States"

Last year, researchers at Loyola University of Chicago, and members of two community groups working with them, found that the Cambodians were once more facing traumatic circumstances.

In a prime example of a fledgling field known as community-based research, the researchers and their partners showed that a threatened cutoff of federal welfare benefits would devastate many of the refugees and other immigrants, and strip tens of millions of dollars from the local economy.

After the Chicago Sun-Times publicized the study, Philip Nyden, a Loyola sociologist, got a call from a powerful state Senator who represented part of the area, and who was worried about the situation.

Mr. Nyden referred him to the two community groups that had requested the study and had helped plan and publicize it -- roles that local groups take on under the community-based model. Within a few weeks, the Illinois legislature passed a bill authorizing \$10-million in state money to ease the impact on both elderly and disabled immigrants and local businesses.

The Policy Research Action Group, a consortium of four local universities and more than 20 community groups that Mr. Nyden heads, is a leader in community-based research -- studies conducted by or with, and for, communities. It also includes scientists and students, so that it often (but not always) involves academe.

Such work now accounts for a minute fraction of the total amount that government, industry, and foundations spend on research. But community-based research is beginning to generate attention in high places. For one, it has been the subject of

discussions at the White House Office of Science and Technology Policy. Neal F. Lane, the office's new director, has urged scientists to better explain to their communities how science serves the public.

With universities under unprecedented pressure to prove a public payoff for the vast sums of federal and state funds they spend, advocates say community-based research should be part of the answer.

They say the power of such research to meet the needs of ordinary Americans -- especially disadvantaged citizens whose needs are most desperate -- could provide one new rationale for the huge public expenditures on academic research, now that the old rationale -- the Cold War -- is dead.

"When you bring research to the level of people, they're going to have a much better idea of what science can do for them," says Anne C. Petersen, former deputy director of the National Science Foundation and now a senior vice-president of the W.K. Kellogg Foundation. Taxpayers who take part in community-based studies, she says, "know very well what they're getting for their money."

Some scientists are skeptical about the new model. It sounds good, they say, but well-meaning researchers may be manipulated by community activists with a strong ideological bias, who may try to include loaded questions in the studies. There's also a danger, scientists say, that a small but vocal minority may set itself up as speaking for "the community."

"You say 'community-based research' and it sounds like apple pie," says Stanley Rothman, who directs Smith College's Center for the Study of Social and Political Change. "But it depends on who's baking it," and on the "quality of the ingredients that go into it."

Including a community in research on an issue that directly affects it, and involving undergraduates in interesting research, are important goals, he acknowledges. But the main criterion for financing a research project, he says, should be the proposal's scientific quality.

"I don't care if it's local, shmokal, dokal, or pocal," he says. "Let's do it if it's good research."

Proponents of community-based research say it is, in many ways, a reinvention of a venerable old model -- land-grant colleges. Their original mission included working closely with communities to meet their research needs. The new model, they say, emphasizes community participation in research, allowing a wide range of both rural and urban citizens to help initiate studies, carry them out, and decide how to use the results.

Still, many scientists who work with communities note that their research faces criticism from some colleagues. They're sometimes accused, they say, of not doing "real science," or of promoting "scare science," skewed by emotion.

In their own defense, some scientists point to the intense pressure on academic scientists to make businesses their research partners. Similar issues of objectivity apply to those studies, and working with community groups is one way colleges can balance that pressure, the researchers say.

Mary E. Northridge, an assistant professor of epidemiology and environmental-health sciences at Columbia University, works closely with West Harlem Environmental Action Inc., an advocacy group. Together, they have studied the links between childhood asthma and air quality in Harlem, including allergens from cockroaches and rodents, and diesel fumes from heavy traffic and bus depots. She has helped train teenage members of the group to collect data.

Yes, she says, the scientists who work with community groups come to care about the people the groups represent. But that makes them more intent upon keeping up the rigor of their science. "When you do care, you care about the work being good," says Ms. Northridge, editor of *The American Journal of Public Health*.

Universities themselves have much to gain from seeking more support for community-based studies, proponents say. The research, they point out, often involves graduate and undergraduate students, and so it can unite all three academic missions -- research, teaching, and service -- in creative ways that enliven each one.

"What we're finding is that for many college students, this kind of learning gives meaning to their educations," says Barbara Lieb, a senior researcher for the Education Department's Office of Educational Research and Improvement.

A new study by the non-profit Loka Institute, which receives support from Kellogg, chronicles the movement nationally. Loka, based in Amherst, Mass., promotes broader public participation in planning and executing the nation's research agenda, and is organizing a worldwide network of researchers and organizations interested in community-based studies.

Its rough estimate suggests that about \$10-million of the \$170-billion spent on U.S. research and development in fiscal 1995, from all sources, went to community-based studies, which it describes as those that focus on issues identified by grassroots or public-interest groups, labor unions, or local government, and that involve the groups in conducting the research.

Richard E. Sclove, the Loka Institute's executive director, says the size of the gap shows a "striking mismatch between well-endowed, mainstream research" -- driven by the federal government, business, and universities -- "and the urgent needs of communities."

Academe's skills could indeed help community groups, says Carlos R. DeJesus, executive director of Latinos United, a group in Chicago. "The work that we do would be infinitely enhanced if we had the brilliant minds at universities come in and do work that's not only relevant to their own research interests, but that's socially relevant to the group," he says.

Latinos United, in partnership with the Policy Research Action Group, the University of Illinois at Chicago, and a state housing coalition, carried out a recent study that showed that few Hispanic people were benefiting from federal housing subsidies. The study helped the group win a lawsuit against federal and local agencies.

Right now, financial and professional incentives are few for institutions and researchers to pursue community-based research.

Few federal programs -- all of them relatively new and small -- encourage or require researchers to set up partnerships with communities. The Departments of Education, of Housing and Urban Development, and of Health and Human Services, and the Environmental Protection Agency, support such work.

Ms. Petersen, of the Kellogg Foundation, would like to see the National Science Foundation join that list. The N.S.F., she says, has a "superb track record" of developing and evaluating innovative models for research and education. With a well-designed pilot study, she says, it could do the same for community-based studies.

At the federal level, one of the strongest pushes for community-based research is coming from the National Institute of Environmental Health Sciences, under the leadership of its director, Kenneth Olden. Part of the National Institutes of Health, it supports a range of research related to "environmental justice." Such studies look for links between -- and solutions to -- the higher rates of disease and death and the higher levels of pollutants in poor communities.

The agency's awards in that area require researchers to work with local groups. Some allow the groups to take the lead on a grant. Community leaders help design most of the studies, and help researchers carry out the public-health efforts that result.

Public-health goals, Dr. Olden says, can't be achieved without such collaboration. "The public really ought to be involved from the very beginning" in developing such studies, he argues.

But there are several disincentives for a researcher to embark upon community-based work -- including the local and even national controversies that may ensue.

Ask Marvin Zelen, a professor of statistical science at Harvard University's School of Public Health. In the early 1980s, he helped conduct a now-famous study of the unusual rate of childhood leukemia in Woburn, Mass., and its relationship to the dumping of toxic wastes near drinking wells there. He testified to Congress about the results of the study, which was based, in part, on data collected by hundreds of local volunteers.

"I think if the chemical industry had had their druthers, they would have bombed my house," Mr. Zelen says. "We kind of wrecked the fund-raising efforts of the School of Public Health for a while."

Scientists also say community-based research often takes more time -- and sometimes more money -- than they originally assume it will. And a local focus requires researchers to be more creative in translating the results into a publishable academic article.

That can make such research risky for someone like Ms. Northridge, who is not yet tenured, she notes. Because of the goodwill generated in the local area, academic administrators often praise researchers for their community studies, she says. But will they be penalized for concentrating on such work? "You're taking a career risk," she says. "We're all watching to see if we're going to be promoted and supported."

If some scientists fear a scarcity of career rewards for treating communities as equal partners in their research, local leaders say that for communities, the rewards of traditional academic studies are clearly lacking. Communities have too often been burned, says Mr. DeJesus of Chicago's Latinos United, by researchers who used them as little more than data points.

"There's been a history of universities coming into a community and researching it to death -- research that was purely for the scholarly purpose of the university, and may not have presented any concrete benefits to the community," he says. "We were more the object of the research. So there never was any true partnership."

Larry Wilson, of Yellow Creek Concerned Citizens, in Bell County, Ky., agrees. Community-based research, he says, means that the people with the Ph.D.'s are finally recognizing the expertise of people who deal firsthand with the social and environmental issues that many academics want to study.

When dozens of hogs on his and neighboring farms died after drinking water from Yellow Creek, he says, he helped start the citizens' group to find out whether the dumping of wastes by a nearby tannery might have been the cause.

A university came in with a contract to study the matter, and declared the evidence to be inconclusive. Its researchers refused to let local citizens participate, Mr. Wilson says, because they wanted their results to be objective.

But his group didn't let the matter rest. It persuaded Vanderbilt University to train the group's members to conduct their own survey. Based on the results, they determined a safe water line and have taken their grievances to court.

"Just because we don't have all those letters after our names doesn't mean we can't talk, we can't think, we can't understand what's happening to us," Mr. Wilson says.

"We have to involve the people whose lives are involved."

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