

Still Moving
Toward
Environmental
Justice

Environmental justice should become a higher priority and communities of concern must play a more active role in research and intervention, according to a report published in March by the National Academy of Science's Institute of Medicine (IOM). Three years in the making, the report, *Toward Environmental Justice*, was funded by a consortium of agencies including the NIEHS, the Centers for Disease Control and Prevention (CDC), the U.S. Environmental Protection Agency (EPA), and the U.S. Department of Energy. The IOM's 15-member Committee on Environmental Justice authored the independent review, which "is meant to serve as an introduction to the issues [of environmental justice] and a guide to how one should look at them and address them," says Baruch Fischhoff, a committee member and a professor of both social and decision sciences engineering and public policy at Carnegie Mellon University in Pittsburgh, Pennsylvania.

Committee members representing academia, the public interest, medicine, law, and industry met with stakeholders, citizens, public officials, and industry representatives from

around the United States to assess the need for better research, education, and health policy related to environmental justice.

They traveled to communities of concern in cities such as Chicago, Illinois; Tucson and Nogales, Arizona; Hanford, Washington; New Orleans, Louisiana; and El Paso, Texas, among others. The committee coined the phrase "communities of concern" to describe those groups of individuals suspected of having disproportionately high levels of exposure to environmental stressors, including chemicals, biologics, allergens, traditional toxicants, light, noise, odors, and particulate matter. Such individuals may also have limited access to health care and education, be politically disenfranchised, have low socioeconomic status, and belong to a racial or ethnic minority group.

Upon completion of the report, IOM representatives briefed the funding agencies and made the document available to relevant congressional committees. "Though the report doesn't break any startling new ground in

terms of environmental justice, it does emphasize how complex this issue is," says Roger O. McClellan, president of the Chemical Industry Institute of Toxicology and a member of the IOM committee. "The point we make is that environmental justice is multifaceted and overlaps other related issues, such as income, nutritional status, and access to health care."

"Environmental justice has been there since the beginning of time," says David R. Baines, a family physician at the St. Maries Clinic in St. Maries, Idaho, and a member of the committee. The St. Maries clinic is on the Coeur d'Alene Reservation, where many residents rely on hunting wild game for subsistence. Environmental contamination from nearby silver mines affects their food supply, says Baines. "Hopefully, this report will help more people see that environmental justice is out there, because a lot of people have their heads in the sand about it."

The report calls for more research to help identify and verify the environmental causes of disease. It also recommends that citizens be recruited to participate in the design and execution of the research, and that communication during all phases of the research be open and reciprocal. The report emphasizes that the scientific approach should be "in balance with the recognition that the community must play an increasingly active role in decisions about research and public health interventions." The report goes on to state that environmental justice issues "do not lend themselves well to cost-benefit analyses," so approaching them from that perspective "would not be helpful at this time." Furthermore, the report concludes, environmental justice requires an "unusual degree of collaboration with the communities in order to be scientifically valid and policy-relevant."

Improving the Data

Nogales, Arizona, is a community of fewer than 30,000 inhabitants on the U.S.-Mexico border. Across the border is another Nogales—Nogales, Mexico, a city of several hundred thousand people and home to several *maquiladoras*, mostly U.S.-owned assembly or manufacturing plants that process imported materials (such as cleaning electrical components) before re-exporting them to the United States and other countries. *Maquiladoras* were created in the early 1970s and are not subject to U.S. environmental laws and regulations.

"I remember what it was like before the *maquiladoras*," says Anna Acuña, director of Living Is For Everyone (LIFE), a now-defunct community-based clinic in Nogales, Arizona, that operated from 1991 to 1997. "My parents lived into their 90s. Then all of a sudden you start seeing cases of lupus and

rare cancers. People came together and pooled their data and we were appalled."

The IOM committee visited Nogales and met with local citizens, including Acuña. They listened to the community's fears about the unusual number of residents that were being diagnosed with such serious diseases as systemic lupus erythematosus, multiple myeloma, leukemia, and other types of cancer. LIFE had already conducted its own grassroots study by reviewing death records, noting the cause of death, and mapping where the deceased had resided and the sick still lived.

"So what was the trigger for lupus?" says Acuña, who has herself been diagnosed with the disease. "We looked everywhere. The only thing we could come up with was, first, the air—there's lots of stuff in it." Discharges from the nearby manufacturing plants, large-scale burning at dumps, and emissions from a specialty resin plant have created a curtain of smoke or haze over the city, according to the IOM report. The townspeople also suspected the water. "There's an arroyo, a long ditch, that runs from the Mexico side to our side," says Acuña. "We're a community of 18,000 downwind from the Mexico side. . . . The arroyo runs through both towns." During their visit, the IOM committee found that the arroyo was filled with solids and runoff water from the *maquiladoras*.

A 1994 study by the University of Arizona at Tucson, the Udall Center Survey of Data Sources and Gaps Regarding Environmental Health Problems Affecting Residents along the U.S. Mexico Border, which was presented at an NIEHS-sponsored conference on environmental equity and justice and described in the IOM report, confirmed LIFE's suspicions. The study found that from 1989 to 1993, the incidence of multiple myeloma in Nogales was 2.4 times the expected rate; the systemic lupus erythematosus rate was 94.5 cases per 100,000 residents for the same period, compared with the next-highest published rate of 50.8 per 100,000. As a result, state and local governments and the local universities have become involved in monitoring the population.

Residents of Nogales say the *maquiladoras* have since cut back on their large-scale burning, and the water in the arroyo is now chlorinated to reduce the bacterial load. However, Acuña says, much more research needs to be done. "I went to EPA and CDC meetings," she says. "They had done some testing for a whole year on the air quality. The preliminary report didn't find anything. It was what I'd expected because I feel at this point we're never going to find out what's making us sick. Lots of money has been

poured into the community for testing and research but nothing has changed for the man in the street."

The committee also visited a public housing community in southeast Chicago, where the 10,000 predominantly African-American residents have been exposed to a variety of environmental stressors, particularly air pollution and contaminated well water, as well as high concentrations of ambient lead and fine dust particles. Among the community's health concerns are childhood cancer, endocrine disorders, and asthma. Many members of the community also believe their houses were constructed on top of chemical and biological waste sites. Several federal, state, and local agencies have been evaluating and investigating the community, according to the report.

"During six days of site visits, we wanted to hear what people had to say in their own terms," says Fischhoff. "We were looking at the issues that made people feel frustrated and not respected. And what we heard was communities being quite distrustful. They see the researchers come in [and take samples], and they feel that science is somehow biased against them." The report strongly recommends participatory research that would provide an opportunity for community members to explain how they live and how they are affected by the exposures. Says Fischhoff, "Communities need to have some way of articulating the beliefs and perceptions of the community [in a way] that will make sense to the scientific community."

As a result of their site visits, the committee acknowledges that adverse health effects are often suspected first by the people who experience them rather than by the health care or scientific community. The committee encourages public health officials and researchers to pay close attention to the experiences of individuals in local communities. The committee also says that public health officials should help community activists and local medical personnel document health outcomes and health status in a reliable and unbiased manner.

Jeffrey French, a research associate in the health sciences policy program at the IOM, says it was difficult for the committee to make precise recommendations in that arena. "Though the concept [of environmental disparities] has been around for a number of years, the data for environmental justice are just starting to emerge," he says.

"I am sympathetic to some of the public's observations that we scientists do all these studies and never come up with anything," says Tim Flood, medical director for the Bureau of Public Health Statistics at the Arizona Department of Health Statistics. "When we first got started, I thought it

would be very easy to do these studies and then we'd simply clamp down and solve these problems," he says. "But I've become very disillusioned; it's very difficult to get to the bottom of what's causing the problems."

"The burden of proof is still on the citizenship," adds Acuña. And because activists are often not scientists, their evidence may be considered anecdotal. "You have to prove to all the different institutions that there is a problem. So when you have people like myself, that's pretty tough," she says. There can also be repercussions from a frustrated community. "Being an activist is probably the loneliest thing you can do," says Acuña. "People in the community got mad at me. They said, 'Anna, you're hurting the tourist industry, the real estate industry with all this.' And then I got criticized because the people were sick and they wanted to know why. I had nothing to report." Acuña says she also speaks for many activists when expressing her dismay with governmental inaction. "I'm tired of dealing with bureaucrats," she says. "I've given up on the government. The degree of frustration at such meetings is intense. You get to the point where you really wonder if anyone cares."

Getting the Word Out

During the IOM site visits, the committee "was struck by the extent to which the citizens of communities of concern felt virtually defenseless against what they believed to be unreasonable and unfair environmental impacts. They felt that they had been abandoned by both the government and the local industry," according to the report. The committee heard repeatedly from participants at the site visits about the difficulties associated with the fact that there is no well-identified point of contact at the various agencies responsible for responding to their concerns. An important part of the solution is to build a well-informed community response system, the committee says.

"The biggest thing I pushed for as a report recommendation was to find a way to coordinate the reporting process for the communities," says Baines. "There are so many different agencies doing this and that, that it's become like a headless monster. If nothing else, people can join a joint task force. But though the . . . community feels they're getting the chance to voice their concerns, still nothing happens."

Don Mattison, medical director for the March of Dimes Birth Defects Foundation and cochair of the IOM committee, agrees. "Just as the committee raised some issues about exposure and disease but were frustrated by an inability to link them, this was the same frustration in the communities. The communities have no single place to go for

help in resolving [environmental justice] issues. One frustration we heard a lot is that citizens will go somewhere to report a complaint or request information and get bounced from place to place. So we recommended that governments look for ways to form a seamless process. One option would be to appoint one agency as the coordinator; for example, the CDC or NIEHS could be tapped as the lead agency for coordinating and providing the primary response."

The report also recommends that health professionals be better trained on environmental justice issues; specifically, medical students and residents should be better trained in environmental and occupational medicine. Such training would help them recognize sentinel health conditions such as bronchitis, recent onset of asthma, contact dermatitis, and other environment- or occupation-related diseases.

Funding for public health practice, research, and education should also be increased, according to the report. Because of a trend toward funding basic rather than public health research, resources are often inadequate to support basic public health services and the training of public health professionals. The report does not say from where this additional funding might come.

The report expresses concern that new health professionals are not being adequately recruited from among the country's racial and ethnic minorities. The number of minority students demonstrating a commitment to providing medical care in their communities should be increased, possibly through targeted scholarship programs, which might facilitate the recruitment process, says the report.

"There was a concern that we [the environmental and scientific community] weren't as active as we could be in recruiting young individuals into environmental sciences," says Mattison. "One potential route would be to get them involved in characterizing the environmental hazards where they live. Here's an example of kids engaging with their community. You could argue it's trivial but who knows [where] it might lead?"

The public also receives little information about environmental health issues, and what it does receive is often delivered in language that is "too technical or full of jargon and . . . illustrated with examples that are obscure or culturally insensitive," says the report. The report mentions several community outreach and education programs in which community leaders and members have effectively collaborated to create solutions.

The report suggests that one such solution would be to educate children in the community. Children should be encouraged to become familiar with all the real and

potential environmental insults in their schools, neighborhoods, play areas, and homes. The report describes the case of a Bronx elementary school student who may have saved the life of her grandmother. The grandmother had been complaining of headaches, stomachaches, and a feelings of tiredness. Following classroom lessons on air pollution, the granddaughter suggested the older woman have her home checked. A faulty furnace was found to have raised the carbon monoxide levels in the home, which was causing the grandmother's illness.

Making Policy

According to the report, when the science is incomplete with respect to environmental health and environmental justice issues, policy makers should exercise caution on behalf of the affected communities. They should be careful to neither overreact nor underreact. Acting prematurely may needlessly end an activity or close a facility that is doing no real harm, and that may actually be improving the local economy through taxes and jobs, says the report. It may also stigmatize a community as being contaminated, and may discourage future development. On the other hand, the report warns, acting too slowly may expose citizens to irreversible damage from risks whose actual existence may never be proven, given the limits of scientific methods.

"There is a responsibility for the policy maker and the community to take action," says McClellan, "but it needs to be taken in a responsible way. And further data may not provide the answer. If there is concern about groundwater contamination, for example, the appropriate approach might be to urge the local authorities to shift from local wells to a community water system. We don't have to wait for all the data to come in."

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