

***Symposium on Health
Research and Needs
to Ensure
Environmental Justice***

***EXECUTIVE SUMMARY &
PROCEEDINGS***



***February 10-12, 1994
Crystal Gateway Marriott Hotel
Arlington, Virginia***

Sponsors:

National Institute of Environmental Health Sciences, NIH

NIH - Office of Minority Health Research

U.S. Environmental Protection Agency

National Institute for Occupational Safety and Health, CDC

Agency for Toxic Substances and Disease Registry

U.S. Department of Energy

National Center for Environmental Health, CDC

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EXECUTIVE SUMMARY

of the

**Symposium on Health Research and Needs
To Ensure Environmental Justice**

EXECUTIVE SUMMARY

The Symposium on Health Research and Needs To Ensure Environmental Justice, focusing on environmental quality and justice, was convened on February 10-12, 1994, as a collaborative action to help close the gap between the health of disadvantaged groups and the rest of the nation. The cosponsors of the conference included the National Institute of Environmental Health Sciences (NIEHS), the United States Environmental Protection Agency (EPA), the National Institute of Occupational Health and Safety (NIOSH), the Agency for Toxic Substance and Disease Registry (ATSDR), the Department of Energy (DOE), and the National Center for Environmental Health.¹

Plenary Sessions

Community representatives at the plenary sessions noted that people of color are particularly likely to live in contaminated communities and challenged symposium participants to build on the symposium's racial diversity to fight environmental racism. In one example, a community in southwest Tucson has struggled to address health problems related to a Superfund site and contaminated ground water. Communities in west Dallas, southeast Chicago, and Chattanooga have also confronted multiple pollution problems. The Cheyenne Nation has dealt with mining wastes and air pollution without government assistance; other Native Americans have also been neglected. During question-and-answer periods, many more examples of problem areas were cited. One government speaker declared that it is time to address the potential cumulative impacts of multiple chemical exposures.

Government representatives asked for increased cooperation among government agencies, as well as among Federal, State, and local governments. They also urged governmental cooperation with representatives from communities, labor, and academia. They noted the importance of research in resolving environmental justice issues and detailed six research objectives, including identifying at-risk populations, enhancing public participation and communication to identify community needs and priorities, and increasing the number and

¹ The cosponsors note that the summarized views and quotes are the views of the symposium presenters and audience participants, and do not necessarily represent the views of the symposium's sponsoring government agencies or any other U.S. government agency.

diversity of environmental health professionals making research decisions. One community speaker pointed out that diversity among scientists can also lead to better choices and that cleaning up the environment does not have to mean sacrificing workers' jobs in industry. An academic representative called for replacing the research paradigm for protecting the environment with one that emphasizes prevention and intervention. Community representatives also declared that the government should not wait for research results when there is evidence of toxicity, but should step in immediately to protect workers and communities.

Community representatives strongly agreed with the need for community input as soon as possible, whether for research or public health issues, and also for relevant community education. In one model program, Xavier University and the local community are equal partners in planning and conducting research. EPA is spearheading a pilot intergovernmental effort in Cleveland to work with the community to encourage economic development through environmental cleanup. Another important first step was the signing on February 11, 1994, by President Clinton in the presence of Vice-President Gore of an Executive Order on Environmental Justice requiring 16 Federal agencies to incorporate environmental justice issues into their work.

The recommendations of 20 core groups that each met several times to discuss environmental justice issues were presented the symposium's final plenary session. A separate executive summary and report are available on these recommendations. Symposium organizers acknowledged the rage and frustration expressed by many participants, then asked participants to help make their recommendations reality through communicating with government agencies, building alliances, and contributing to research.

Central Issues Sessions

Six subjects were addressed in a series of sessions on central issues: respiratory diseases, lead poisoning, hazardous waste problems, pesticides, workplace hazards, and EPA's Superfund. Differential exposures and potentially different susceptibilities to pollutants are likely to be found in different subgroups of the general population, and a statistical association was found between proximity to a major source of pollution and ethnicity and income. Yet, few studies have focused on low socioeconomic areas and minority populations. Moreover, we do not yet know whether findings on human subjects in experiments apply to chronically affected individuals.

Community representatives proposed that the community help to educate itself, identify research needs—including social relevancy—and answer concerns about who is exposed to what toxins and how to prevent such exposures. The community also must confront corporate power in transportation, industrial, and regulatory policy. In one example of community self-help concerning **respiratory diseases**, ordinary people in one Los Angeles area, (primarily Hispanics and

Latinos) contacted in outreach and educational programs demonstrated willingness to help improve community air quality. Now a campaign, with followup evaluation, is planned that includes consumer tips in Spanish on reducing smog, along with information on smog-related health problems, car maintenance, and relevant local ordinances.

A large study of asthma among inner-city children in eight cities is already underway. The second phase of the project will propose and test interventions to reduce asthma severity and morbidity, based on the risk factors identified in the first phase. It appears that those factors may include smoking in the household, as well as high levels of cat and cockroach allergens, but not the house dust mite identified in more "middle class" studies.

More than 6 percent of children screened for lead poisoning in 1993 had elevated blood lead levels, indicating the scope of the lead poisoning problem in this country. An interagency Federal task force has been established. The Centers for Disease Control and Prevention (CDC) funds lead poisoning prevention programs, as well as programs that track and monitor children with high blood lead levels. Besides conducting research, EPA is working with the Department of Housing and Urban Development (HUD) on a community-based lead abatement demonstration program.

One local program in Alameda County, CA, was successful in raising funds to educate the community about lead poisoning and combat problems when the county created a special district in which fees were assessed on homes built before 1978. This community was also successful in getting the State to require several industries to pay for testing children for lead poisoning. Another community success story involves a \$40 million award to an impoverished community in Colorado after many years of exposure to heavy-metal pollution from a smelting company.

The problems of one individual whose new home turned out to be contaminated with lead paint at levels unsafe for young children led to her political involvement. She later completed training as a lead-based paint inspector and reported that the training program was not readily accessible to the community. Other conference participants added that many programs concerning lead pollution problems have not been carried out in a manner appropriate to community needs.

Addressing hazardous waste problems, one government representative noted that NIEHS has been responsible since 1987 for establishing a university-based research program that has supported the work of more than 1,000 scientists. He called for a multidisciplinary research approach that examines the combined impact of pollutants—as well as the impact of pollutants acting separately—and that looks at how these substances change as they move through organisms and the environment. It is important to look at effects on children, not just adults.

One epidemiologist told how an unusually high rate of mortality from three diseases in Nogales, AZ, led some epidemiologists and community members to search for potential hazardous exposures that might correlate with multiple myeloma, systemic lupus, and leukemia. He cautioned that research data for any community must be as accurate as possible because of the reluctance of State and local health departments to conclude that clusters of excess disease above expected levels are caused by environmental factors. Another researcher said that flaws in studies of environmental justice should not be used to deny or distract from the existence of environmental injustice. He proposed an "activist" research agenda that evolves from collaborating with the community and that classifies environmental burdens by how they are experienced by the affected communities. Other scientists and community representatives also urged community involvement in research and in generating the political will that can ensure that research findings are translated into law and policy.

Exposure to pesticides and other chemicals is a major problem for America's 4 million farmworkers and their children, who live and socialize near the fields where they work. Yet, States have taken few protective measures; unions have done better than government in requiring protection. Researchers have difficulty studying migrant workers because of their mobility. Several research programs on pesticides were discontinued, and pesticides are only one component among many chemicals in the remaining National Human Exposure Assessment Survey. Federal interagency collaboration is needed, because pesticides and their health risks fit under the auspices of four Federal agencies.

Since preliminary evidence suggests pesticides affect the immune system, good immunoepidemiological studies are needed. Safety levels of exposure for adults won't protect children, who are more susceptible than adults. Research must look for potential delayed and latent effects of exposures as well as immediate effects. Pesticides have been linked to tumors, reproductive effects, birth defects, and mutagenic effects.

A government representative discussing workplace hazards pointed out that under the Occupational Safety and Health Act, employers are required to provide information about safety and health hazards and protective equipment, workers are expected to use the information and equipment, and a complaints procedure is spelled out. However, independent contractors—25 percent of the workforce—are not covered by workplace safety regulations for employees.

A researcher proposed that more and better occupational health research is needed, addressing socioeconomic, ethnic, and racial issues and obtaining data about toxins. The available literature suggests that people with low incomes and people of color are more likely to get occupational diseases and be exposed to toxins. A community representative said that it is time to implement more effective primary and secondary prevention.

A government representative explained how EPA applies a hazard ranking system to place Superfund sites on the national priorities list (NPL) and then

studies each site to determine risks and how much must be cleaned up. Recently, EPA changed the criteria to allow more sensitivity to bioaccumulation and ecosystems and recognized that environmental justice communities may need a special focus.

A Native American suggested that the Federal government must change national priorities and that problem analysis must include tracing the path taken by the waste that people create. Another community member suggested that the Superfund process is rigged, that government personnel poisoned many sites themselves, and that communities must get involved.

A researcher commented that there are major gaps in health data, particularly regarding the problems of color and people in poor communities. However, she cautioned that we cannot afford to wait until all the questions are answered to devise public health solutions. A government representative spoke of ATSDR's charge to look at the effects of environmental contamination on communities and to work on preventing and decreasing adverse health effects. One result was a 1990 conference on minority health in the Nation.

Press Conference

Government representatives spoke about the kinds of studies and information that can be developed to resolve questions about the impact of the environment on minority populations. One example involved pesticide residues in body fat that probably came from subsistence agriculture and fish. Science played a critical role, by developing measures to determine lead levels so that exposures to lead poisoning could be identified. University-based Environmental Justice Research Centers linked to communities are being developed to conduct scientific research, monitor exposure, and provide outreach to their communities. Furthermore, researchers need to understand whether certain alleged toxins are causing diseases.

Before initiating prevention-based research with the funding expected under health care reform, NIEHS will involve the regulatory agencies to ensure that it asks the right research questions. While the most humane, cost-effective approach is to prevent exposures, some prior exposures exist as a result of previous pollution that has since been stopped. Research that NIEHS conducts on noncancer health effects may help regulatory agencies to develop more rational policy.

A potential interagency agreement would send mobile units to communities to monitor exposures measuring what is in the air, water, and soil. At sites on the NPL, ATSDR will work with NIEHS on these activities. Government representatives expressed determination in attacking environmental factors that are hazardous to the poor and less educated people who live where such exposures occur.

Breakout Sessions

In discussing environmental and occupational health research to eliminate lead poisoning, one physician described the breadth of the problem in terms of the millions of children affected, the many potential sources of lead, and the blood lead levels that are now known to be toxic to the brain (levels much lower than was previously thought). Additional research is needed on lead's contribution to chronic diseases and possible damage to male and female reproductive systems. The best strategy is prevention through cleaning up the environment. NIOSH and CDC are exploring the magnitude of the problem that occurs when workers expose their children by bringing lead home from their workplaces on their clothes, skin, and hair.

CDC's current program focuses on children at high risk of childhood lead poisoning and includes prevention and community activities jointly sponsored by HUD, EPA, the Department of Labor, and other agencies in the Department of Health and Human Services, as well as collaboration with State and local health departments. Children's blood lead levels did decline as lead in gasoline declined, and other strategies for lead reduction are being examined. Current policy is to universally screen children under age 6 unless an area can prove it has no lead poisoning problem. In studies of lead-poisoned children, upper-income children had better reversal of lead effects than poor children, for reasons not yet known. The effects of early lead poisoning can carry over to older children. Session participants desire legislation for a "polluter pays" tax to generate funds for cleaning up environmental sources of lead.

With regard to occupational and environmental cancer, it is easier to estimate exposure to toxins in the workplace than in the community, because workplace exposures are usually higher. Four to 20 percent of cancers may result from workplace exposures, but studies are complicated by the health influences of multiple chemical exposures, smoking, socioeconomic status factors, and access to medical care. Furthermore, national statistics are inadequate for women and minority groups, although changes in data collection have been recommended.

A large racial difference is found in overall cancer 5-year survival rates, with African Americans at 39 percent and white Americans at 54 percent. Researchers need to study exposures and risks of individual types of cancer among minority and underserved populations to identify potential differences from white populations and to initiate preventive measures. Alternatives to risk assessment that involve the affected community are needed in these studies, because communities are concerned that government agencies are unmotivated in promoting the risk assessment process.

Chemical accident research needs to emphasize methods to measure chemical releases soon after their release, in order to establish a relationship between the exposure and any subsequent illness. Various guidance levels suggest whether or not the amount released is environmentally safe, but information on long-term exposure is needed as well.

Some unions have action plans, including training, to help chemical industries implement the national Process Safety Manufacturing standards, which have employee participation requirements. Chemical industries have developed a voluntary Community Awareness and Emergency Response program to prevent and coordinate responses to accidents. Community representatives suggested that companies need to use community panels more seriously and that communities would participate more effectively if the companies funded an independent community technical advisor. Examples were cited in which some companies did not cooperate in trying to resolve community concerns.

Improved **surveillance research** is important for low-wage workers, low-income communities, and communities of color, for whom the available data on occupational disease are very limited. Surveillance can identify new opportunities for prevention, define the scope of a problem, and target prevention resources. ATSDR is working with other agencies on surveillance projects in west Dallas and Texarkana, TX.

Physicians could play a critical role in surveillance research by recognizing disease, disability, or untimely deaths that are likely to be work related. Community participants want surveillance of hazards, not just of sick workers, and want results disseminated in a format understandable to workers. Unions are trying to include ongoing surveillance in standards of the Occupational Safety and Health Administration. Community groups and researchers may need facilitators to help them work together. Research grants should include requirements for community participation.

In a session on **models for technical assistance**—identifying, articulating, and documenting problems—community representatives cited problems in having the community groups that apply for technical assistance grants follow the same procedures as universities, in requiring them to wait for reimbursements, and in limiting the activities the grants will fund. Suggestions were made for how both community groups and EPA could improve the process.

In reporting on components of **successful models of community empowerment**, one community leader in lead poisoning education recommended several strategies: using patience and persistence to get the media to respond; targeting obstetric units of hospitals; seeking company donations; asking local health departments for better communication about lead poisoning and appropriate lead abatement procedures; and working for relevant State legislation.

One university works with nearby communities to build model programs around various health issues, training community advisors on health and receiving community input. Through a coordinating network, a coalition on pesticide issues pools fundraising, administration, and other resources for its member groups. Community representatives asked the Federal government's interagency coalition focusing on lead poisoning to collaborate with community groups.

Conference participants recommended that **environmental health education** involve a series of activities, from general public science literacy to training at advanced levels. They also urged that people of color receive particular encouragement, both early in their education and through such mechanisms as an environmental consortium that DOE developed among minority colleges and universities. Communities want programs for non-English speakers and need environmental education curricula to be more available, both to students and to the community in general. Some DOE and NIEHS funding is available for curricula, but community activists must petition their school systems for the inclusion of environmental education materials.

One speaker described the large potential exposure of the U.S. population to dioxin and related compounds, which are emitted in several major manufacturing processes, and the absorption by our bodies of significant amounts of **dioxins, furans, and polychlorinated biphenyls (PCBs)**. Not all potential health effects are known, but dioxin can cause mortality, embryo or fetal toxicity, low birthweight, and birth defects of the immune and gastrointestinal systems, as well as gross birth defects and possible reproductive effects. There is some evidence that dioxin may also be a carcinogen.

Children in indigenous societies are particularly vulnerable to environmental contamination taken in, for example, through fish and their mothers' milk. In one Indian nation located near several sites of hazardous waste, nursing Mohawk mothers were able to lower chemical contaminants in their breast milk, but only by radically altering their lifestyle to avoid fish consumption. Through establishing good cross-cultural communications, researchers have been able to interact with the community.

While scientists are engaged in long-term studies of dioxin exposures of populations near industrial sites, some conference attendees stress protecting and training workers to minimize exposure and replacing technologies that create harmful by-products with safer methods and processes.

The session on **ethical issues in environmental health research** questioned whether health care should be provided to communities being studied for exposure to hazardous chemicals. Another issue concerned whether to offer testing for exposures to chemicals when there is not enough information about the effects of those chemicals to either counsel or treat the persons exposed. Some studies were conducted for too short a period or on too small a group to provide definite proof of safety or harm, and others lacked sufficient information on the amount and kind of chemical exposure. Community representatives suggested that successful studies would involve communities from the beginning. Separate handbooks to guide scientists and community members on the ethical issues relevant to the study should be developed.

While discussing Federal programs and federally funded community **asthma** projects, one session asked about **outreach and accountability**. EPA's Indoor Air Program on asthma provides curricula, guidance documents, and

training courses on preventing exposure to indoor pollutants; targets specific groups, such as those choosing ventilation and building materials; and recently funded production of a research agenda and recommendations for action. The National Heart, Lung, and Blood Institute (NHLBI), which reported in 1992 on its health behavior research working with minority populations, is also targeting minorities in a public education effort concerning asthma and in new collaborative projects on minority health. In an earlier collaborative project, a university and a clergy group worked together for 4 years under an NHLBI grant to reduce smoking in an east coast community. While an NHLBI task force has developed a list of research needs, some conference participants prefer to emphasize preventing indoor and outdoor pollution and training for minority researchers.

In addressing **pollution prevention through economic empowerment**, one government representative noted that minority contractors had been excluded from cleanup activities under the Installation Restoration Program and that each cleanup dollar spent in poor communities generated far less response than in wealthier communities (80 cents vs. 8 dollars). A historically black university in Mississippi is aiming for community empowerment through linked curricula in environmental management and economic development, community outreach to grassroots organizations and minority contractors, and networks to bring these groups together with government staff and prime contractors.

Recognizing that millions of Federal dollars will be spent over the next few years for lead abatement, one community representative proposed that companies demand that municipalities buy services within their own borders to keep that money in their own communities. Training programs for workers were also proposed.

In discussing recent shocking reports of government-sponsored **radiation experiments on U.S. citizens**, government representatives described the efforts of the current Federal administration to open up the process of examining previously secret records, to ask ethical and scientific questions about the situation, and to develop recommendations to ensure such experimentation can never happen again. One physician was concerned that his own investigations had been impeded by government officials and asked whether they could conduct a fair investigation; he also criticized many procedures in the controversial experiments as unscientific and unethical. Session participants, who had other concerns about the possible inadequacy of current procedures at sites where nuclear materials are present, generally exhibited strong emotions at this session.

In addressing environmental and occupational health **research to eliminate respiratory disease**, medical researchers noted that lung cancer, tuberculosis, and asthma all disproportionately affect people of color and the socio-economically disadvantaged; that blue-collar laborers are likely to have greater exposure to pollutants at work than those working in managerial and professional areas; and that ongoing surveillance of workers is needed to detect disease early and prevent deaths. Since outdoor air pollution does not differ among groups with different asthma rates, indoor factors need more study. An eight-site national

cooperative inner-city asthma study is examining why asthma problems are rising among inner-city poor black and Hispanic children and is trying out interventions.

In a session on environmental and occupational health research to **eliminate pesticide exposure**, farmworkers and community representatives described distressing incidents in which workers were sprayed with pesticides and became ill. They asked for better inspection and enforcement of proper procedures and hygiene. One researcher—noting that the many other health, economic, and social problems of migrant farmworkers cloud pesticide exposure studies—urged an understanding of political realities and of the need for workers to develop organizational strength. (The experiences of two communities—Austin, TX, with emissions from oil companies and Alameda County, CA, with lead and other contaminants—were included in the report on this session.)

In addressing **community-based health surveys**, community representatives told how individuals collected the data on health problems and exposures in their communities when health departments were uncooperative. The Environmental Health Network is willing to help communities with training, surveys, registries, and workshop development. Conferees agreed that more disease registries and community health clinics are needed.

A labor activist discussing the right to understand and the right to act (**workers' rights**) said that communities and workers must work together to ensure environmental safety and health. Some community representatives were very concerned about the power of corporations, the failure of companies to train their employees properly, and continued exposures to toxic substances in the workplace.

At the session on **models for academic researchers and institutions** to promote community participation, two university-community partnerships were described. In one, a Texas university provides legal advice and assistance to a health effects study; in the other, a consortium of four Louisiana universities and community representatives guides environmental justice projects.

The session that addressed both **models for local and State governments** to promote community participation and environmental health education for elected officials focused on a situation in Alameda County, CA. Productive solutions evolved through community involvement and through taking a broad view of environmental exposure problems after initial resistance from some health officials.

A medical researcher looking at **children as sensitive populations** described how toxic materials have both immediate and latent effects, affecting children from embryo through adolescent. The researcher and other conference participants were concerned that pediatric research does not include provisions for fixing problems identified during the research. The Children's Environmental Health Network has been formed to meet the need for data on toxic exposures in children and to emphasize the field of pediatric environmental health.

During a session on **pollution prevention and intervention**, the recorded part of the session addressed the problem of cleaning a house properly to rid it of lead. Recommended procedures and dangerously incomplete advice from a State official were discussed.

The challenge of dealing with exposures to multiple toxic chemicals is twofold: Research must address **multiple risk factors**, and policies must emphasize the broad reduction of the use of toxins that can affect health. Research must study the role of environmental factors in the development of asthma, which disproportionately affects minorities and the poor. Research should not serve as an excuse to delay action to help communities.

Community participants who discussed **lead poisoning and outreach and accountability** were concerned about weakened Federal regulations and weak enforcement of existing lead exposure regulations. They proposed turning to local and State statutes dealing with public housing conditions and public nuisances. Community involvement was strongly recommended, as well as sensitivity to whether one's own actions might lead to a pollution problem.

Participants in the session on **occupational exposure prevention** first heard about health problems of workers in companies that did not handle solvents properly. Other difficulties included combined effects of certain medications with workplace chemicals and exposure at home to workplace chemicals brought in on clothing. A government representative noted that when a device becomes available to reduce workplace exposures, publicity to encourage its use is crucial.

In addressing **pollution prevention and health intervention**, one government representative described how a Colorado community wanting environmental equity educated itself and successfully sued a lead smelter; another community sought advice from conference participants on apportioning the NIEHS budget and told of the electronic availability of the toxicology database. One speaker recommended that community groups *not* formally participate with government agencies, but other discussants opposed this position.

Two breakout sessions that addressed issues of indigenous people were not recorded by the choice of the participants.

PLENARY SESSIONS

SYMPOSIUM ON HEALTH RESEARCH AND NEEDS TO ENSURE ENVIRONMENTAL JUSTICE¹

February 10–12, 1994
Arlington, Virginia

February 10: Welcome and Introduction

The cofacilitators, **Dr. Bunyan Bryant**, University of Michigan, and **Dr. Jerry Poje**, National Institute of Environmental Health Sciences (NIEHS), welcomed participants.

Opening Addresses

Dr. Kenneth Olden, Director of NIEHS and the National Toxicology Program, National Institutes of Health (NIH), reported that the conference cosponsors include NIEHS, the United States Environmental Protection Agency (EPA), the National Institute of Occupational Safety and Health (NIOSH), the Agency for Toxic Substance and Disease Registry (ATSDR) at the Centers for Disease Control and Prevention (CDC), the Department of Energy (DOE), and the National Center for Environmental Health (NCEH).^{2,3} The symposium is part of a new research and collaboration paradigm and results from 18 months of work by community and union leaders, government representatives, scientists, and academicians. Convened because environmental quality and justice are a high priority for Americans, it is the beginning of a collaborative interaction to ensure a healthy environment.

¹ These proceedings were developed from taped records of the conference.

² The cosponsors note that the summarized views and quotes of symposium presenters and audience participants are their own views and do not necessarily represent the views of the symposium's sponsoring government agencies, or any other U.S. government agency.

³ Organizations are referred to by acronyms after their first mention in the text. An index of acronyms and other abbreviations appears in Appendix A.

Rose Marie Augustine, Director of Tucsonians for a Clean Environment, noted that people of color are more likely to be victims of contaminated communities. In 1981, a 30-square-mile area in southwest Tucson, populated mainly by Mexican-Americans, was declared an EPA Superfund site. The ground water, the community's only source of drinking water, was contaminated by chemicals thought to cause birth defects, miscarriages, and other health problems. Chemicals trickled into the aquifer, creating an underground toxic plume five miles long, two miles wide. When excessive chromium was detected in a city well next to a government-owned defense plant run by a major aircraft company, contamination was traced to the 1950s. Later tests of community wells showed the chromium level was 400 parts per billion (ppb), more than the 50 ppb Federal guideline. Trichloroethylene was 10,200 ppb, exceeding the Federal guideline by 2,000 parts. About 47,000 people used contaminated water for 20 years because Tucson resisted testing the well field, attributing community health problems to diet and lifestyle. Lack of government response led to formation of Tucsonians for a Clean Environment in 1985. Then in 1990, wells in upper-class Tucson were shut down because a declining water table was suspected of killing trees.

The community in southwest Tucson is mainly composed of Mexican-Americans and people of color relocated because of a 1960s urban renewal project. Different forms of cancer are problems in the community. Government and science must build trust with victims like these, rather than with beneficiaries of scientific progress. A letter from the Southwest Network for Environmental and Economic Justice (SWNEEJ) to DOE Secretary Hazel O'Leary that was read at the conference said environmental racism is inherent in radiation experiments, citing tests conducted on prisoners and low-income children, who are disproportionately people of color. The letter urged a Federal interagency committee to conduct radiation-related inquiries that include informal, formal, medical, and scientific experiments and to expand its membership to include the Civil Rights Commission and EPA. The committee should also report on the extent of civil rights and constitutional violations and ensure that environmental justice is a major focus of its work. The letter added that substantive, un rebutted evidence exists indicating that formal and informal radiation testing and experimentation were racially discriminatory in intent, execution, and impact.

Dr. Phillip Lee, Assistant Secretary for Health, Department of Health and Human Services (DHHS), asked for collaborative efforts to help solve the problem of closing the gap between the health of disadvantaged groups and the rest of the nation. Bringing together representatives from communities, government, labor, and academia must continue, and the government must work cooperatively across agencies and departments. Early positive steps include the Federal antismoking campaign and the DOE initiative on radiation testing. Closer cooperation must occur among Federal, State, and local governments, with attention to concerns of community leaders. A window of opportunity is open for health reform, including environmental issues. There is consensus about how to deal with the crisis that the public perceives in health care. The Health Security Act, a consensus response to the health care crisis, addresses such public health issues as reducing environmental hazards and combating unhealthy behaviors, many of

which have environmental roots. Title III of the Health Security Act proposes three public health initiatives to address these environmental issues: increasing funds for prevention research, including environmental health studies; restructuring the delivery system so disadvantaged populations can benefit from public health initiatives; and revitalizing the public health infrastructure. The revitalization is critical because local and State governments use health budgets to finance care for the uninsured rather than to finance public health infrastructure. Public health problems, such as illness caused by water- and food-borne disease, are increasing. As part of the revitalization, funds will be available for surveillance to identify community health problems, such as violence, lead poisoning, and diabetes, and to support community programs for controlling chronic diseases and preventing injuries.

Reverend Dr. Benjamin Chavis, Executive Director of the National Association for the Advancement of Colored People (NAACP), declared that environmental racism is evidenced by the racial discrimination in environmental policymaking, the targeting of communities largely populated by people of color for exposure to environmental hazards, and the failure of government to address these issues. Studies have documented the existence and impact of environmental racism, but little has been done. A challenge for symposium participants is to focus on (1) changing national behavior, politics, economics, and attitude; (2) respecting one another's struggles; and (3) building on the symposium's racial diversity and common experience to fight environmental racism.

While some progress has been made in environmental justice, the administration must reverse attempts of previous administrations to blame lifestyle for the illness and death caused by environmental hazards. NAACP will focus more energy on environmental justice and work with community groups to eradicate hazards that disproportionately impact people of color. Having the same passion for environmental justice that they have for voting rights, housing rights, and other injustice, NAACP and other symposium participants must build a multi-racial, multicultural, multilingual force for change.

Goals and Objectives

Dr. Robert Bullard, University of California at Los Angeles, spoke of replacing the research paradigm for protecting the environment with one that emphasizes prevention and intervention. The current paradigm institutionalizes unequal protection and enforcement, trades human health for profit, puts the burden of proof on the victim, accepts using risky technologies, exploits disadvantaged communities, and subsidizes ecological destruction. Prevention must be an overarching concern, applying prevention in research designs to ensure that study results affect an array of illnesses. The public, especially disadvantaged communities, must be involved in scientific research, monitoring, and evaluation to ensure that environmental justice is enforced and science is not seen as oppressive. In some situations, action, not scientific study, is needed.

Dr. Ken Sexton, Director of the Office of Health Research, EPA, noted that research is important and necessary to resolving environmental justice issues. The credibility of environmental justice decisions depends on science, and better data is needed to identify risk, recognize the best prevention strategies, and measure progress toward environmental justice. In 1992, EPA, NIEHS, and ATSDR held a workshop to determine research needs associated with environmental justice. The papers that were subsequently published in *Toxicology and Industrial Health* all noted indications in the literature of environmental inequities, with authors' opinions differing on the strength of evidence and importance of research objectives. Scientists at the meeting agreed on the need for active, equal enforcement of environmental protection laws and for community input into environmental health research.

Dr. Barry Johnson, Assistant Administrator, ATSDR, presented the following six research objectives to support the symposium's goal of developing research strategies that eliminate environmental inequities:

1. Identify at-risk populations, key research gaps, and ways to conduct meaningful, lasting research for use in at-risk communities.
2. Develop new models for interagency coordination that incorporate community needs and priorities.
3. Delineate new models of prevention and intervention as part of a larger research, education, training, and community outreach effort.
4. Increase public input and participation and enhance communication between agencies and communities.
5. Strengthen the mechanism for increasing the numbers and diversity of environmental health professionals trained as science advisors and participants in peer review of research grants and policy papers.
6. Develop a paradigm outline for health research that targets the need to ensure environmental justice.

Lunch Session: Education and Human Resources

Dr. Shirley Malcom, head of the Directorate for Education and Human Resources Programs, American Association for the Advancement of Science (AAAS), noted that there is not one public but many, and many ways to reach them. Some people are afraid of science because of bad school experiences and difficulty dealing with scientific terms, but the need to know is a great motivator. If issues are presented in a way that can be understood, they will be understood, especially if the message is for survival. AAAS is experimenting with different modes of information, communication, and reaching people where they live and congregate—such as shopping malls, church basements, and community

organizations. Radio is a powerful tool for communication, but the messenger must be credible, technically excellent, and have a sound knowledge base. AAAS is working to increase the number and diversity of people engaged in science.

I grew up in the steel town of Birmingham, AL, where there was a choice between jobs and a healthy environment. Many found themselves in a degrading position when trying to negotiate for technologies that industry said it could not afford. It does make a difference if policymakers include those who personally know of such tradeoffs and injustices, and individuals can make a difference in policymaking if they are prepared. I worry about people in the education pipeline in technical areas who later will affect environmental science issues. In 1991, only 24 African Americans completed doctorates in the physical sciences. In 1992, only 50 African Americans received doctorates in the life sciences. This may be an insufficient number to serve on educational faculties, on policy-setting boards, and as technical advisors. What can we do about it? Now is the time to discuss solutions.

Partnering for Solutions: Opportunities for and Impediments to Interagency and Intergovernmental Cooperation

Kathleen McGinty, Director of the White House Office of Environmental Policy, stressed that while the total impact on human health of a single chemical from a single source is unknown, it is nevertheless time to understand the cumulative impact—the additive effects on health and synergies that may exist among chemicals. Furthermore, individuals and communities must have access to real, meaningful information and have a role in decisionmaking that affects their communities. An example is the administration's Superfund proposals, which state that all communities are entitled to equal health and protection and call for community information centers, technical assistance grants, and identification of high-impact areas through a new environmental justice grants program. Communities will help decide how clean a Superfund site will be. Many agencies besides EPA and DHHS must be involved, including DOE and the Department of Housing and Urban Development (HUD).

Deeohn Ferris, Director of the Environmental Justice Project, Lawyers Committee for Civil Rights Under Law, Washington, DC, described government as a set of service units with a duty to protect the interests of those it serves—people's health and their ability to be educated—and to provide transportation, protect environments, make the food supply safe, protect economic interests, protect workers, and protect rights to equal opportunity. Government service is built on communities, and any interagency cooperation and coordination must include community input at the beginning and throughout the process.

The government has a history of ignoring those most affected and injured by environmental events; yet, they are a fundamental reason for establishing governments. An overarching issue is the Federal government's obligation to ensure that States protect the environment of those in their borders. In west

Dallas and southeast Chicago, as enterprise zones are developed, watch to be sure that they do not themselves foster adverse health consequences and negative environmental impacts. West Dallas was victimized by a RSR Corporation lead smelter that is now being relocated to Mexico. Despite having information on high levels of lead pollution accumulating over decades, the government waited 20 years to study the problem. By then, the damage was such that 16 square miles of west Dallas were designated as a Superfund site. After a \$25-million cleanup, HUD plans to build public housing for 2,000 people there. This plan raises a fair-housing issue for HUD.

Southeast Chicago is ringed by many sources of pollution and receives waste from across the nation. A focus on exposure is needed, instead of a case study that was done focusing on risk-based examination. Esoteric principles like risk assessment will not solve problems in these communities.

Furthermore, information on the environment should be presented in language and vocabulary people can understand. If not, this meeting on interagency cooperation may be in vain. The word "environment" needs redefining. It is where people live, work, and play, not just an area to be protected for hunters and fishermen. EPA and the research agencies must be mobilized, with social service agencies, health care entities, education and training organizations, and others. Government-funded voter registration drives must strengthen the community so that irresponsible elected officials in places like west Dallas and southeast Chicago aren't reelected.

Elliot Laws of the Office of Solid Waste and Emergency Response (OSWER), EPA, said that the issues of this office relate to Superfund sites, landfills, hazardous waste incinerators, other hazardous waste facilities, and underground storage tanks. For EPA to succeed in dealing with hazardous wastes, OSWER must be effective. Cleaning up a Superfund site may not always help community members who suffer from the effects of living near a site that is not adequately supervised, and who may need health care. If OSWER has no authority to respond, it must bring in the State and local agencies that do have such authority. Furthermore, DHHS should respond at community meetings when people ask for services.

EPA has an intergovernmental effort under way to revitalize urban brown fields, abandoned after being contaminated by environmental pollution. The Cleveland brown fields pilot project, designed to encourage economic development through environmental cleanup, is a collaborative effort between the Federal government, the State of Ohio, and the local county commission. The program is designed to attract business back to inner cities, create jobs, and improve living standards for urban communities. EPA plans to repeat this pilot at other sites, training local workers and hiring them to participate in the cleanups. In Cleveland, a college environment curriculum is grooming people to become chemical engineers, toxicologists, and environmental managers.

OSWER signed a cooperative agreement with the NAACP national office, awarding \$252,000 to study the impact of waste sites on life quality in some low-income and minority communities. Health effects in those communities will be studied, aided by citizen participation.

Panel and audience comments

▼ **Phyllis Glaser:** An east Texas mother from a rural, low-income minority community, described life near a large, commercial, hazardous-waste-injection well facility—one of 10 in the country. She and Mothers Organized to Stop Environmental Sins have sought assistance for 12 years from Federal and State regulatory agencies.

▼ **Ms. Ferris:** She believes deep-well injection should be made illegal. She suggested that Glaser meet with individuals and groups who have successfully sought environmental justice.

▼ **Audience member:** Environmental justice is blocked by budgetary problems, racism, and willful ignorance of government officials.

▼ **Dr. Torres:** We are trying to ensure that statutes are followed and community concerns are strengthened, possibly through litigation.

▼ **Phyllis Sikorski:** Her 13-year-old son was diagnosed with non-Hodgkin's lymphoma when he was 5. She wants the National Cancer Institute (NCI) to help her learn if the child is part of a cancer cluster in her Detroit suburb. A cancer registry and birth defect registry are needed in Michigan and across the nation. The U.S. census in 2000 should include questions on family cancer incidence and its type, the existence of birth defects, and the birthplace of an affected family member.

▼ **Native-American audience member:** EPA does not always listen to the traditional elders of indigenous people, who have monitored the well-being of America's environment for thousands of winters. The scientific community should be aware of other knowledge paradigms.

February 11: Opening Addresses

Dr. Linda Rae Murray, Director of Winfield Moody Health Center in Chicago, observed that minority workers have the dirtiest jobs in the most polluting industries. Before uranium mine tailings poisoned Navajo lands, Native Americans were in the mines dying from lung cancer. Elsewhere, without warnings written in languages that non-English-speaking workers understand, exposed people face liver disease and other illnesses at remarkably high rates. African Americans die of asthma at high rates, and black steelworkers who have worked on coke ovens for decades die of lung cancer. Across the country, minority factory workers can tell scientists and government agencies how toxic chemicals get into the body, what to do about it, and why contaminating practices should stop.

How did the North American Free Trade Agreement (NAFTA) legislation pass if so many people worry about environmental justice? Greater problems than

those that exist in this country occur in Mexico, Guatemala, Puerto Rico, Africa, and Asia. There is an obligation to solve all those problems, but people die faster from hunger than from a carcinogen. Corporations have no rights equal to people's rights. No one has a right to soil the Great Lakes. The labor movement, the civil rights movement, the women's movement, and the struggle for sovereignty of Native-American nations show how to solve some environmental justice issues. The question is not how do we design a more streamlined incinerator or write regulations with fewer loopholes. The question is how do we protect human health? Let everyone on the block know what the lead smelter does to their kids. You don't need someone from EPA or an ATSDR toxicologist to answer that. You need the church at the corner and the elder down the road to explain the problem, the same way that workers on the floor learned from their unions. Organize and make changes.

Superfund should pay for community training; educational information should be available at local libraries, not from Atlanta or Washington. NIEHS should establish centers like those at NIOSH and should work to assure that community organizations needing technical help get it from people who care about the community.

To learn the names of government scientists and administrators who care about community health, call the labor unions; they know who these people are. A comprehensive public health approach supports science and calls for more information, then uses the available information to take action to minimize human health risks. It's not good science to wait until *all* the evidence is in. The energy and information in this room must be organized to build a political power base and force Federal and State governments to follow community direction and protect human health.

Hon. Carol Browner, EPA Administrator, told the conference that EPA has not done what is needed to protect the people of the United States.

We should be able to use the laws Congress has passed so everybody in the country is protected. I can't say we have done that, and that's something I will work to change. I can only change it if we work together. At the White House today the President and Vice President will sign an executive order on environmental justice. It took longer than expected so they could include all agencies with a role to play, and some did not come to the table easily. The executive order requires 16 Federal agencies to incorporate environmental justice issues into their work. No other such executive order has been signed before, but it is only a first step.

Panel and audience comments

▼ **Martha Blackwell**: Natchafee County, MS, is 75 percent black. Her area is targeted for hazardous waste landfills and incinerators. Over 10 years, citizens have fought to disband four megadumps in the agricultural county. The State of Mississippi has a capacity-assurance process based on State law. However, the state currently has no approved capacity-assurance

plan because citizens blocked it. The governor is trying to submit a "cap" plan based on 1988 EPA guidelines; this plan uses 1989 data from Mississippi that has nothing to do with a real cap plan for the State. The governor is trying to put a 200,000-ton landfill in her county and this is why the governor tried to submit that cap. Would Browner let the governor submit a cap based on 6-year-old guidelines?

▼ **Ms. Browner:** If the law and guidelines require using current statistics, EPA will require it. If the guidelines and the law don't require current statistics, EPA should work to change it.

▼ **Larry Wilson,** from Yellow Creek, a small Appalachian community in eastern Kentucky: Eight of 10 people in the community have died of cancer since EPA was involved. Cissy Hearst died recently, before her 16th birthday, poisoned by drinking water. The community knows the Middlesbury Tanning Co. of Delaware poisoned her water. Browner and EPA licensed that poisoning. He asked why she and the Middlesbury Tanning Co. weren't charged with mass murder?

▼ **Ms. Browner:** There are times I'm not proud of what EPA may have done. I want to change it, that is why I am here. EPA is here to serve people. In the next year Congress may change more environmental laws than at any other time in history. Four laws are in Congress that could be strengthened to give EPA useful tools for the agency: the Clean Water Act, the Drinking Water Act, the Superfund Program, and pesticide laws. Ms. Browner calls for increased, informed public participation in the decisionmaking process.

▼ **Judy Schreiber,** New York State Department of Health: Her department has studied indoor air contamination occurring near drycleaning facilities. Such contamination exposes a large population of urban children, pregnant women, and lactating mothers to high levels of pollution. Under the Clean Air Act, drycleaners are inadequately regulated. How does EPA plan to provide air quality protection?

▼ **Ms. Browner:** The authority given EPA by the Congress relating to indoor air is not of a regulatory nature. She has been sued by the Tobacco Institute of America, which claimed she did not have the right to inform the public that smoking is a problem for nonsmokers. EPA is working with several members of Congress who introduced a bill giving EPA greater authority to deal with indoor air issues. In studies she has found convincing evidence that indoor air is a serious public health problem.

▼ **Eliezer Colon,** Puerto Rico: The island is polluted. The Caribbean EPA office gives information and documents in English, but 75 percent of the population speaks Spanish. The island has nine Superfund sites. His town has a landfill used as a toxic waste deposit that was submitted as a candidate for the National Priority List in 1986; EPA denied access to information, saying that such information is not in the public interest. Yet, people are ill from asthma, bronchitis, and skin diseases. Fish die in the lake where the site pumps water. What is EPA policy for Puerto Rico?

▼ **Ms. Browner:** EPA should give information in Spanish to people in Puerto Rico. A few weeks ago EPA announced it would expand the list of chemicals on which industry must report emissions as required by the Toxic Substances Act. Since 1986, there have been about 300 chemicals on the list; she just signed a rule adding another 300 to the list. Now the number of facilities that must report will be expanded. Superfund information will be made available in Spanish as well as English.

▼ **Dr. Jose Fernandez:** This participant fought the EPA in Louisiana for 13 years, then he got so frustrated that he joined EPA. He came here to pull together public policy issues, especially the question of perceived risk. Regarding laws to protect people: where the burden of

proof is on the product manufacturer, there is a way of managing risk. When the product is waste, the burden is on the people. We don't need more health clinics; we need more law clinics. It's a matter of shifting the problem of proof from the people to the producer.

▼ **Ms. Browner:** Communities are grappling with the question of risk and use of risk assessment. Some say EPA should limit its decisionmaking to risk analysis. If later cost-benefit analysis finds the cost of protecting the public health too high, EPA should not provide protection. That is how some people suggest risk assessment and cost-benefit analysis should be used. I don't agree.

▼ **Mary Sissen:** This participant lived in Alaska from 1979 to 1990 and left to protect her health and safety. She was on the hydrology task force, attended EPA conferences, and tried getting assistance from EPA. When she failed to get action on water quality by working through the State of Alaska, she tried working with the Federal EPA office, but it forced the issue back to the State. The Exxon *Valdez* disaster was a small part of the problem. The first oil discoveries were made in Kenai Peninsula in the 1950s. People have put up with waste streams, injection wells, recovery and enhancement fluids, oil depositories, and air pollution. Her group identified 150 sites for cleanup. Companies have dumped more than 6.5 million pounds of toxic substances into Cook Inlet. It must stop. The area is ranked first in toxic air releases in Region X, which includes California, Idaho, Oregon, and Alaska. The water is contaminated and the air is polluted. The community wonders why EPA has not been there to help them, despite their many efforts to make contact.

▼ **Chris Bedford, Chair, Communities Concerned about Corporations:** Bedford's organization represents Vietnamese, Hispanic, and Caucasian shrimpers and fishers of the Texas Gulf Coast. Browner should name the polluters—Exxon, Mobil, Waste Management—in public. Formosa Plastics has a large plant in Port Comfort, Texas. Browner just allowed a \$1.6-billion expansion that will destroy shrimping, fishing, oyster harvesting, and a way of life on the Gulf Coast. EPA and the Texas agencies to whom EPA gave responsibility systematically failed to enforce the law. EPA scientists and staff in the Dallas district office work hand-in-glove with the company. He asked Browner to meet with Diane Wilson, a fourth-generation shrimper, who would travel to Washington to attend a hearing.

▼ **Ms. Browner:** Agreed to meet with Ms. Wilson.

▼ **Irma Dey Ande:** Her home base is Hood River County, OR, but she now lives in Umatilla County. Does Browner intend to protect all workers, including farmworkers?

▼ **Ms. Browner:** Yes. The administration asked Congress to pass food safety legislation, the first time an administration has asked for a comprehensive approach targeting cancer, birth defects, and effects on the brain and nervous system. Existing law registering pesticides did not let the Federal government evaluate these effects. The government should be required to make a finding that protects public health.

▼ **Ms. Dey Ande:** The new law scheduled to go into effect in April does not include farmers; their children are being killed by pesticides.

▼ **Ms. Browner:** EPA worked on the Farmworker Protection Standards for several years but could not get the previous administration's approval. The standards will take effect April 1. Farmworkers will have protection, but these standards are only a first step.

▼ **Buck Jones:** This participant is from East St. Louis, which has 50 percent unemployment and 25 abandoned toxic waste sites. The population has a greater likelihood of dying from cancer, heart disease, and stroke than most other cities. Near the Lanson Chemical site, 25

people living on one block died of cancer during a 5-year period; 45 percent of the families on the street have one or more members with cancer. It is a Superfund site; toxics are being removed but remain in the soil and groundwater. EPA says people are dying because they are old. We want justice, healing, and wholeness.

▼ **Ms. Browner:** EPA thinks that Superfund is broken and must be fixed. A week ago the administration gave Congress comprehensive Superfund reform legislation. One important feature is a requirement that every Superfund site have a community group to guide EPA and the contractors.

▼ **Wanda Erwin, Winona, TX:** This participant lives next to Gibraltar Chemical Resources, two-tenths of a mile from chemical injection wells that contaminated her water. She wants EPA to explain why it gave the company a permit to destroy her land and why it let Gibraltar stay in operation after the company broke so many laws. People are suffering and dying in her community.

▼ **Faye Bush:** This participant lives in Howell County, 50 miles north of Atlanta, GA. The county is divided by a street. Wealthy people live on the north side of the street and low-income people live on the south side. Sixteen factories in the county dump waste on people every day. The soil, air, and water are contaminated. Twenty people on one street have died; she has lupus. Chromium, iron, and other materials were found in the soil in EPA tests. Before the tests, people claimed that lifestyle caused the problems. Browner's office should declare a moratorium on the dumping.

▼ **Katsi Cook, a Native American woman from the Mohawk Nation in New York:** EPA has a treaty with industry called the PCB Guidance Document. Her people want this treaty abrogated. It is a coverup of the Superfund site directly adjacent to Mohawk lands. Her people are insulted at being called the "typical industrial site," when the waters and lands where the pollution will sit for years is land where their children swim and her people fish. How can we break the coverup so that the tribe will be respected?

▼ **John Banalee, Big Mound, AZ:** This participant gave Browner a formal submission and challenged EPA to be accountable on behalf of all people of color.

▼ **Phyllis Sikorski, Troy, MI:** The NCI and other health agencies should be represented at future conferences. She is a member of Parents of Cancer Plus. Her son has cancer. She wants to know whether she lives in an area prone to cancer or other diseases. Questions about cancer, birth defects, and other diseases should be added to the census in 2000.

▼ **Ms. Browner:** She wants to change problems that cause suffering. Many do not trust the EPA. Hold me accountable for how EPA responds to the needs of the people and demand that EPA incorporate their needs into every action. Keep up your outrage and anger, but know that EPA wants to work with you to solve these problems.

Lunch Address: Native American View

Gail Small of Native Action told how in the 1970s the Cheyenne learned that the tribe's Federal trustee, the Bureau of Indian Affairs, leased more than half their reservation to coal companies for strip mining. Cheyenne coal was sold for 17 cents a ton, and no environmental safeguards were written into Federal leases. She was among a small group of Cheyenne sent to the Navajo Coal Mine and then to Wyoming coal fields. She was one of 20 high-school-age Cheyenne

youth who had their pictures taken inside a coal shovel. At age 21, the only one of her tribe with a college degree, she sat on a tribal board charged with voiding the coal leases. A young lawyer helped the tribe sue the Federal trustee and the coal companies. After 15 years, the tribe convinced Congress to void the leases. However, the battle is endless, and Cheyenne coal is more valuable than ever.

With few allies, the Cheyenne fight on many fronts. As the strip mines came closer, Cheyenne leaders decided to protect their air. In 1977 they redesignated the reservation's air quality as Class 1, pursuant to the Clean Air Act's significant-deterioration amendment. Implementing and enforcing the standards was a bureaucratic nightmare. It took 10 years for EPA to acknowledge the Cheyenne as a government with the right to establish an air-quality plan that should have triggered funding and enforcement authority. Almost 20 years later, the tribe continues to fight for air quality. With little money, the tribe was forced to go to the coal companies for a settlement that would provide funds for air-monitoring stations on the reservation. This is institutional racism by EPA. Some tribes are drafting their own laws to assert tribal self-government. Some have established environmental agencies.

Beset by problems from gold, coal, and uranium mines and nuclear waste, tribes and their homelands are under siege. They need the help of scientists to gather data and establish tribal regulatory agencies. Tribal representatives want economic development options and jobs and oppose economic "blackmail" that would deny them that opportunity. Energy companies, government agencies, and speculators have learned to manipulate the economic poverty of the reservations' natural resources. Conditions compare to the country's worst Superfund site: There are not enough allies or money to rectify the situation. Tribal environmental laws and courts must be strengthened. EPA funding should go directly to the tribes, instead of to intermediary organizations that say they provide technical assistance, yet do not deliver for months.

Richard Moore, Coordinator of the SWNEEJ, noted that the executive order seems to be a positive step, but environmental democracy is a bottom-up process. The network wants full participation by its members in anything affecting its members. Because its members did not participate in framing the executive order, the SWNEEJ does not endorse it. I propose more discussion about dissatisfaction with the core groups' input. I want to leave the meeting with a set of recommendations and carry out the recommendations in communities at home. I call for 20 minutes of grassroots suggestions on moving forward in the core group process.

Audience comments

▼ **Janice O'Neill**, Flint Genessee United for Action, Justice and Environmental Safety: If there is a finding of environmental racism and the EPA Office of the General Counsel is involved, there might be duplicity. This issue deserves consideration.

▼ **Vervet Tilden** of the Edgewater people: Children herd sheep in fields near open mine pits, tons of coal are strip-mined, and bones of Native American ancestors are crushed along with coal. A planned uranium mine will use in situ leaching with water below it. Several communities will be affected. He asked attendees to honor Native American spiritual values and recommend developing a way to ensure that treaties are recognized and enforced.

▼ **Vina Colley**, a worker from a bomb factory who has suffered environmental contamination: This participant is from an all-white Appalachian community that ships radioactive waste to landfills around the country. She has DOE records from Oak Ridge, TN, about experimental use of radioactive material in humans by the old Atomic Energy Commission, guidelines for uranium experiments on humans, and a description of experiments on animals and humans with polonium, uranium, plutonium, and lead. If her union had not given the information to the community, many would not be alive today.

▼ **A woman from Albuquerque, NM**: There are 12 Superfund sites in New Mexico and she lives in an Albuquerque community where one is located. Decisions are made without including the community. Seventy percent of billboards in her community represent other polluters, including tobacco and alcohol.

▼ **Rev. R.T. Connelly**: This participant represents six organizations in west Dallas concerned about lead pollution. He came to this meeting for information and support. His community's problem is with the city of Dallas, not EPA, which had announced in 1988 that west Dallas was polluted with lead. The city denied the charge, and EPA said nothing further. He appealed to the sincerity and integrity of public employees to do the right thing. His fight against lead pollution began in 1969. In 1993, EPA recognized west Dallas as a Superfund site; there was enough lead there to fill three Dallas Cowboys' stadiums.

▼ **Kim Rettberg**, Earth Vision Productions, San Diego, a nonprofit, womanowned organization: The company is doing a six-part documentary on the environmental justice movement. If participants are willing to help the project, Poster 74 outlines the six parts. The focus is on solutions.

Afternoon Plenary Session: Challenges to Conducting Meaningful Health Research

Panel and audience comments (*Note: The tape recording does not include any earlier presentations.*)

▼ **Susan Clarke**, Environmental Health Advocacy League, Concord, MA: Ethnic minorities, by occupation and geographical location, are a sensitive population, but children, women, the elderly, and the previously ill are more sensitive to toxic exposures. Chemically injured people who respond acutely to chemicals are not represented here. The conference should address the neurotoxic effects of common products such as cosmetic chemicals and synthetic cleaning chemicals. Experimental mice exposed to some products have had seizures and died. This result indicates human brains are being damaged. Consumers should use alternative products.

▼ **Debra Hasan**, Savannah, GA: This participant lives 90 miles from the Savannah River site of a nuclear bomb factory. A study of accidental and intentional releases of radioactive iodine and strontium from the 1950s will not include people of color. For 2 years, scientists will try to trace radioactive releases, but exposed community members may not even be included in the

study. Government scientists have declined to accept the connection between exposure to this radioactivity and cancer deaths. Her community seeks assistance.

▼ **“Nina”:** This participant sought assurance from conference sponsors that community people, like her group from the South Bronx, will have a place at the table. She hopes that core groups will include people from NIEHS and will cover the many types of pollution experienced in the South Bronx.

▼ **A New Zealand woman** affiliated with the Children’s Rights Project: Indigenous peoples themselves have solutions; government officials and agencies need to listen to them.

▼ **Audience member:** A structure should be created at this meeting to allow indigenous people (not just agency officials) to contribute to the meeting. Community-based problems should be at the center of core-group discussions, and scientists and government agencies should be asked to respond.

▼ **Marty Sonenfeld**, a political organizer from New York City and cofounder of Innovative Empowerment Strategies: Dispense with the next morning session to allow core groups to meet from 9 a.m. to lunchtime. In planning future conferences, organizers should choose a site where owners respect the workers’ right to organize. Instead of investing so much money in beautiful core-group name tags, organizers should provide language-translation technology.

▼ **Hispanic woman**, Madeira, CA (This participant spoke in Spanish but had a translator): She works in a packing house near an area where chemicals are added to the shipped fruit. One day a strong odor came from an oven used in the chemical process, and many women workers fell to the floor and lost consciousness. She was among those poisoned; even now she doesn’t feel well and has stomach problems. The packing house of Vesorio Farms is based in San Francisco and pays workers \$5 an hour. But in Madeira, where she works, the firm pays \$4.25. Inspectors need to monitor the chemicals area, bathroom facilities, and medications given to workers. The day of the poisoning, many workers became ill from medication they received—aspirin that had expired 6 or 7 years earlier.

▼ **Audience member Jean Simmons:** This participant described herself as a victim of high technology and urged that chemical companies be made to comply with standards of safety and to protect their workers.

Informal Press Conference

Dr. Bunyan Bryant invited the press to the stage and said that this conference is now more like a people’s conference because this session is more participatory. Community members ready to be interviewed were invited to the stage.

Dr. Devra Davis, Senior Advisor to Dr. Philip Lee, in the Public Health Service (PHS): The Federal government is willing to sit at the table with community members. There is a history to be overcome but the process has begun. Inequalities faced in public health have been well characterized for many years. Diabetes is twice as common among Hispanics as it is among whites. Blacks are more often diagnosed in advanced stages of cancer than are whites. These differences indict the health care delivery system. Republicans in Congress say we should let things go as they are. But we must make sure our children get better health care than

many of us have had, and we must determine the next steps to achieve environmental justice.

Vicki Reese, a reporter with "Environment Week," Washington DC, said that she'd probably written more about environmental justice than anyone else in Washington, but has been criticized for not talking enough to Washington outsiders.

Lee Sprague of San Francisco, CA, stated that the most fundamental human right is the right to a clean environment. We must learn how to live so we don't need toxic waste dumps. We must change the way we raise our children and the infrastructure of our economy and lives. Territorial lands can't be seen as sites for extracting minerals without consent of indigenous people, who have the wisdom to make changes but are sometimes unheard.

Carletta Tilousi of the Havasupai Nation in Arizona stated that Native Americans are deeply affected by industrial corporations that came into homelands, exploited natural resources, and endangered the native peoples' health. Six hundred tribal members live at the bottom of the Grand Canyon. Their main source of water will be contaminated by Energy Fuels Nuclear and Union Pacific. As uranium seeps into the water, radiation will contaminate water for the millions who live downstream. The National Forest Service and National Parks supported uranium development on the Colorado plateau. There are 90,000 uranium mine claims in and around the Grand Canyon area. Mines were developed near a native sacred site. Freedom of religion does not apply to Native Americans. We demand that EPA exert pressure to prevent issuing aquifer and groundwater permits to mining companies and industrial corporations; that EPA give information, funds, and education to tribal communities on programs provided by EPA laws; that EPA fund Native Americans to conduct their own health studies, support victims, and seek damages for industrial contamination; and that the Indian Health Service, the Bureau of Indian Affairs, and EPA be held responsible for this damage.

A woman from the Hawaiian Islands and Pacific Ocean area of Micronesia and representing the coordinator for the United Nations Convention for Children's Rights stated that her group demands the United States follow the convention for children's rights developed in Geneva. She asked all attendees to sign her petition to the U.S. government.

February 12: Morning Plenary Session

Opening Addresses

Sam Winder of the National Tribal Environmental Council (NTEC) declared that the Federal government has not looked after the interests of Native Americans for the last 180 years. Its main goal in leasing native lands was to confiscate land and make money. Native American land has been poisoned, and people have been poisoned. For example, DOE abandoned more than 1,000

uranium mines on Navajo reservations, with processing plants and mountains of hazardous waste that emit low-level radiation close to people's hogans. Some Navajo people who used leftover mining materials to build homes have diseases associated with continuous exposure to low-level radiation. The NTEC was created to empower tribes and give access to information they need to correct these problems and heal themselves. If Indians are not given a place at the table, they will challenge any plans that are developed, and government efforts will be wasted.

Dr. David Satcher, Director of CDC and Administrator of ATSDR, described how CDC is affiliated with NIOSH, NCEH, the National Center for Injury Prevention and Control, the National Center for Chronic Disease Prevention and Promotion, the National Center for Infectious Diseases, and the National Center for Health Statistics (NCHS). All of these agencies deal with issues central to environmental degradation and should target their resources in that direction. It will be both a burden and an opportunity to work on these problems.

Pam Tau Lee of the University of California at Berkeley said that although a principle of environmental justice is to affirm the right of workers to safe, healthy work environments, research that targets environmental racism in the workplace is past due, and people in the environmental justice movement have not done enough to deal with problems of workers, particularly workers of color. People in the movement should rethink their approach because workers of color are nearly twice as likely to be injured or taken ill in the workplace as are white workers, and the workplace is usually the setting for environmental degradation and destruction. Noting that representatives from the Occupational Safety and Health Administration (OSHA) were conspicuously absent, she called for OSHA reform. More research on the health of Latino, Native American, Asian, and African-American workers is needed, particularly on exposure to multiple hazardous substances and on synergistic effects of toxins. The government should not wait for research results when there is evidence of toxicity but should step in immediately to protect workers. African-American workers in poultry plants are crippled; Asian women working in electronics plants have miscarriages; children of fieldworkers are born with birth defects; and other workers are poisoned by radiation. Cleanup of toxic sites is a growing industry, but its jobs must be safe and open to people of color, and workers must receive proper training and protection, stable income, and union membership. People in the environmental justice movement need links to leaders in government agencies so that they know whom they can talk to and how to reach them directly. Government and universities should also stand against environmental racism.

Thomas Grumbly, Assistant Secretary for DOE Environmental Restoration and Waste Management, advised that the Clinton administration is serious about implementing a justice-based environmental policy. Under the current administration, DOE's vision is to transform how government relates to people. This process begins with the acknowledgment that DOE has made serious errors and the recognition that the central issue is to challenge the idea that good policy is made in Washington by people who are white, male, and over 40, with similar

last names and educational degrees. Good policy can be made at the local level by the people involved in the problem.

DOE's obligations to Indian nations are as follows:

1. To broaden and deepen grants to Indian communities adjacent to hazardous sites. This effort will include providing the funding, in a timely fashion, for the technical expertise necessary for Indians to participate knowledgeably in the regulatory process.
2. To begin immediately the process of including all Indian nations in all regulatory negotiations, so that they may be active participants instead of bystanders. He promised that all future negotiations will include formal discussions with the Indian nations.

Whenever a State or Federal agency that is involved with DOE in environmental restoration agrees to do so, DOE will raise the priority of restoring sites that impinge on tribal holy places, burial grounds, and other areas of importance to Indian nations. Furthermore, DOE will change how it administers its \$18 billion worth of contracts by reforming minority contracting in the environmental area—increasing minority contracting by 100 percent in each of the next 2 years. Working with unions, DOE will ensure that by the end of Clinton's term, workers on reservations will not be exposed to unsafe conditions.

DOE will also establish priorities for sites that affect people of color. When land that has been restored is ready to be transferred, DOE will give priority consideration to what the Indian communities near that land want to do with it. Even in areas that present major technological and practical obstacles to cleanup efforts, DOE will require restoration to a level that the ancestors of Native Americans would approve. It has been a struggle to get to this point, but DOE is taking small steps toward change. Symposium participants should turn away their anger at past administrations and work with this administration, which will make no more empty promises regarding the environment.

Connie Tucker, Coordinator of the Southern Organizing Committee for Economic and Social Justice, announced that it is time to release the old guard in government agencies and let in new voices so agencies better represent those they serve. A wholesale change is needed in conferences and other environmental justice activities to include community representatives. The chief complaint about including community workers is that they become too emotional over environmental justice issues. It should be recognized that they are emotional because they are sick or dying. While scientists and government workers may not want to be around strong emotions, *they* need more emotion to solve these problems.

Participants must not leave the symposium without raising the issue that EPA's regional office tried to suppress the Chattanooga study, which demonstrated that high levels of toxic chemicals are being emitted in densely populated communities of nonwhite, uneducated poor people. EPA officials also curtailed the

Chattanooga researchers' attempt to link the chemicals with a particular disease, claiming lifestyle was to blame for the disease, or that it is impossible to determine causal relationship.

Panel and audience comments

▼ **A South Carolina physician:** He noted many cases of cancer, including clusters of cases, in areas that are obviously affected by toxic waste. But statistics are so poorly kept that it is impossible to establish a link between adverse health effects and toxic exposure. He asked Satcher whether CDC will work with the Bureau to improve recordkeeping so links between cancer and particular locations or industries can be established.

▼ **Mr. Grumbly:** DOE is committed to involving African Americans as well as Native Americans. The agency is at the forefront of changing the way citizens are involved in government, particularly in cases such as the Savannah River nuclear site. DOE is moving away from the frankly secretive model it had under past administrations toward one that regularly involves citizens. Communities must have the ability to choose their own experts so they can come to the table with the same degree of technical ability that the State government has at its disposal.

▼ **Audience member:** This participant grew up in a radioactive fallout zone of Rocky Flats and has buried many friends and neighbors who died of leukemia and brain cancer. She and members of her community are concerned about radiation containment during cleanup activities in Rocky Flats, particularly because of recently reported plutonium spills there. She asked for Grumbly's assurance that cleanup efforts will not make a bigger mess than the one that already exists, and that local communities will be consulted on cleanup efforts.

▼ **Mr. Grumbly:** DOE must respond to past injustices as it pursues cleanup efforts. Officials in the Treasury and Justice departments expressed concern over making such an announcement, but the administration will stand by it. There must be no further radiation releases during the cleanup process. Occupational safety and health will be critical for the workers who tear down these facilities, some of which are as large as the State of Rhode Island. Participation of Colorado citizens must increase. Community members impaneled to work with the government typically are upper-middle-class white males. Although Colorado chooses its own participants, he will work with the State to diversify their input to DOE.

▼ **A worker in an Ohio nuclear facility:** She lost her job and medical benefits after becoming ill from radiation contamination and complaining about safety issues. At her workplace, more than 300 people are sick or dying. Workers don't need more research about contamination; they need immediate medical care and compensation for illnesses.

▼ **Audience member:** As DOE's Native American policy is implemented, Grumbly must get input from elected tribal officials and from community members. These members are frustrated when Federal staffers listen only to tribal officials.

▼ **Mr. Grumbly:** He hopes all tribal members get educated about building facilities on their lands because some Indian nations have requested that facilities be located on their land to bring economic benefit to the community. Nuclear power can't be considered good for society until we deal with nuclear waste.

February 12: Lunch Address

Dr. Beverly Wright of Xavier University Center for Environmental Programs spoke about the distrust of government agencies caused by governments' ineffective response to environmental problems. There is a pervasive perception that the government acts in the interests of polluting industries and that government staffers are incompetent in dealing with chemical risk issues and insufficiently skilled to interact with citizens. Furthermore, citizens believe government officials have mismanaged regulatory programs, made questionable decisions, lied, and made errors. The government must develop a mechanism to address community grievances, possibly based on a model program for research at Wright's institution, that embraces science and the community. This equal partnership—called “communiversity”—eliminates academicians' ability to use communities as guinea pigs in research. Communities are leery of universities and skeptical about whether they will act on behalf of citizens. But when sensitive faculty members and capable scientists and administrators see their mission as serving the community, and when many students and faculty members live in the community, a working partnership can develop. Communiversity was hard to develop: When input from community members altered the original plan, professors found it hard to have less educated people dictate to them, especially about research. It was also hard to get the academic community to agree that funding for community groups should equal funding for university participants. But only when funding is equal can authority be equal.

To date, communiversity has received accolades but no funding other than an EPA grant that supported one project but not the concept. Xavier University has resources that would be ideal for environmental health problems and it includes participation by toxicologists, chemists, and epidemiologists. When a community has such resources and when a university responds to the community's research needs, the community can become a cleaner and safer place. Symposium participants should pressure universities to do research that communities truly need.

Audience comments

▼ **A Native-American man:** In the 1980s, a case involving a polychlorinated biphenyl (PCB) landfill in North Carolina brought attention to the issue of environmental racism, which intensified with publication of the study, *Toxic Waste and Race*. Environmental groups have burgeoned in minority communities; people in the environmental justice movement could never have imagined then that this symposium would be convened and an executive order on environmental justice would be signed.

▼ **An African-American environmental sociologist:** Justice often involves getting skilled and trained individuals in the pipeline so they eventually will be able to work against injustice. African Americans who study the sciences must remember that their roots are in the community, and they should return to serve their community after they have been trained. At the end of the symposium, recommendations, accountability sessions, and monitoring mechanisms will

be in place—tools to make government, institutions, and communities work together against environmental racism.

▼ **Audience member:** As the environmental justice movement gained popularity, a range of people and groups has tried to start environmental justice projects without understanding the issues. They don't recognize how issues of race, gender, and culture affect the staffing of their organizations. Attention to the makeup of organizations is as much a part of environmental justice as identifying toxic substances. Decisionmaking practices are based on how institutions are constructed. To make sure that structural changes called for by the environmental justice movement are accomplished, barriers to equality must be overcome in each organization. Environmental justice activists are different colors, have different cultures, and are from different regions. Every time they have a meeting they must have representation from Asians, Native Americans, African Americans, Latinos, and women.

▼ **Audience member:** This participant represented the Northeast Environmental Justice Network. After a 27-year legal battle with the city of New York, a community in Harlem received a \$1-million court settlement. There are many indigenous people in the northeastern regions of the United States, particularly New England.

▼ **Audience member:** Asians are an invisible minority because other ethnic groups consider Asians model Americans who have no problems. Asians are culturally diverse—Chinese, Japanese, Korean, Vietnamese, Laotian, Cambodian, and Pacific Islanders. Asian farmworkers have been exposed to many toxic chemicals. Pacific Islanders have been exposed to herbicides, pesticides, and radiation. Asian women working in electronics factories have high rates of miscarriage. Symposium participants should look into minority communities to find “invisible” people who have an environmental problem but no organization to help them.

▼ **Dick Gregory, civil rights activist and comedian:** He lived for years near the University of Chicago and raised his children there. After he moved away, many residents developed a form of bone cancer. The Manhattan Project, based at the University of Chicago, generated nuclear waste that experts didn't know how to dispose of. They ended up “disposing” of it in the construction of every new building on campus, exposing people in the area to radiation that caused bone cancer. Violence in the black community is not a result of social disintegration. It is spurred by science: the need for organs and bodies for scientific research. Passage of seatbelt and other traffic-safety measures decreased the number of organs and bodies available to researchers and doctors. Most black victims of violence are shot in the head, which preserves their organ function long enough for harvesting.

February 12: Wrap-up

Summary Recommendations From Core Groups

Core group sessions were held throughout the conference to develop recommendations for action. A separate summary report is available on the core group recommendations.

Core Groups 1-3

1. **Allow communities to speak for themselves rather than have consultants do it.** Typically, a community will do initial research on its environmental problem, then hand it over to scientists and

other experts. When these intermediaries report to government agencies, they often don't accurately reflect community concerns.

2. **Ensure government validation of a community's experience with an environmental problem, rather than dismissing community reports.** The government should work on behalf of people, not industry. Any penalties or fines imposed on an industry by a regulatory agency should be turned over to affected communities.
3. **Increase government funding to communities,** fully inform communities about available funding, and provide technical assistance with the application process so communities can more readily obtain funding.
4. **Ensure that researchers must explain to community members what data they need to study an environmental problem,** then report their findings to the community in an understandable format.

Core Groups 4-7

1. **Respond to the urgent need for public education and outreach efforts,** so communities can be more involved in their own protection. Two possibilities are how-to clinics and in-home clinics that teach people about, for example, radon poisoning in their communities.
2. **Inform the public about the effects of products they use on the environment.** Products should be priced to reflect their impact on the environment.
3. **Establish an environmental information network independent of government or industry.** It should include a telephone hotline, a clearinghouse, and computer networking. Government agencies should give communities computer hardware and software that is user-friendly and connected to data-collection systems that are independent of the government and should provide computer training to community members.
4. **Establish legal safeguards so "whistle-blowers" who report violators will not face retribution.**
5. **Increase ethnic and cultural diversity on the staffs of government agencies,** particularly in positions that require contact with affected communities. Too often, agencies hire white males to investigate situations in which most complainants are black women.

Because these groups have divergent sensibilities, misunderstanding results.

6. **Honor whistle-blowers and protect their legal rights.**
7. **Ensure that consumers have the right to sue the government** when they are affected by environmental pollution.
8. **Subject corporations (and executive officers) who knowingly violate regulations to criminal penalties.** President Clinton's "three strikes and you're out" policy with criminals should apply to corporations: Imprisonment should be mandatory for executives who head companies that habitually violate environmental regulations.
9. **In legal cases concerning chemical toxicity, shift the burden of proof so chemicals are considered toxic until proven safe.**

[Note: No recommendations were listed as deriving from Core Group 8.]

Core Groups 9-11

1. **Eliminate unsafe pesticides used in the United States and exported abroad.**
2. **Increase action to reduce farmworkers' exposure to known toxins, such as lead in paint and soil.**
3. **Increase research on asthma, particularly among people of color, and take more action against known causes of asthma.**
4. **Generate a written report of symposium proceedings.**
5. **Agencies sponsoring the symposium should plan the next step.**
6. **Community members need financial support to have real participation in the next symposium. Agencies must provide travel and lodging costs.**
7. **Ensure that researchers recognize local expertise in environmental health matters and that any government intervention be done in partnership with the community.** In researching an environmental problem, the burden of proof should be removed from victims and placed on the hazardous materials themselves.

8. **Enact, strengthen, or enforce legislation that gives everyone equal protection against environmental degradation.** Civil and criminal penalties against violators should be increased, and existing legislation (including the Clean Air Act, Clean Water Act, Superfund, and pesticide legislation) should be strengthened. A Superfund should be created to provide job training for workers who lose their jobs because of environmental technologies or innovations.

Core Groups 12-15

1. **Repeal the Werner Amendment**, which guarantees sovereign immunity. The amendment makes it impossible for citizens to sue the government; repeal would give them that right.
2. **Make all communication materials in the environmental justice arena multilingual** so all linguistic groups in the population can understand them. Similarly, all communication materials must use simple, clear language instead of technical jargon.
3. **Revamp the funding process.**
 - ▼ Eliminate government subsidy of corporations and redirect the money to community justice groups. Generate new sources of funding by making polluters pay fines; direct that money to local justice groups. This move switches control of funding from government and industry to citizens.
 - ▼ Eliminate provisions for local justice groups to receive reimbursement for their expenses. They need the funding up front.
 - ▼ Simplify procedures for obtaining grants so community groups can apply more easily for them. Let community groups set up general criteria for awarding grants, and let community committees oversee funding and research. Draft legislation and regulations that require community-based organizations to be included in the funding process.
4. **Mandate institutional change.** Overhaul personnel, hiring, and evaluation procedures in government agencies and academic institutions so that staff and leadership reflect the cultural diversity of the community being served. Enforce laws that require such change.
5. **Ensure that recommendations made at this symposium are enacted.** Report accomplishments of the symposium to the public and hold a followup conference.
6. **Insist on full disclosure of all relevant data** and let communities use data on their own behalf. Communities often are not given

access to data. Once they have access, they are not allowed to use the data for their own purposes.

Core Group 16

1. **Establish an interagency forum to address environmental justice issues** to make certain that involved agencies are aware of their roles and will not duplicate efforts.
2. **Ensure that the interagency group is actively involved in affected communities**, educating residents and allowing them to set the agenda for further action.
3. **Ensure followup to this symposium**, so the report of its results is not shelved and forgotten.
4. **Encourage agency employees to stand together with community workers to get things done.** Many agency employees seem to be good people with a lot of heart, who say their hands are tied until citizens get their legislators to enact laws that allow agency people to act.

Core Group 17

1. **When addressing any case of environmental injustice, include community groups from the outset**, along with local health and environmental agencies and State and Federal groups (such as Congress and the Departments of Justice, HUD, Labor, and the Interior).
2. **Make all relevant information available to affected communities in their own languages**; include videotapes that illiterate citizens can understand.
3. **Provide money to include professionals in the communities**, such as local toxicologists, in environmental justice efforts; they will ensure that community members aren't "snowed under" with technical jargon from government and industry representatives.
4. **Urge symposium organizers to obtain a signed executive order** so all participants return to their communities with something solid to show for this conference and a starting point for further work.

An **unidentified speaker** from the core group said that risk assessment is a concern to indigenous people, who believe there are no acceptable levels of environmental contamination. A clean environment is the fundamental right of Native Americans, who have a long history of resource management based on

detailed understanding of long-range impacts on the environment. The use of risk assessment as a tool and policy allows activities that damage the land, animals, and people. Indigenous people assert the right to reject levels of contamination that industrial societies consider acceptable. The position of indigenous peoples, which must be considered in environmental studies conducted in their territories, is as follows:

1. Precedence must be given to traditional considerations over economic considerations in determining the future of Native American children.
2. Educational programs in indigenous communities should reflect traditional values.
3. Tribal representatives and representatives of Federal agencies should be trained in and sensitized to traditional values.
4. Funding should be adequate to ensure implementation of traditional values.
5. Indigenous peoples must be equally involved in decisions, and health research must consider all parameters identified as important by indigenous people.
6. A permanent ombudsman position should be established in Federal agencies that interact with indigenous people and should include oversight authority on programs affecting indigenous communities.
7. An electronic information network must be established, ensuring that indigenous people have the opportunity to identify problems and initiate proposals.

Another **unidentified speaker** from a core group told how that group dealt with a Maori woman from New Zealand who wanted to bring the plight of her community to the attention of the symposium attendees. She noted that 50 years ago, the New Zealand government borrowed the community's island to explode bombs. The people were relocated, but pregnant women now are giving birth to tissue masses, not babies. In response to her description, a member of the core group who is a toxicologist said it seemed that this population had experienced permanent, irreversible genetic damage. The woman was seeking help for her community: What could scientists and Federal government officials offer her? Would her civilization survive? Could her community return to the island? Has their race been altered? Participants must come up with concrete solutions for problems such as this one. Any information that could be useful to the Maoris must be given to them, and if it is classified, it must be declassified so it is accessible. These people know their own history and their own environment intimately, and they will prove to be the most important information source for whoever

proceeds with an ecological risk assessment or epidemiological study of their reproductive problems.

Core Groups 18-20

1. **Recognize that people are not a tool for science; science is a tool for people.** Scientific knowledge has limits. Other “ways of knowing” are as valid as are scientific ways.
2. **Ensure that research is done in the community, for the community, by the community.** No more research should conclude there is no solution to an environmental problem, nor make it appear that the government has done something useful about a problem when it has not.
3. **Ensure that the purpose of environmental research is explicitly clear to everyone involved from the outset** and serves the needs of the community instead of the needs of industry or government.
4. **Do not tolerate negative research** that is designed to prove that there is no environmental problem.
5. **Ensure that researchers empower the community** and involve community members, not exploit them.
6. **Ensure that community members are involved at all stages of a research study**, including defining the problem, designing the research, gathering the data, analyzing the findings, and publishing the results.
7. **Disseminate findings** so that people are aware of and can use the information.
8. **Encourage partnerships among government agencies, research institutions, and community members.** These relationships are essential and must be characterized by mutual respect and recognition of the different “ways of knowing.”

A **final speaker** declared that the scientific and environmental justice communities must jointly develop a new model for environmental research that includes affected communities as active participants in the research. Citizens must be involved in planning and conducting studies, disseminating results, generating hypotheses, discovering new problems, interpreting results, and ensuring that study results are translated into appropriate public health action whenever possible. New epidemiologic models and methodologies must be developed to analyze smaller population groups, cluster phenomena, low-dose exposures, and exposures to multiple toxins. Recruiting, advancing, and retaining people of color

and members of affected communities must be a high priority. Environmental research has included the regular practice of omitting, suppressing, and destroying information critical to environmental health. Burdens of scientific proof ignore the norms of most communities that need environmental research. New molecular technologies will have an increasing impact on risk assessment and policy formulation. The environmental justice movement must target the development of these tools to serve affected communities.

February 12: Closing Session

Dr. Kenneth Olden, Director of NIEHS, iterated that NIEHS is committed to environmental justice. The rage and frustration expressed by many participants were long overdue. He expects communities to inform government agencies, particularly NIEHS, about their needs so agencies can act on them.

Dr. Janet Phoenix, Director of the National Safety Council Lead Clearinghouse, noted that the process leading to the symposium took more than a year and was never easy. It was hard for the two camps to establish mutual trust and to work together, but the symposium forced action and a commitment to take environmental justice seriously. It was no accident that the executive order was signed this week.

Participants must return to their communities and make the recommendations a reality, communicating the recommendations to Federal agencies (which must change their approach to community members), informing fellow citizens, and continuing to build alliances across ethnic barriers. In addition, people of color who are scientists or Federal employees have contributions to make and must be acknowledged.

CENTRAL ISSUES SESSIONS
and
Press Conference

CENTRAL ISSUES

February 10, 1994

Central Issues Plenary 1: Respiratory Diseases

(The moderator was **Dr. Bailus Walker**, Dean of the College of Public Health, University of Oklahoma Health Sciences Center in Oklahoma City.)

Dr. Ken Sexton, Director of the EPA's Office of Health Research, observed how he and his coauthors in *Air Pollution Health Risk: Do Class and Race Matter?* defined environmental equity and justice as a commitment to adequate protection for everyone. Environmental health problems occur through a sequence of events that begins with a pollution source, its contact with people (exposure), and adverse health effects. Exposure assessment means (1) trying to understand what exposures people experience and how they occur, and (2) identifying what dose-response relationships occur once a person is exposed. Given the amount of contaminant that entered the body, what are its potential adverse effects? These measures characterize risk assessment, which pinpoints groups potentially at greatest risk. Given exposure to a specific chemical, a person or group or population could be more susceptible or potentially at greater risk if exposed further, or both.

In the U.S. population, subgroups are defined by geography, socio-economic status, race, or ethnicity. Even in the absence of scientific documentation to prove differential exposure, specific subpopulations have different exposures and perhaps even different susceptibilities than the general population. Scientists must understand subgroups, particularly those that are most exposed. In one study, the U.S. population was grouped according to exposure to carbon monoxide. Everyone with higher exposure than EPA's carbon monoxide 8-hour standard is potentially at risk for health effects, so some racial and ethnic groups will be harmed disproportionately if their city has urban air problems.

Over 10 to 15 years, exposure to air pollution often occurs indoors, whether the source is an outdoor or indoor contaminant. Some subgroups are exposed to higher levels of indoor and outdoor air pollution. The best data showing environmental disparities are from an ATSDR study on children's blood lead levels. As family incomes rose, lead levels in children's blood declined for

African Americans and white Americans. However, even at higher income levels, a disparity between white and African-American children occurs, with the latter having higher lead levels. The most likely explanation is a combination of exposures to peeling lead-based paint, lead-filled dust, and the hand-to-mouth activity of children playing on the floor. Wherever researchers look, they find a statistical association between proximity to a major source of pollution and race and ethnicity.

Dr. Henry Gong of the University of Southern California School of Medicine in Los Angeles noted that many factors prevent researchers from drawing simplistic models concerning increased susceptibility, exposure, or both for given populations. In performing air pollution research, including animal experiments, human experiments, and epidemiological studies, scientists have identified factors that affect lung function after controlled exposure to ozone and learned that people vary by genetic susceptibility to ozone. But scientists have not determined whether findings on human subjects in experiments apply to chronically affected individuals. Furthermore, there is a lack of data on nonwhite groups, although one EPA study showed that when white and black volunteers entered an ozone chamber, there was no statistical difference in effect by gender or race. For the whole group, increased ozone concentration caused reduced lung function.

Epidemiological studies—based on systematic comparisons between communities, individuals in communities, across points in time, and combinations of these—seek to identify disease patterns and risk factors, indicate specific mechanisms, and suggest causality and interventions. Many scientists rely on the weight of evidence: For example, if many studies all point to one tendency, many give credence to that tendency. A literature review on air pollution health effects reveals that most studies feature white, middle-income communities, with few focusing on black, Hispanic, Native American, and Asian groups. Future research must target racial and ethnic groups and get good information on age, gender, and socioeconomic status before the relevance of socioeconomic status to effects of air pollution can be analyzed. This research must involve communities, scientists, and health care providers, and it must make a special effort to involve researchers of color. The projects must be adequately funded and encourage interagency efforts that are critical in a time of limited resources.

Chris Mathis of the labor community's Watchdog in the Los Angeles Project asked first how the community can help identify research needs and answer basic concerns of who is exposed to what, how exposure can be prevented, and how to intervene. Second, he asked how disseminating the research can help create policies on air pollution-linked illness. In Los Angeles County, more than 5 million people are Latino, black, or Asian Pacific Islander, and more than half the county is considered at risk for or sensitive to ozone pollution. Periodically, the Air Quality Management District announces smog alerts, broadcasting that the air is harmful to sensitive people, but without defining "sensitive." Those potentially affected include children, the elderly, people with health conditions, and those who are HIV-positive. Many people of color who would

qualify as sensitive live in industrialized communities ringed by freeways and busy streets. Large corporations produce much pollution and help shape government policies, while ordinary citizens have no say in the products made or the industrial processes used to manufacture them.

The public health crisis resulting from air pollution is a symptom of how large companies exert power over people of color. Grassroots movements among people of color, low-income people, and working-class people must confront corporate power in transportation, industrial, and regulatory policy. Watchdog is a microexample of such a movement. The project began by publishing *Los Angeles' Lethal Air*, an examination of scientists' work written for a general audience. Education is key to building an informed constituency to fight for clean air because the issue is political, not technical. While we need more scientific studies, research alone is insufficient, particularly if it neglects environmentally caused or exacerbated disease. There is an urgent need to bring together the best community-based, university-based, and public health scholars, practitioners, and activists to compile a body of existing work and develop new socially relevant research. The government could use its leverage to make companies do the right thing, and individuals could press to raise the minimum wage, eradicate poverty, support a Superfund for displaced workers, make trade with other countries contingent on worker and human rights, and talk to each other.

Gerrie Kilburn, a registered nurse concerned about occupational health and safety issues, described two American Lung Association (ALA) community education projects. "Care for Your Air" targets outdoor pollution, and "Working Healthy is More Productive" targets workplace pollution. Focusing on a small community in greater Los Angeles, both addressed the Latino/Hispanic population that constitutes 40 percent of the region's residents. Care for Your Air tried to increase Latino awareness of air quality and its health effects in the community. ALA stressed the importance of car care in reducing emissions after defining program objectives by asking community leaders and residents about their needs. ALA held resident meetings, conducted in Spanish and English, to solicit more data. It carried out an in-depth survey (333 responses were received from 1,360 residents), which showed that 87 percent of respondents owned a vehicle. Respondents recognized air pollution health risks, were reasonably knowledgeable about most common health effects and causes of air pollution, and were receptive to more information. They would be willing to make personal sacrifices to improve community air quality, including monthly financial contributions. In the next stage of Care for Your Air, a media campaign will work with Spanish stations and use a "Reporter's Guide" that contains air quality reports, consumer tips on reducing smog, discussions of the impact of smog on at-risk residents, relevant local ordinances and laws on car maintenance, and the California State Smog Check program. The project's evaluation component will monitor Spanish-language print and electronic media.

"Working Healthy is More Productive" seeks to give supervisors of Spanish-speaking workers information and educational materials about basic

concepts of worker health and safety. Employers must tell employees what toxins they work with and how to protect themselves. The project was born when ALA staff found that only 28 percent of companies interviewed offered education in Spanish for Hispanic-Latino workers and that workers had little knowledge about personal health and safety. The Hispanics and Latinos who form the majority of blue-collar workers in Los Angeles, and who work disproportionately at high-risk jobs, have few opportunities to get information about health and safety concerns. ALA developed an instructional video in Spanish and English; tested it in focus groups; enlisted the cooperation of companies to film the video in restricted areas; and tested it for accuracy, appropriateness, and understandability. Forty companies now use the video.

Dr. Peter Gergen of the National Institute of Allergy and Infectious Diseases (NIAID) told about the National Cooperative Inner-City Asthma Study (NCICAS), an asthma study of inner-city children in eight cities that is examining risk factors and determining prevention strategies, focusing on asthmatic children ages 4 to 9 who live in census tracts where more than 40 percent of residents are below the poverty line. Important predictors of asthma morbidity and mortality are poverty and minority status. Although the environment plays a large role, how to intervene optimally remains unclear. NCICAS runs from March 1991 through February 1996: Phase 1 identifies risk factors and phase 2 proposes and tests interventions to reduce asthma severity and morbidity in these children, based on phase 1 findings. Phase 1 is currently ending, and phase 2 planning is underway.

Phase 1 looked at the morbidity experiences of asthmatic children over 1 year of age, collecting information on sources of care, sensitization to allergens, passive smoking exposure, psychosocial background of child and family, the health care delivery system, adherence to medication, pulmonary function, and economic costs of asthma. Children were recruited from emergency rooms and clinics. NCICAS data are not yet formally analyzed, except for results from the pre-phase 1 pilot test using dust samples taken from the children's bedrooms. Although the house dust mite is an important allergen for asthma and ubiquitous in many studies, this study found that only 6 percent of homes had even light levels of house dust mites, but almost one-third had high levels of cat allergens, and 20 percent had high levels of cockroach allergens. Pilot test data also showed a high level of children's secondary exposure to smoke and a lack of knowledge by families about the effect of smoking on those with asthma. During the study, the use of community-based recruiters and clinic members enhanced community participation. Afternoon, evening, and weekend interviews were needed. Researchers found that providing day care and taxi vouchers to and from home made participants more likely to stay involved. Staff used telephone interviews for 90 percent of followups, with 10 percent conducted in person or by letter. The project also provided a toll-free telephone number. Because literacy was another problem, researchers created a simple English-Spanish questionnaire.

Panel and audience comments

▼ **Dr. Gergen:** NCICAS researchers, faced with limited money and expensive technology, chose what variables to study. NCICAS has started to fill the gap on information about outdoor air pollution. The eight NCICAS cities have EPA monitors who collect routine pollution data reported in the United States. Now NCICAS is trying to work with EPA to collect those data and attach them to the NCICAS morbidity-mortality data to see correlations and associations. NCICAS researchers will not collect the data themselves.

▼ **Mr. Mathis:** On channels of communication from researchers to people in neighborhoods: Science is not neutral. Watchdog comes to the struggle for clean air and environmental justice out of a commitment to social justice. Different agencies regulate different sources of pollution. His organization has received boxes of information.

▼ **Audience member:** Regulatory and helping agencies are fragmented. A Latino woman living in the South Bronx and working in the garment factory gave birth to a low-birth-weight baby while suffering from poor nutrition and breathing neighborhood air. OSHA, EPA, the local health department each will study parts of the larger contamination, but no one agency will help the woman. He called for a larger social movement and urged health sciences advocacy to help people make the best choices.

▼ **Dr. Walker:** Certain populations are underrepresented in scientific research, a failing that should be addressed. If we want to move forward, we need funds. Community groups have a role in assuring that there will be resources for these projects.

Central Issues Plenary 2: Lead Poisoning

(The moderator was **Janet Phoenix** of the National Lead Information Center.)

Dr. Stephen Thatcher, Acting Director of NCEH at the CDC, explained that CDC is a task force member and the primary agency in lead poisoning prevention that provides grant money for local and State programs, with NCEH giving grants for screening, case management, and education. Of nearly 1.5 million children screened in 1993, 100,000 had elevated blood lead levels. The education programs of NCEH, which include a telephone hotline and conferences, are administered in cooperation with other Federal agencies. NCEH also conducts epidemiological studies to review program effectiveness, other special epidemiological studies, and public health surveillance, which includes routine collection, analysis, and dissemination of data for program activities. Since inception of the Interagency Task Force in December 1993, NCEH has been an active partner in the effort, working to develop coordinated approaches to implementing the Residential Lead-Based Paint Hazard Reduction Act (Title X) and environmental justice initiatives.

Joseph Carra, Deputy Director of EPA's Office of Pollution Prevention and Toxins, described Title X as providing the infrastructure to tackle problems generated by lead in the environment, including lead in public and commercial structures and residences. The Act emphasizes housing-based primary preven-

tion activities implemented on the State and local levels. These activities include ensuring that people engaged in lead-based paint activities are trained and certified; developing standards for abatement activities; promulgating model state programs for training and prevention; awarding grants to develop these programs; establishing and maintaining laboratory standards and accreditation concerning the measurement of lead in the environment; working with other agencies to develop an active, up-to-date public education campaign; and developing regulations that define lead-related hazards. EPA is involved in research that includes improving the understanding of lead exposure, its sources, pathways, and biokinetics; developing improved and low-cost technologies for detecting and measuring lead; identifying those renovation and remodeling activities that cause the largest lead exposure problems; and developing less costly methods to reduce children's exposure in homes with lead hazards. EPA is working on a community-based lead abatement demonstration project supported by Title X with HUD, DHHS, and the Department of Labor (DOL).

Steven Schwartzberg, Director of the Alameda County (CA) Lead Poisoning Prevention Program, reported that a study conducted in various sites across California in 1988-1989 documented the existence of lead poisoning among youngsters. Of 550 children tested in Oakland, 60 percent had blood lead levels of more than 10 micrograms per deciliter ($\mu\text{g/dL}$), the CDC action level. In response, People United for a Better Oakland (PUEBLO) worked with area residents, the media, and the health department to find financial support for a program to alert and help the community. A benefit-assessment district was created, with four cities assessing fees of \$10 per year for 3 years on homes built before 1978. Fees underwrote the Lead Poisoning Prevention Program, which included case management, environmental investigation, community education and outreach, remediation, and training for local health professionals. Since some basic issues for preventing and responding to lead poisoning remained untouched, the Alameda program applied for and received funding from HUD and CDC to address these issues. It now has an annual budget of \$5 million. As a result of political activity by PUEBLO and similar groups, the State requires several industries to pay fees so children can be tested for lead poisoning. The program also develops outreach programs for specific groups.

Lorraine Granado of the Cross Community Coalition in Colorado told about a State suit filed in 1983 against a smelting company, the ASARCO Corporation, for pollution associated with refining near Denver. The community around the plant wasn't told about the suit or a settlement that gave Colorado \$600,000 to study arsenic, cadmium, and other heavy metal pollution related to company activities. The money was added to the State's general operating funds. In 1987, Granado began working to involve the community in the legal process. The coalition sought to educate local residents about pollution and legal action, to get funds to clean up the pollution, and to close the plant. These objectives pitted a community of fewer than 12,000 people, half of whom were below the poverty level, against an international chemical refining company with a history of involvement in chemical pollution lawsuits. Eventually ATSDR funded a study of blood lead levels in children that indicated recent lead exposure, but did not

suggest overall body injury. Through door-to-door canvassing, coalition workers found that asthma, learning disabilities, and behavioral problems among young people in the neighborhood seemed disproportionately high. A complication in the issue of determining fair remediation was the coalition's finding that no standards existed for acceptable levels of heavy metals in soil or air. Meanwhile, the community is still poisoned.

By using the media and political pressure, the coalition was able to take its Comprehensive Environment, Compensation, and Liability Act (CERCLA) lawsuit to court, winning after 5½ years. Remediation included cleanup of the plant site and four blocks around it. A class action suit that the coalition filed for the community resulted in the largest award ever made in the State of Colorado for community damages. The \$40-million award will be used for yard cleanup and to compensate community property owners.

Sandra Roseberry, a New Hampshire parent, told how her attempts to purchase a home and live out the American dream turned into an American nightmare. The home that the Roseberry family purchased from the Veterans' Administration (VA), which repossessed the house from the previous owner, turned out to be contaminated with lead paint. Over 2 years, **Ms. Roseberry** had a miscarriage, her dog developed grand mal seizures, and her 3-year-old daughter had head and stomach pains. A pediatrician diagnosed the daughter as insecure about having a new sibling, but the daughter was later found to have a blood lead level of 35 µg/dL. Her other children also had blood lead levels above the CDC action level, and evaluations of paint and dust showed that the house was unsafe for children under 6 years old. The family rented a home, was told that repairs on their own house would cost \$30,000, and was directed by the VA to keep paying the mortgage. For 4 years, the family contested the government's decision. Then **Ms. Roseberry** became politically involved. Now she has completed training for lead-based paint inspectors sponsored by EPA and works to use Title X requirements to improve New Hampshire lead-poisoning legislation. The lead-abatement training course was expensive, often held at inaccessible locations, and presupposed a technical background that most people taking the class didn't have.

Dr. Lisa Rosenblum of the CDC Childhood Lead Prevention Program reported that CDC provides funds for State and local health departments to track and monitor children with high blood lead levels and special services. Lead screening and education projects could be linked to other health promotion programs. Participants in lead-related programs can be made aware of other health promotion projects, and vice versa. The agency funds local public health agencies to integrate lead screening and case management services with other health screening and treatment services for Medicaid-eligible children. Screening is part of secondary prevention. CDC also will fund primary prevention that improves housing stock. Title X was landmark legislation because it set aside funding to reimburse landlords who remove lead hazards.

Panel and audience comments

▼ **Audience members:** Those who live near a lead-smelting plant in Dallas, Texas, say that more testing is not needed, but that funding and advice from the government are needed to help regain their health, educate their community, and protect future generations from lead poisoning. People from other communities volunteered similar experiences.

▼ **A government representative:** EPA can only provide services authorized by Congress. Community groups must pressure legislators to change the law so EPA has a different mandate and tools. One possible source of funding is Superfund, which might become a better source if community groups work with Federal legislators while Congress debates Superfund reauthorization. Keeping apprised of legislation is important if community programs want jobs for people they trained as lead-abatement workers. Program directors in the audience trained local residents to become abatement workers, but private contractors took the jobs. By tracking and being involved in legislation, program directors would know which agencies have received funds for grants and contracts and would be more competitive with private contractors.

▼ **Government representatives:** More training funds will be made available. As part of the environmental justice initiative in Title X, model programs will be developed that train workers and respond to local demands for services. But model programs will be established in limited communities and should not be viewed as a major funding source.

▼ **Ms. Granado:** People of color are locked out of opportunities to get Federal funds. We need more affirmative action regulations and better implementation of existing ones.

▼ **Panelists and audience members:** Other forms of discrimination against people of color and low-income groups that work to promote environmental justice include the following:

- At all levels of government, people of color often were given public relations positions with no decisionmaking authority.
- Local residents' knowledge, born of experience living in contaminated communities, often was discounted by agency scientists and administrators.
- Programs developed to train and educate community members and eliminate lead pollution problems were not sensitive to community needs, were not geared to the appropriate education and literacy levels, did not use the most effective methods to reach community groups, and often did not address what the community diagnosed as problems; nor do they offer solutions that were appropriate to the community.

Suggestions offered during discussion to remedy these problems included the following:

- Include community groups in decisions on the most effective ways to implement existing government programs.
- Develop programs that promote community-government partnerships to define lead-related problems and shape attempts to resolve them.

— Make available a range of services—including medical, public health, housing, and educational programs—to address the spectrum of problems created by lead-based paint hazards.

▼ **Panelists and audience members:** These participants discussed screening and tracking people with high blood lead levels. One panelist said registries are expensive and hard to develop, but an immunization registry being planned might be a model for a future lead-poisoning registry.

▼ **Audience members:** A community outreach worker from Los Angeles said lead-screening programs in that area were more likely to identify high blood lead levels among Hispanics than among African Americans because Hispanics usually obtain medical care from neighborhood health clinics, which conduct aggressive screening programs, while African Americans usually obtain care from county medical facilities, which do not screen aggressively. Some physicians don't believe that lead-paint poisoning is a serious issue in their localities, or they lack education about the problem. As a consequence, they don't consider lead poisoning as a possible diagnosis and fail to support public education programs.

▼ **Dr. Rosenblum:** Screening is part of secondary prevention. CDC will provide funds for primary prevention that will improve housing stock. Title X is landmark legislation because it sets aside funding to help landlords and homeowners remove lead hazards.

Central Issues Plenary 3: Hazardous Waste Problems

Dr. William Suk, Chief of the Chemical Exposures and Molecular Biology Branch, NIEHS, called for a multidisciplinary research approach to achieve environmental justice. Studies should determine the additive, synergistic, and combined impact of pollutants, as well as the impact of pollutants acting separately. Research data are critically needed on how hazardous waste substances change as they migrate through soil, air, and water; enter the food chain; and are otherwise ingested or absorbed by people. The NIEHS Superfund Basic Research Program is working to address these research needs and other problems associated with hazardous substances and hazardous wastes. When Congress passed the Superfund Amendments and Reauthorization Act in 1986, it mandated that NIEHS establish a university-based grants program to study basic research issues related to hazardous waste exposure and remediation. The four objectives of the NIEHS Program are to develop (1) methods and technologies to detect hazardous substances; (2) advanced techniques to detect, assess, and evaluate the effects on human health of hazardous substances; (3) methods to assess risks to human health from hazardous substances; and (4) basic biological, chemical, and physical methods to reduce the amount and toxicity of hazardous substances.

Since 1987, the NIEHS Superfund Basic Research Program, a unique prevention approach that includes research on basic mechanisms, epidemiological studies, and developing and applying technologies, has funded 18 projects at 29 institutions, supporting the work of more than 1,200 scientists who are

developing new techniques to assess and reduce hazardous waste exposure. Studies include research that identified an excessive level of PCBs in the breast milk of some Native American women and linked it to consumption of fresh-water fish contaminated with PCBs. Researchers are also validating the use of noninvasive diagnostic tools to measure bone-lead levels in children and have already developed and validated the use of steam injection for soil decontamination. Future methodological directions include developing advanced combustion engineering technologies; biologically based risk-assessment methods; and bioremediation technology. Future ecological issues include biodiversity, bioavailability, and bioaccumulation; as well as environmental equity and justice, especially for children. Research issues germane to technology transfer are also agenda items to be considered by the program.

Dr. Lawrence Clark of the University of Arizona Cancer Center, along with other scientists, has worked with the community group Living Is For Everyone (LIFE) to investigate high rates of multiple myeloma, lupus, and leukemia possibly related to hazardous exposures. These groups developed data that gained media exposure and political attention, as well as government funding to address the problem. When LIFE was worried about excessive mortality from the three diseases but couldn't obtain data from local or State health departments to use for comparison studies, a member of the staff at the local morgue gave a LIFE member information from death certificates that was then provided to **Dr. Clark**. Compared with previously collected national data, 5.7 cases of multiple myeloma should have been diagnosed in Nogales over 5 years; instead, 25 cases were reported. Four cases of systemic lupus should have been found; records revealed 19 possible cases. (Some of the cases did not have all the signs of lupus.) Fifteen cases of leukemia should have been diagnosed; 26 cases were diagnosed. Believing there might be environmental causes for the disease rates, the epidemiologists and LIFE identified potential hazardous exposures. Nogales, AZ, is north of Sonora, Mexico, and air and water flow north from that country. One possible source of exposure to hazardous substances was a municipal dump in Sonora. The dump, now being cleared, burned spontaneously in winter and caused inversions over Nogales.

Other possible sources of exposure included soil and water contamination. The diseases might be linked to excessive exposure to diesel fuel fumes from trucks crossing the border, pesticides and herbicides sprayed on vegetable crops after shipment from Mexico, kerosene and wood fumes used for heating in Mexico, fumes from waste burning at a cattle dipping station in Mexico, and pollutants from American-owned factories in Mexico that disregard hazardous waste concerns. Exposure to paint and solvents and use of hair dye and some medications also might contribute to the diseases. Once these potential hazards were identified, intensive scientific research was needed to link specific exposures and diseases. Such time-consuming, complex research can be frustrating to a community. For example, documents needed to support conclusions in Nogales included medical permissions and records from many sources, and standardized systems for recording and evaluating data had to be developed and implemented. To assess the presence of lupus, community screening was needed. (If all

reported lupus cases were confirmed, Nogales would have the highest rate in the world.) **Dr. Clark** is planning a household survey to gather additional information.

Epidemiologists can use known exposures to determine those diseases that would be community problems, but it is difficult to document specific links between the environment and illnesses, especially when the diseases are rare and difficult to diagnose. Community groups may be able to use intermediate markers of exposure and disease to prompt government action. To truly link exposures and effects, cohort and large cross-sectional studies are needed. These studies produce possible disease correlations for statistical analysis, but between 98 and 99 percent of the studies have found that excess disease clusters are caused by chance or by unidentifiable exposures. Research data for any community must be as accurate as possible because State and local health departments are often reluctant to conclude that clusters of excess disease are caused by environmental factors.

Dr. David Ozonoff of Boston University School of Public Health termed environmental justice a matter of justice, not a matter of science or research. Science, such as epidemiology, can help establish fair and just policy by helping to determine the nature and extent of systematic, unequal distribution of environmental burdens and benefits, but a society that allows these unequal burdens to exist does not make them easy to discover. The obfuscation is accomplished by criticizing the scientific merit of environmental justice studies. While many studies have methodological problems, and scientists should always design and implement the most rigorous studies possible, study flaws should not be used to deny the existence of environmental injustice.

An activist research agenda must be informed and derived from collaboration with the affected communities, as **Dr. Ozonoff** did with a poor Boston neighborhood that found trash to be its principal environmental problem. Activists framing a research agenda must focus on a key question: Are there useful ways to classify environmental burdens that express how they are experienced by the affected communities, and might such classifications reveal effects that are not visible when more academically conventional categories are used? To answer this question, researchers must address complex mixtures and multiple conditions that occur simultaneously in affected communities, including health status indicators, violence, and rodent infestation. Scientists must develop broad research categories and a holistic approach that considers ways to determine or quantify the context of the problem. Social context is relevant for epidemiological research; research questions must evolve from collaborating with the community.

Dr. Burnett Gallman, a physician from Columbia, SC, observed that despite known disproportionate waste dumping in low-income and minority communities, the concept of environmental racism is not well received by people with power, who are likely to consider money more important than the health of future generations. People whose traditions emphasize respecting the earth tend

to be most adversely affected by environmental injustice. Environmental racism is a symptom of the larger failure of the culture to develop a holistic approach to life. Although some may believe environmental racism does not exist, evidence exists that environmental racism is indeed a problem. **Dr. Gallman** has an interest in excessive cancer rates among minority groups, especially those who live near polluted sites. He believes that the deaths from cancer that are common in his own family are related to early living conditions experienced when he was a child. He grew up near Lake Robinson Nuclear Plant. He remembers water skiing on the lake with people who have died from cancer or are battling the disease. However, attempts to find relationships between cancer clusters and corporations in South Carolina were blocked by several means, including death threats. Current cancer records include little information about possible links between racial inequalities and disease. He urged that people work together to create a society that values quality of life for coming generations.

Irasema Coronado, a Ph.D. candidate in political science at the University of Arizona, told how in 1990 she participated in a binational, interdisciplinary study of shared water resources in the border region that includes Nogales, AZ, and Mexico. A group of hydrologists, lawyers, political policy analysts—including **Coronado**, economists, and civil engineers from Mexico and the United States—analyzed resource management along the Santa Clara River, which starts in the United States, loops through parts of Mexico, and then flows back across the border into the Colorado River. During the study, **Ms. Coronado** found that government agencies often impeded the resolution of problems by focusing on regulation rather than prevention.

While the government defines environmental justice as the fair treatment of people of all races, cultures, and incomes with respect to developing, implementing, and enforcing environmental laws, regulations, and policy, she considers this definition to be bureaucratic and inadequate. Fair treatment means that no racial, cultural, or socioeconomic group should bear a disproportionate share of negative environmental consequences of operating industrial or commercial enterprises and executing local, State, and Federal programs and policies. She asked the audience to send her less bureaucratic definitions.

Better research designs are needed to address environmental justice issues. They must be multidisciplinary; must distinguish among social, cultural, political, and environmental variables; and must include all those involved in making and sustaining policy, including representatives from industry, science, academia, government, and the community. This approach will ensure that each group is heard and committed to the study and that no group discredits the work. Political will must be generated to ensure that research findings are translated into law and policy; without political will, all the research in the world will not ensure environmental justice. Researchers can find problems and identify causes, but nothing happens without the support of the community and politicians. As part of the process, the community must be educated about research limitations, and researchers must learn that problems require more than technical solutions. Forging effective collaborations can be challenging, but

the era of cooperative study is here to generate creativity and economize on research funding. To facilitate cooperative research, community groups and researchers must ask themselves deeper questions and share the answers. Community groups must determine what they want to do when the contaminant is identified, especially if it is a byproduct of an industry that employs them. They must understand that their role includes generating part of the political will and votes needed for change. Researchers must decide whether they are conducting a study to facilitate change, enhance a theory, publish an article, or help a community. In addition, research quality can be improved if information is published about research designs that succeed *and* fail.

Panel and audience comments

- ▼ **Dr. Clark:** Epidemiologists can use known exposures to determine which diseases might plague a community. But it is difficult to document links between the environment and illnesses, especially when diseases are rare and hard to diagnose. He is looking for intermediate markers of exposure and disease that community groups can use to elicit government action.
- ▼ **Audience member:** Scientific studies should be conducted with the Mexican government, when appropriate. Polluters may knowingly release hazardous wastes into the environment.
- ▼ **Dr. Clark:** He was encouraged by American authorities to work with the Mexican government. Extrapolating research from one community to another is limited by research problems and attitudes of many State and local health officials. Current epidemiological methods do not exist for widespread extrapolations. Key exposures may be missed. The challenge of environmental epidemiology is to find a link between exposures and effects.
- ▼ **Dr. Ozonoff:** Results of the type of study he described could be used in court to get relief for a community.
- ▼ **Audience member:** Community groups should develop and support legislation leading to criminal prosecution for environmental injustice.
- ▼ **Dr. Gallman:** These laws should apply to both the government, especially the military, and the private sector.

Central Issues Plenary 4: Pesticides

(The moderator was **Dr. Marion Moses** of the Pesticide Education Center in San Francisco.)

Arturo Rodriguez, President of the United Farm Workers of America (UFWA), described farmworkers as tending to be people of color, minorities, and the people most likely to be affected by the use of chemicals in the fields, especially pregnant women and children. California has mostly Mexican, Filipino, and Asian farmworkers, with some workers from Latin America. Florida and Louisiana have large migrations of African Americans and

Haitians working in the citrus fruit and sugar cane fields. Puerto Ricans work in the fields of New York and New Jersey. Because many are migrants with no permanent residence, it is hard to measure what happens to migrants in the fields. They have no political or economic base and little power over their lives. They live from day to day, with no pensions, savings, or retirement plans. Worker protection legislation such as the National Labor Relations Act excludes farmworkers. Among States, only California offers farmworker protection, and its Republican leadership does not enforce it.

Chemical exposure is a major problem for farmworkers and their children, but little has been done to address it. Workers have minimal protection from pesticides and get little training or instruction. When they do get information, it is usually in English, which many farmworkers don't speak or read. The workers understand pesticides as a medicine; they believe crop dusters apply medicine to the fields, but do not know they are working with toxic chemicals. Yet, the effects of the chemicals surface when, for example, pregnant women who work the fields give birth to children with congenital defects such as missing limbs. Exposure is compounded because people not only work in the fields; they live near the fields and socialize in farmworker towns nearby. Several times a day, crop dusters pass over the fields, spraying while workers pick crops. Pesticides enter the water supply and permeate the soil. The result is cancer clusters.

Dr. Richard Fenske of the University of Washington, who has spent 15 years studying pesticide exposure in different environments, noted that while people working in agriculture live where they work, regulators oversee the workplace one way and the home another. Children should be classified as a special subgroup because they play and live in environments that are designated as production facilities. But even when the workplace and residence are separated, chemicals may be carried home by workers on clothes and shoes. Since researchers have documented take-home exposure for lead, mercury, and other chemicals, logically such exposure also occurs with pesticides; preliminary studies support this hypothesis. In the 1960s and 1970s, the Federal government established a surveillance program for community studies with regional branches throughout the United States, primarily through State departments of health. But in the late 1970s and early 1980s, the program was discontinued. EPA's university-based Pesticide Hazard Assessment Project, in which 10 to 12 universities with research teams conducted human population field studies on workers and children, also ended in the early 1980s. The National Human Exposure Assessment Survey is the only existing program focused on exposure to many chemicals, and pesticides are a component.

States now have poor enforcement capabilities and haven't extended laws to cover agricultural workers. Research is needed to identify and enumerate populations that are at risk, which obviously includes workers and their children. The task is expensive and logistically challenging; it must include systematic assessment of exposures among workers and children and focused studies on chronic health risk. Interagency collaboration on research is needed because

pesticides and their health risks fall under the umbrellas of four Federal agencies. The National Academy of Sciences (NAS) has been a catalyst for moving toward greater collaboration among the agencies.

Dr. Michael Luster of NIEHS pointed out that the immune system is composed of multiple organs throughout the body that involve many cell types, making it hard to study. Pesticide or chemical exposure can trigger three types of immune diseases: autoimmunity—when the immune system recognizes host tissue as foreign; immunodeficiency—when the immune system responds abnormally to infectious agents or cancer cells, leading to more severe and frequent infections; and hypersensitivity—when the chemical or pesticide binds to skin tissues. The immune system recognizes this complex of pesticide plus skin tissue as foreign and tries to reject it. In humans, the evidence for immunodeficiency in chemical exposure is weak, but some data exist. For example, researchers have seen moderate changes in immune responses associated with exposure to pesticides such as carbamates and some fungicides. Researchers also see changes in lymphocyte populations. The problem with the changes is that individual studies are scant; researchers have studied only a few individuals, have seen moderate changes, and have not documented an association between exposure levels and immune changes. Researchers found no obvious clinical changes, such as increased incidence of influenza. Although data are better from animal studies, in which tested animals were exposed to chlordane and some organophosphates like malathion and parathion, it is hard to extrapolate these results to humans because the test doses are higher than humans would receive.

Researchers have shown no association between autoimmunity and pesticides, but evidence documents the presence of auto-antibodies. A person with auto-antibodies does not necessarily have a disease, but the antibodies may indicate the possible onset of disease. This situation has been observed in people exposed to pesticides and organic solvents, and several cases of humans with autoimmune disease have been reported but not confirmed. Evidence for a link between hypersensitivity and pesticides is strong. For example, there is evidence linking allergic contact dermatitis (skin hypersensitivity) in humans to fungicides and carbamates, and there is considerable evidence for irritant contact dermatitis, an inflammatory response that mimics hypersensitivity without involving immune cells. This result is more often associated with inert ingredients like copper sulfide than with active ingredients in pesticides, and this problem is serious.

The very young and very old are most sensitive to immunodeficiency. For the young, immunosuppression can cause long-term persistent effects because their immune cells are still developing. Adult exposure to immunosuppressant compounds is usually short term. The elderly are at risk because they already have compromised immune systems, and further immune-system suppression may cause more diseases and potential death. Because autoimmunity usually occurs in females, any association with pesticide exposure will likely happen in female populations. Most who develop autoimmune disease have a specific genetic phenotype. The result is that people with preexisting diseases are at very

high risk when exposed to pesticides. Data on hypersensitivity and irritation give hard evidence of pesticide dangers; data on immunosuppression and autoimmunity give warning evidence. Animal studies and some human case reports exist to verify the dangers. There is enough evidence to warrant concern; the primary research need now is for good immunoepidemiological studies.

Dr. Joan Cranmor, editor of "Neurotoxicity" and a staff member at Children's Hospital in Arkansas, noted that key differences make children more susceptible than adults. A transplacental route is a pathway for contaminants: Whatever the mother ingests or is exposed to—especially low-molecular-weight chemicals or lipophilic (fat-attracted) chemicals—can reach the fetus and the fetal brain. Children have higher respiratory rates, absorbing more contaminants faster and more effectively than adults, and they have more skin surface area and greater caloric and fluid intake in milligrams per kilogram of body weight. Safety levels of exposure for adults will not protect children.

Research is needed on "silent toxicity," involving delayed and latent effects of exposures. The nervous system is vulnerable and unique because it cannot repair or replace itself: it is easily accessed by chemicals and has inter-related parts, which means minor changes can have major consequences. Because the nervous, endocrine, and immune systems are interrelated, altering one of them affects the others. If during development—when cells proliferate, migrate, and differentiate—some cells are lost, the person may function normally for a time, with consequences appearing later in life. Some conditions such as hyperactivity, mental retardation, and learning disabilities have led to pediatric test batteries for early diagnosis. When dysfunction is recognized early, interventions can be implemented.

Panel and audience comments

▼ **Mr. Rodriguez:** After publication of Rachael Carson's *Silent Spring*, which raised public concern about pesticides, union organizers recognized the problem of chemical exposure. In the early 1960s, they recognized pesticides as a critical pollen related to the safety and health of farmworkers and consumers. In 1968, the UFWA was instrumental in using collective bargaining agreements to ban dichlorodiphenyltrichloroethane (DDT). In 1970, the union's first major boycott of the California table grape industry used the issue of pesticides to hold up settlement for an additional year. When the strike ended, four chemicals were banned from grape fields, the most labor-intensive agricultural crop. To date, labor's traditional tools—boycotts and collective bargaining agreements—have been the major levers for forcing growers to heed environmental warnings. Unions have gone beyond government regulations in their collective bargaining agreements by requiring clothing, testing, and monitoring the use of chemicals.

▼ **Dr. Moses:** In 1984, growers used 175 pesticides. Two years later, the number dropped to 133. Today the number is 75. However, one constant hasn't changed, he noted. Citing medical toxicology data from the State of California, gathered under State law (the Birth Defects Prevention Act), **Moses** said that 40 percent of pesticides in use cause tumors in animals, and most tumors are cancerous. Thirty-four percent of pesticides cause reproductive effects, 24 percent cause birth defects, and 36 percent exert mutagenic effects, damage chromosomes, or alter DNA.

Central Issues Plenary 5: Workplace Hazards

(The moderator was **Dr. Richard Lemen**, Acting Director of NIOSH.)

Irma Dey Ande, a former farmworker and advocate for farmworkers, said there are between 3.2 million and 4 million farmworkers in the United States, mainly people of color, and that farmwork is dangerous. Most farmwork-related hazards aren't regulated by the Occupational Safety and Health Act, possibly because of pressure from the agribusiness lobby. Farmworkers often are uneducated about the dangers their children face from exposure to pesticides, harsh sunlight, and other hazardous conditions. Without adequate day care, they take their youngest children into the fields. Pay rates for adult workers must be raised so that children are not forced to work. The plight of farmworkers has not changed in 60 years because no regulations pertain specifically to farm work, and applicable regulations that do exist are poorly enforced.

Linda Anku, OSHA Administrator for Region III, asserted that most workplace disputes can be resolved if employers and employees respect each others' rights and responsibilities. Among the sections of the Occupational Safety and Health Act that empower employees to address workplace issues more effectively, one section ensures that workers receive the information they need to react knowledgeably to occupational hazards. Employers must give workers (1) access to OSHA information; (2) training in workplace safety; and (3) environmental monitoring data and results. Employers must display lists of worker's rights; log workplace illnesses and injuries; and post an annual list for employee use. The Act also establishes a worker complaint procedure. Because OSHA is underfunded, these investigations take about a month to process, with a quicker response if a worker is in immediate jeopardy. An appeals process is available. Furthermore, if employers discriminate against workers who register complaints with OSHA, a special appeals process can be implemented, although this process is lengthy. OSHA's jurisdiction covers any business that affects commerce. However, agribusinesses are exempt from most OSHA regulations, except for sanitation and housing rules.

OSHA tries to encourage employers and employees to comply with basic workplace guidelines: Employers are to provide pertinent information about safety and health hazards and protective equipment, and workers are expected to use information and protective equipment provided by their employers. For information, call NIOSH at 1-800-35NIOASH or national and regional OSHA offices, and State and local occupational safety and health committees.

Dr. George Friedman-Jimenez of Bellevue Hospital in New York City reported that available literature suggests that low-income people and people of color are more likely to get occupational diseases and be exposed to toxins. Occupational health studies can contribute to advances in our understanding of environmental science; occupational health studies have included community participation and can serve as examples for developing a new environmental

research paradigm. More and better occupational health research is needed, including data on toxins and socioeconomic, ethnic, and racial issues. Of the more than 60,000 commercial chemicals that may be present in the workplace, only 10,000 have been tested for toxicity. Every year, between 50,000 and 75,000 people in the United States die of occupational diseases, defined as those that are caused by environmental exposure in the workplace. A General Accounting Office study conducted in New York City found about 50,000 people—many of whom were people of color—work in sweatshops (such as garment factories) that violate labor, safety, and health codes. But OSHA only had funds to inspect 1 percent of apparel factories and restaurants in New York City over 5 years.

Female workers of color traditionally work in health care, clerical, and home-based jobs, many of which involve high risks for developing occupational illnesses. They have three separate risk factors for occupational illness: sex, ethnicity or race, and likely employment. Low-income individuals and people of color usually have more difficulty gaining access to health care and a higher risk of occupational illness. Because many women lack accessible clinical services and education, and because research on their problems is inadequate, information and political will are needed to allow all individuals to access competent clinical health services.

Dr. Knute Ringen, Director of the Center to Protect Workers' Rights, observed that government can be effective—one example is the success of Federal efforts to protect the health of coal miners. But industry often will try to get around Federal and State regulations. Many businesses, such as the construction trades, have hired people as independent contractors rather than as employees. An estimated 25 percent of the workforce is comprised of independent contractors. The Federal government considers independent contractors to be self-employed and not covered by workplace safety regulations that apply to employees. In one California study documenting differences in the health status of individuals based on occupation and race, the life expectancy of laborers was 20 years less than the life expectancy of physicians. Among laborers, the life expectancy of blacks was lower than that of whites. The United States must do a better job of primary and secondary prevention. The time may be right to work toward this goal.

Panel and audience comments

▼ **Audience member:** Health researchers and educators should contact workers in schools and other community facilities because employers won't make workplace space available to train employees about occupational hazards and environmental justice issues. A government representative said OSHA and EPA cooperate, but this cooperation has limitations. In some States, State government enforces OSHA regulations; these are "state-plan" jurisdictions. Regardless of whether the State or Federal government enforces the law, enforcement agencies have financial problems.

▼ **Audience member:** OSHA should be able to use criminal penalties as remedies for violations. Ringen said the reforms of the Occupational Safety and Health Act currently

being debated in Congress include criminal penalties; he predicted that asking for this provision probably would lead the Senate to block passage.

▼ **Audience members:** Participants talked about people fired for complaining about worksite dangers or filing workers' compensation claims. Ringen and Anku said the Act provides recourse through whistle-blower protection provisions and oversight of state-plan jurisdictions. In some circumstances, the Federal government can bring suit on the worker's behalf.

▼ **Dr. Ringen:** National and State cancer registries do not collect information on occupation. But the information collection processes instituted as part of health care reform may enable researchers to capture these data.

Central Issues Plenary 6: Superfund

(The moderator was **Sandra Coulberson**, program manager for ATSDR's Minority Health Program.)

Timothy Fields, Director of EPA's Superfund Revitalization Office, said the 1980 Superfund Act required EPA to have a hazard-ranking system for developing criteria for national priority sites; this system had to account for threats to drinking water, populations at risk, human food-chain toxicity, and damage to sensitive environments. The system ranks the likelihood of hazardous release of a substance and actual releases and determines how dangerous the releases are (by their toxicity and quantity), how difficult they are to manage, and how people might be affected. In 1991, EPA revised the criteria on the national priorities list (NPL) to include more residential areas and school or day care properties with contaminated soil; surface water food-chain sites according to bioaccumulation (a measure that accounts for human food-chain uptakes from fish and other elements that contaminate people); and sites that had major adverse impacts on small communities. In addition, the hazard-ranking system now deals with sensitive environments, including ecosystems.

The NPL includes 1,288 sites that score higher than 28.5 on the Federal hazard-ranking system, 155 of which are Federal facilities. About 73 million people live within 4 miles of an NPL Superfund site. While the hazard-ranking system is a screening tool designed to identify sites of Federal interest, it is not the final determinant of risk. Once a site makes the NPL, EPA conducts further studies to determine its risks and how much of the site must be cleaned up. Under current law, EPA recognizes that environmental justice communities may need special focus. The EPA is studying NPL sites in communities where environmental justice issues are a concern and is promoting legislative changes in the process. The bill requires that multiple-risk sources to affected communities must be among the criteria for setting priorities, which would let EPA take multiple exposures or cumulative risk into account when considering such hazard source. The new model factors cumulative risk into the ranking system and response timetables and has provisions for a 5-year demonstration program.

Earl Tulley, representing a 23,000-square-mile sovereign Native American nation, remarked that communicating pollution dangers to Native Americans isn't easy. When people do not have or understand electricity, how do you help them understand radiation? How do you explain an energy that pierces skin and creates cancer? People attended the conference because of survival instincts. The Federal government should spend money for direct investigations on where it has gone wrong and what national priorities it must change. It is more important to learn why people hurt from cancer than to learn how long it takes to cook an egg. Now that the issue of environmental justice has been raised, he urged participatory dialogue between corporations and individuals. Environmental quality issues must consider the waste people create that typically goes in to someone's backyard, then to a landfill that evolves into toxic soup. When the landfill liner ruptures, contaminants go into somebody's water.

Pat Bryant of the Gulf Coast Tenants' Association said the Superfund process is rigged so the government won't have to clean up poisoned communities. About 24,000 sites were poisoned because of actions of individuals in the Federal government, not industry. After the country spent trillions of dollars to develop the military infrastructure of weapons plants and testing sites, there's no money to clean it up. People of color are disproportionately poisoned, and there's not enough money to clean everything up. The objective becomes a limited cleanup that bring sites up to standard for a future industrial site, an approach that's cheaper and easier than a total cleanup. People at EPA are part of a rigged system. For example, the Office of Management and Budget (OMB) tells EPA how much money it can ask to clean up sites, so EPA's request to Congress has little basis in reality. Since funds won't be increased until communities protest, communities should get involved as soon as someone thinks there is poison. There should be a technical resource bank of experts who can help average citizens understand the science. Establishing resource banks in the South would unite historically black universities and community organizations to give information to suffering communities. Then the communities can wield political pressure on congressional representatives. Is there enough money? If there is, people can be trained to clean up the mess, and universities and businesses can be involved in the training.

Dr. Linda Rae Murray of the Winfield-Moody Health Center in Chicago, IL, declared that in this political debate, science's role is to determine where to implement change. People of color are between a rock and a hard place, which is nothing new. Her principal problem as a physician is lack of data. Epidemiological studies are important. The biggest problem is no one cares why lung cancer in black men is rising. Nobody is worried about what uranium mines are doing to Native Americans. Society has misused science and scientific data to exploit people of color and poor people. Recognizing this misuse has made poor black patients skeptical about medical pronouncements. She wants to know how many people in her community have elevated lead levels, why the prevalence of asthma is skyrocketing, and why blacks and Latinos are showing huge increases in asthma deaths. It doesn't matter whether you work for the Federal government or are a skilled professional or a community leader. The information

available doesn't target the information needed. People want a simple answer to a simple question: Will this contaminant make me sick? Nobody knows. Everyone must understand the limits of current knowledge. One lesson from occupational health is that you don't need all the answers. Asking the right questions marks good science, but cannot afford to wait until all the answers are in. If one does a health study, one tries to make the data as good as possible. Consider auto workers in a plant, 70 percent of whom are white, and 30 percent black. A study of these workers might have a small number of blacks whose different health profiles (cancer rates, prevalence of high blood pressure, kidney failure) could muddy the research methodology. One can't ignore the differences.

In a nation that can't even count people who are born, we have major health data gaps. Environmental and occupational causes of poor health are hard for people to accept, because accepting the carcinogenic impact of the environment and workplace is politically dangerous. The solution is a public health solution. We look at the data, ask questions, take the information we have, and come up with the best solutions. Next year we do the same, trying to improve our solutions. Erring on the side of protecting human health takes courage and money. We are a rich nation that is not overtaxed. We can pay more taxes.

Dr. Cynthia Harris, Chief of ATSDR's Community Health Branch, spoke of ATSDR's charge by Congress in 1980 to look at the effects of environmental contamination on communities. In 1986, that responsibility was broadened to include preventing and decreasing the adverse health effects from exposure to hazardous substances in the environment and training health care professionals in environmental medicine, developing toxicological databases, and disseminating information to the public. As a PHS agency, ATSDR took the United Church of Christ's landmark report on toxic waste and race, the black and minority health report from DHHS, and all other data on health status and care that it could locate for people of color, and elected to address fundamental inequities by investigating the extent of disproportional impact of contaminants on people of color. As early as September 1990, ATSDR organized a conference on national minority health—the first time a PHS agency sponsored a conference focused on environmental contamination and people of color.

Panel and audience comments

▼ **Audience member:** This participant asked for information on research on DNA prints that ultimately would let a researcher discover when a person was exposed to a specific toxin. An attendee from NIEHS answered, citing research on biomarkers involving samples easily gathered (hair, feces, fingernails, skin, blood, urine). Biomarkers are also available from liver or bone biopsies, but these can be expensive and difficult to gather. Scientists are working with biomarkers to identify genetic changes—if any—from a given contaminant. They are not looking for biomarkers to indicate the time of the exposure, however, because "the science just isn't there."

▼ **Audience member from Detroit:** One agency gave a company permission to pollute, that is, a legal consent order to improve its operations over 10 years. Because the

enforcement agency set no timetable or consequences, at the end of 10 years, the company closed its doors. The company moved its money elsewhere to enable it to legally declare bankruptcy and close down. It never cleaned up its operating facility.

▼ **Audience member from Pensacola, FL:** Federal agencies did not respond quickly to a community request for information and help. Fields said he would check on that community's status. Communities in Louisiana, Texas, and Florida are being considered for the next NPL update due out this spring. Each year, EPA lists 100 sites with two new listings a year. A site that scores above 28.5 will be listed, although EPA lists a limited number of sites. This fall, EPA started a new program of State deferrals. If a State can manage to clean up a site scoring above 28.5 and follows EPA guidelines, EPA will allow a limited number of State deferrals. A site that scores above 50 makes the NPL.

▼ **Dr. Harris:** She said she will check on Pensacola. The process is supposed to work as follows: As soon as a site comes to ATSDR's attention, an onsite team is sent to talk to the community about its concerns. This dialogue should be ongoing throughout the health assessment process. She welcomed input on how ATSDR might improve its operations. Another attendee said this process had not begun in his community.

Environmental Justice Press Conference

Dr. Devra Davis: There are all kinds of studies and information we can develop to resolve questions about the impact of the environment on minority populations: for example, "black Love Canal" in Alabama, which never made the headlines but occurred through the 1970s and finally was settled in 1980. That rural Alabama population had the highest levels ever recorded of DDT and DDE in human fat. Residents were exclusively black with subsistence agriculture and fish in their diet. They (20,000 of them) received a settlement in 1980 from the Olin Company.

Dr. Phillip Lee: Lead poisoning is an example of how, by developing measures of lead levels, we can identify exposures. Leaded gasoline posed a significant environmental hazard that was abated by removing lead from gasoline. We must do similar things with other hazards, but we need science to identify the problems. That's why we're developing university-based centers linked to communities.

Dr. Kenneth Olden: The guidelines for such centers included that they develop community relationships. We want evidence that they have support of community organizations and they can do the science, exposure monitoring, or outreach. The three we funded met these criteria. Collaboration could be with a hospital, a local clinic, or any other community group. We want to show that the scientific and parent organizations have community participation. That is key.

Dr. Davis: Under health care reform, NIEHS will receive funds for prevention-based research. I'm sure you will see more money made available for these kinds of questions. With respect to health care reform, it's important to realize that core public health functions are based in State and local health

departments, and we're trying to figure out ways to help them serve the needs of their communities with respect to environmental health issues.

Reporter: Could you tell me what the trickle-down effect of all this will be on the regulated community? They will have to play a part.

Dr. Olden: We think there will be a major impact. We have been trying to involve the regulatory agencies at the outset, when we go to communities to monitor and do the research. We want to involve EPA, FDA, OSHA, and the Food and Drug Administration in developing the science. We want to make sure we ask the right questions so regulatory agencies can do their jobs. Dr. Lee said Federal agencies haven't always cooperated and collaborated the way that they should. Scientific agencies often generate science that is not user-friendly, needed, or desired by the regulatory agencies. So we are making sure that regulatory and scientific agencies collaborate to generate the data needed to do human risk assessment.

Dr. Davis: There is great interest in many of these communities in noncancer health effects. Traditionally, risk assessment has relied on cancer as an end point, but it's costly, takes time, and there are legitimate questions about its use. Questions about asthma, low birthweight, reproductive effects, and immunological effects deserve assessment. NIEHS is leading in that kind of work, which will help regulatory agencies develop more rational policy and allow industry to have a sense of what the future will bring for these issues.

Reporter: EPA requires companies to give out toxic release inventory data every year, and increasingly, people have correlated toxic release data to communities in terms of race and income. What is the next step in looking at diseases that might have come from a given chemical? Communities have started correlating this stuff. There has only been one attempt that correlated to a particular disease. On a national level, you could pinpoint it to the communities. Do you know if that is actually going on?

Dr. Olden: We started the Environmental Justice Research Centers to make certain that this correlation will occur. I have been Director of this Institute for 2½ years. Such correlation was an area I felt we had to strengthen to make sure we know that exposures exist. We must begin to understand if the exposures cause diseases. The only case where we know that happens is lead poisoning. Kids who are poisoned live where the lead is. But people live in areas where we know there are carcinogens or other toxins in the environment, but we don't know with certainty those toxins cause disease or dysfunction. That information is critical. If you want to ask policymakers to allocate resources differently for a public health policy, you need more science. We must go into some communities and show that the agents people are exposed to cause cancers, respiratory dysfunctions, and birth defects. Regulatory agencies and communities can act on these kinds of data. At this point, they don't have the data.

Chemical engineer: How much does risk assessment cost? We could prevent the problems with 10 percent of the money you are spending in your awards for risk assessment. You need to understand process engineering.

Dr. Olden: You need both. The most human, cost-effective approach to human diseases is to prevent them. If we can prevent exposures, that approach is the right one. But there are some exposures we cannot prevent; society didn't become industrialized yesterday. The environment is polluted; lead has gone way down, but millions of kids are lead-poisoned every year.

Chemical engineer: Lead did not go down because of the studies that were done. It went down because of public policy. The cost of the substitution was much less.

Dr. Olden: There would be no legislation on lead and the present standard set by CDC would not exist without science. Two years ago when I took over as director of this Institute, the regulatory standard set by CDC was 25 $\mu\text{g/dL}$ of blood. CDC changed that within a year of my appointment to 10 $\mu\text{g/dL}$ of blood. It changed because the science had advanced with regard to low lead levels. Ten years before that, the standard was near 44 or 45 $\mu\text{g/dL}$ of blood. The standard changed because of science.

Dr. Davis: The best solution to pollution is design control. Pollution is a failure in design. Innovations in chemical engineering will help reduce the pollution load. But reducing lead in gas is a public health success story. This reduction was fueled in part by findings that there may not even be a threshold for lead. We have to drive it further. Research in this area was substantially funded by NIEHS over many years. It continues because lead has neurotoxic effects and seems to have osteoporotic effects on older women and hypertensive effects on working men. We must reduce pollution.

Dr. Olden: I have been working hard for 2½ years to make sure the Institute gets out into communities to reach people. I have visited hazardous waste sites, cancer alleys. We have trips scheduled to the central chemical corridor in Texas. We go to the community, talk with mothers, fathers, workers, industry representatives—anyone who will take the time to talk with us—to find out what the issues and concerns are, and how they feel we could address them.

Dr. Davis: (Regarding a question on the problem of experiments at government facilities exposing workers and community residents to hazards) I hope you in the audience will make sure that the right agencies working on this now—DOE, CDC—will get the information that you have. The Secretary of Energy has committed herself to a major policy with the President's full support for complete disclosure on these things. Representative Markey and Senator Glenn are monitoring it closely.

Audience member: When are EPA and the Air Pollution Board going to instruct State and local agencies to conduct air quality studies? We have the

technology today, but when you talk with EPA, it doesn't have the techniques to work in the field.

Dr. Olden: We recognize that exposure monitoring is a real problem. We are trying to work out an interagency agreement with the Department of Defense (DOD) because it has mobile units that can go into communities and do exactly what you want. If we can work out that arrangement, we could send out a mobile unit to your community to measure what is in the air, water, or soil to determine what toxins you are being exposed to.

Dr. Davis: If a site is assigned to the NPL, then ATSDR can become involved, working with NIEHS on the site's problems. And **Dr. Barry Johnson**, ATSDR Assistant Administrator, is speaking now in the other room. I suggest you talk with him.

Dr. Olden: NIEHS has a mandate to determine the role of the environment in the etiology of any human diseases or dysfunctions—cancer, birth defects, Parkinson's disease, Alzheimer's, asthma. We look at a spectrum of diseases to identify environmental agents and prevent exposures. As we build the infrastructure with the community, we will have answers, because you will help us on the important issues.

Dr. Davis: We are committed to improving the way to assess the link between environment and health. One's environment does not explain all of one's health, but it's hard to change things like your genes and what you ate 30 years ago. We focus on factors in the environment that affect health in order to allow society to reduce those exposures to prevent disease. That's the ultimate goal.

Dr. Olden: In the previous administration, the emphasis on the environment in public health policy focused on environmental factors over which people had control—smoking, alcohol, drug abuse. There are environmental factors over which individuals have no control. If you are poor and uneducated, you have to live and work in certain environments. Studies show those environments are the most hazardous. Let's get at environmental factors affecting human health over which people have no control.

BREAKOUT SESSIONS

BREAKOUT A

TITLE: ENVIRONMENTAL AND OCCUPATIONAL HEALTH RESEARCH NEEDS TO ELIMINATE LEAD POISONING

Dr. Philip Landrigan of Mount Sinai School of Medicine said that research on lead toxicity not only documents problems, but also clarifies the reality of those problems to policymakers, identifies prevention strategies that work and are a sound investment, and helps marshal more resources for pressing problems. The ATSDR and the CDC estimate that 2 million preschool children have elevated blood lead levels, making it the most important environmental health problem in the United States today. The burden of lead poisoning is not distributed evenly; in poor, inner-city, minority communities, up to 40 percent of children have elevated blood lead levels, versus less than 5 percent in suburban areas.

Despite century-old scientific reports that lead paint poisons children, from the 1930s through the 1960s the lead industry vigorously marketed lead paint as the ideal coating for houses. Although Australia and many European countries banned lead paint earlier, a representative of the lead industry persuaded State health departments that lead paint was safe. Today, the removal of lead paint will cost billions, and the injuries sustained by the public cannot be ignored.

Sources of increasing releases of lead into the environment include paint dust, occupational exposures, industrial emissions, water, food, and cars that used leaded gasoline. (Blood lead levels have dropped 70 percent since 1975 because of a decrease of lead in gasoline.) The margin between a safe lead level in the body and a level that marks toxicity is narrow. For adults, lead enters the body primarily through inhalation in the workplace, while children swallow lead—often in paint chips. Physicians test for lead in the blood; however, 90 percent of lead moves to the bones. Other sites where lead accumulates include developing red blood cells, the kidneys, the central nervous system, and the reproductive organs.

Studies over the past 10 years have established that lead is toxic to the brain at exposures as low as 10 to 20 $\mu\text{g}/\text{dL}$ in the blood—levels thought to be safe 20 years ago. Symptoms of lead poisoning include decreased intelligence,

hyperactivity, inability to concentrate, and difficulty in focusing. Despite these facts, the real estate and lead industries still oppose some lead prevention and cleanup initiatives.

Some important research questions remain unanswered: How does lead contribute to the development of chronic diseases of the nervous system in adults? For what percentage of people with Alzheimer's, Parkinson's, or Lou Gehrig's disease was lead exposure a factor? To what extent does lead contribute to kidney disease? Workers in smelters and battery factories die of chronic kidney disease at two to three times the rate of workers not exposed to lead. Researchers at Mt. Sinai School of Medicine are planning to investigate the potential damage of lead exposure to male reproduction because of reports of effects on sperm count and quality.

Researchers know that lead can cross the placenta to the developing fetus, which is particularly sensitive in the third trimester. However, it is not known whether the lead in the mother's bone that accumulated long before mobilizes during pregnancy to cross the placenta. Researchers also are interested in determining whether lead is mobilized from bone during both male and female menopause. And, if so, where does it go and what damage does it cause? Researchers suspect that more damage from lead occurs in minority communities than in other populations.

It is important to note that children need not be exposed for any minimum amount of time to suffer damage. (An acceptable blood lead level for children is 10 $\mu\text{g}/\text{dL}$, which is lower than that for adults.) A child who eats only one lead chip could have convulsions within a few hours. The best course of action is to prevent a child from being exposed to lead. Therefore, health officials recommend that families in houses built before the 1960s (which presumably were painted with lead-based paint) either move to a new home or keep the house very clean and in good repair. Because lead can also be found in tap water from old pipes, solder, and acidity, parents should let tap water run 2-3 minutes in the morning to flush out any accumulated lead. Children may also take iron or calcium supplements to decrease lead absorption, but neither supplement is as effective as preventing primary exposure. The best strategy involves both individual and group efforts, with people banding together to force community governments and landlords to do the right thing.

Chelation therapy has been used since the 1960s as a lifesaving technique for children with acute lead poisoning, but it cannot take the place of cleaning up the environment. It is not known whether children with a blood lead level of 25-30 $\mu\text{g}/\text{dL}$, who typically have no symptoms, can be helped by chelation, nor is it known whether chelation therapy prevents further damage. NIEHS has begun a major 5-year study of a new, oral chelating agent that is less painful and less cumbersome than the intravenous agent. Many pediatricians are prescribing the new agent.

Jefferson Rowland, a CDC/NIOSH epidemiologist, told about a fairly new CDC/NIOSH program, Adult Blood Lead Epidemiology and Surveillance (ABLES), that will track workers exposed to lead in the workplace and examine whether they bring lead home to their children (take-home exposure).

An example is a man who saws commercial-grade, lead-core batteries that are filled with sulfuric acid. As he works, he breathes in lead dust and sulfuric acid fumes, which also impregnate his clothes, skin, and hair since he is not likely to have a respirator or protective clothing. The worker takes that lead home on his body and clothing, thereby poisoning his children. The children's exposure to low levels of lead can produce an insidious retardation of brain and nervous development, resulting in learning, behavioral, and physical disorders. Cumulatively, these effects on the families of the working poor perpetuate overall social and environmental injustice.

The problem of take-home lead surfaced 20 years ago, when James Chishold wrote the seminal "Fouling One's Own Nest," which appeared in the *Journal of Pediatrics*, but we still have no estimate of the magnitude of the problem in the United States. ABLES is starting to address this knowledge gap by collecting and analyzing lead surveillance data on adult workers in the United States. Currently, lead-using industries are required to monitor the blood lead levels of employees; when the test results are higher than 25 $\mu\text{g/dL}$, that information is forwarded to ABLES. Elevated blood lead levels mean that a company is required by law to take additional preventive or corrective actions and cannot fire or lay off an affected employee. State authorities try to collect additional information on all reported cases, usually by telephone.

This information underlies the epidemiological analysis that ABLES performs. When analyzed, these data can give insight into the types of businesses involved and the workers exposed in a given State or locality. Currently, 20 States systematically report data to ABLES, and 10 States are in some stage of preparing to do so. Ideally, all States will eventually participate in ABLES programs. Typical businesses seen in the ABLES database include auto body repair shops, commercial printers, radiator repair shops, battery recycling plants, painting contractors, and bridge infrastructure/rehabilitation firms. Because OSHA inspectors cannot constantly monitor all work sites, a business usually does not clean up any problems until it is caught or reported for noncompliance.

Currently, ABLES is trying to link the information collected on workers with information on their children. In addition, CDC funds 10 States to conduct laboratory-based surveillance, but we do not yet know how well this system identifies children exposed to and affected by lead through the take-home route. A recent finding was that the children of affected workers at a battery recovery plant had blood lead levels much higher than those of neighboring children.

State-based ABLES programs are providing anecdotal reports of potential cases of take-home lead exposure. ABLES is also working with New Jersey, Illinois, and Massachusetts to identify children younger than age 6 whose

parents appear in the ABLES blood lead registry. These data are then used to describe the distribution of the children and their blood lead levels, the proportion affected through exposure, and which specific industries are involved. Routine screening is not likely to identify children contaminated via takehome lead, in part because screening is generally done as an entitlement or a need-based benefit, which would not apply to these children.

When one session participant asked whether it is possible to measure the part that lead plays in children's performance, screening of all children age 1 to 5 for lead was recommended, as well as the possibility of testing women just before or during pregnancy. Another question concerned bringing small factories that do not protect their workers into compliance. It was noted that small businesses are just starting to come under OSHA's regulations and need education to get on the right track.

Dr. Lisa Rosenblum from CDC described how CDC's current program focuses on children who are at highest risk and their greatest hazards, with the goal of eliminating childhood lead poisoning. The program funds 37 grantees for screening, case management, and education activities. Newly planned programs include a primary prevention program undertaken with HUD; an environmental justice program in collaboration with EPA, HUD, DOL, and other agencies; and a community empowerment initiative in collaboration with other DHHS officials.

After NIH's contributions in basic research, the most critical unanswered questions relate to applied prevention research: Can prevention work, and how can we improve it? Prevention effectiveness research has traditionally evaluated lead hazard reduction strategies. Data from the first National Health and Nutritional Examination Survey (NHANES 1), a study published by the NCHS of the CDC, showed that children's blood lead levels declined from 1976 to 1980, as lead in gasoline declined. The data convinced EPA to implement more stringent regulations vis-à-vis lead in gasoline, a rare environmental health success story. Then, when CDC evaluated hazard reduction activities regarding lead-based paint in selected cities, analysis showed even minimal hazard reduction activities lowered blood lead levels in children who had initial levels of at least 35 $\mu\text{g}/\text{dL}$, but these activities were inadequate for children with lower blood levels. (This fact is of great concern because children with lower blood lead levels still suffer neurological damage.)

CDC's current studies assessing the effectiveness and the safety of varied strategies for lead reduction differ from earlier studies in that they have more stringent standards for (1) environmental interventions, (2) relocation of families during abatement, and (3) abatement worker protection. The goal is to find out what can lower blood lead levels in children.

CDC and EPA have several cooperative agreements with State and local health departments to assess prevention strategies, and CDC also is collaborating with HUD. In 1994 CDC expects to put forth a new Request for Applications to fund primary

prevention of lead poisoning, with emphasis on community-based programs that collaborate with the health, housing, and environmental sectors within the community.

CDC also evaluates program and policy. For example, from 1985 to 1990 the recommended policy was to screen only high-risk children. In 1991, however, universal screening for all children under the age of 6 years became policy, except in areas that could prove they had no lead poisoning problem. Today, besides recommending screening in high-risk communities, CDC is examining strategies for screening in low-prevalence communities, as well as analyzing questionnaires to identify high-risk children in low-risk communities. (The ABLES program was described earlier in this breakout session.)

In addition, CDC studies the sources of lead, assisting in EPA's study of contaminated soil (which demonstrated only a modest benefit from soil removal and replacement in inner-city areas); investigating outbreaks of lead poisoning linked to the use of leaded ceramic pottery and tableware; and evaluating the risk of folk remedies popular in Hispanic and Asian communities. In California, after 40 children were found poisoned in 1992, the folk remedies were found to have a high lead content.

CDC has set year 2000 objectives that no U.S. child shall have a blood lead level greater than 25 $\mu\text{g}/\text{dL}$ and that no more than 500,000 U.S. children will have blood lead levels greater than 15 $\mu\text{g}/\text{dL}$. For inner-city, low-income black children, the objectives are that no child shall have a blood lead level greater than 15 $\mu\text{g}/\text{dL}$ and the prevalence of blood lead levels greater than 25 $\mu\text{g}/\text{dL}$ shall be 37,000 or fewer. To achieve these objectives, CDC needs communities to develop primary prevention activities and for research to proceed.

In response to a question about incineration, **Dr. Rosenblum** said that ATSDR, a PHS sister agency that deals with industrial wastes, and Georgia Tech's Lab Line could provide information on soil testing. When another participant asked about provisions for testing older children and adults, it was pointed out that CDC's limited funds are used for younger children because they are at higher risk.

Dr. Marinelle Payton of Harvard Medical School first described an important prospective cohort study by Bellinger and colleagues that looked at early development and low-level lead, stratified by social class. The results of the study suggested the linkage of lead problems to poverty could be reversed. The speaker then emphasized that research should serve the needs of children and provide support to community health centers. Researchers should become partly accountable to the patients, who should no longer feel like "guinea pigs."

One pilot project linking a community health center and an academic center that received some support from ATSDR in 1991 sought to evaluate the adequacy of lead prevention strategies through a retrospective cohort study of children from the Harvard Street Neighborhood Health Center located in the highest risk area for

childhood lead poisoning in Boston, MA. The research questions included whether lead-poisoned children benefit from participation in Head Start and remedial education; the magnitude of that benefit compared with that for children with low to no lead poisoning; how the benefits of early childhood remedial education programs compare with benefits from primary prevention and secondary therapy; whether these strategies increase the likelihood of a child participating in early intervention programs; whether the programs are adequate to meet the needs of high-risk communities; and what further collaborative initiatives between health care providers, educators, and other environmental professionals might mitigate, if not reverse, the neuropsychological damage to young children with histories of lead poisoning.

In response to discussion questions, **Dr. Payton** said that there are not enough Head Start and remedial education programs; she does not know why upper-income children had better reversal of lead effects; and she hopes that eventually agencies like CDC and EPA will be able to establish enforcement standards for community wastes. Concerning a *Wall Street Journal* article that suggested that lead poisoning was not a grave problem, comments included an analogy with tobacco because a few scientists will differ from the majority by saying that cigarettes do not cause smoking. Further, the second and third generations of studies absolutely confirm and corroborate previous data, and the "Alliance" prepared a response to the *Wall Street Journal* article.

Session participants were interested in opportunities over the next 10 months to get the Federal government to finance the cleanup of lead hazards, including a bill moving through Congress for a "polluter pays" tax on lead that could generate \$1 billion per year for the cleanup of lead-contaminated soil and lead hazards in houses. This bill—the Lead Abatement Trust Fund Act, or Carbin-Bradley bill—might be rolled into health care reform.

One attendee reported on a study that analyzed data from children tested in the first and second grades 15 years ago and followed until they turned 18. The study found that the differences attributable to lead carried over across time: The individuals who had higher levels of lead were more likely to have reading difficulties, to have failed school, or to have had problems with the law.

BREAKOUT B

TITLE: OCCUPATIONAL AND ENVIRONMENTAL CANCER

Dr. Marilyn Fingerhut of NIOSH said that making a distinction between environmental and occupational exposure to toxins is incorrect. However, workers generally suffer a higher exposure than other people in the community. The reason is that workers may be employed for as long as 5 to 10 years with or near a hazardous material that may also contaminate the community. As a comparison, ordinary individuals have about seven parts per trillion (ppt) of dioxin in their bodies from environmental exposures, mostly from food, but at the last date NIOSH studied occupational exposure concentrations in chemical workers, the concentrations were as high as 2,000 ppt. One individual was estimated to have a concentration of 30,000 ppt.

Estimates of cancer because of workplace exposures range from 4 to 20 percent of all cancer incidents, and NIOSH estimates that 3 million to 9 million workers are potentially exposed to carcinogens. OSHA regulates the level of exposure for humans for 24 carcinogens; NIOSH recommends that another 106 chemicals be controlled as carcinogens. Unfortunately, occupational cancer studies cannot account adequately for the discrete influences of onsite chemical exposures, smoking, socio-economic status factors, and access to medical care on worker health.

There is a paucity of adequate studies of people of color. A recent review of cancer studies published over 20 years found only 14 percent of these studies focused on women, 7 percent on men of color, and 2 percent on women of color. Yet, the U.S. workforce is composed of 46 percent women and 18 percent people of color, with the latter concentrated in blue-collar occupations where both skilled and unskilled minority workers incur risks of exposure to occupational carcinogens.

National statistics are not adequate for studies of minority groups, because the only readily obtainable national rates are for whites and nonwhites—categories that are not meaningful for particular ethnic groups. For example, to obtain a comparison population to study the effects of radon exposure on Navajo uranium miners, NIOSH had to use nonwhite death rates from New Mexico and Arizona, where Native Americans compose the principal nonwhite population. In another study, NIOSH was not able to provide a definitive statement on whether there is a relationship between

antimony and heart disease in a Hispanic worker group, because there is no Hispanic category in the data collected on U.S. mortality rates.

Recommendations for improving health statistics among minorities were published in a May 1992 PHS report. Adequate and appropriate racial and ethnic data must be collected and recorded in work, medical, and other records that track exposures in the workplace. Recently, NCHS recommended that all of DHHS use the same five racial and ethnic categories for uniform data sets: American Indian, Eskimo, or Aleut; Asian or Pacific Islander; Black; White; and Other. In the case of ethnicity, Spanish descent would include options for Mexican-American, Cuban, and Puerto Rican origins. The current health care reform effort may present an opportunity to develop systems that link employer data to medical data while effectively addressing privacy issues. In addition, people of color must become involved in the decisionmaking process. With these changes, we may be better able to evaluate the distribution of cancer in minorities and its relationship to environmental exposures.

Dr. Tom Sinks, an environmental cancer researcher from CDC's NCEH, provided the following data. In 1973 and 1974 the difference in age-adjusted mortality rates for all cancers between whites and nonwhites was 23 percent. By 1990 this difference had climbed to 35 percent, with mortality rates for whites and African Americans growing by 6 and 16 percent, respectively. The largest racial differences appear in cancer survival statistics. The 5-year survival rate for all cancers combined for African Americans is 39 percent; in contrast, whites have a 54 percent chance of surviving 5 years. This difference in cancer survival is influenced by several factors, including early detection, barriers to health care, and health care delivery.

Each type of cancer has a unique set of causal factors. While the single most preventable cause of cancer is tobacco (30 percent of all cancers might be avoided by eliminating exposure to tobacco), studies are needed to evaluate the risks of tobacco exposure and use among minority and underserved populations. Quality data on environmental exposures to carcinogens—not just data on the proximity of workers to hazardous industrial waste sites—also are needed and should be obtained by objective measures that capture actual exposure. Data on human tissue concentrations for two potential carcinogens, PCBs and DDT, show significant differences in body burdens between whites and nonwhites, that is, in how much their bodies take in and retain. More differences such as these need to be identified. When exposure levels are found above an acceptable range, preventive measures must be taken to avoid the further exposure of individuals, regardless of race, ethnicity, or socioeconomic status.

Dr. Peter DeFur, a scientist from the Environmental Defense Fund, described environmental protection from the government's view as a distinctly human issue because the government is not concerned with carcinogens in fish or wildlife. Since our knowledge about cancer is limited, we often take an overprotective approach in controlling carcinogens. For people of color, however, a protective course may be warranted, particularly as occupational and environmental causes of cancer are the same when people cannot separate where they work from where they live. Indeed,

people of color may live within a mile of hazardous waste disposal sites or in the backyards of chemical plants. For these communities, the issues of occupational health and environmental health are the same.

Use of quantitative risk assessment to protect people from exposure to toxic agents raises additional problems because some communities, especially those with people of color, have become concerned about the motivation of government agencies and Congress in promoting the risk assessment process. Eric Mann from a Los Angeles neighborhood center focused on this when he recounted that when the Right-to-Know law (the 1402 Rule) was passed in Los Angeles, companies were allowed to comply with orders to reduce cancer risk by erecting a taller smokestack, thereby diluting their emissions and blowing them out upon more people. This procedure was acceptable because of the reduction in individual exposure and risk even though more people were now exposed to emissions albeit at lower levels.

One of the inherent problems with risk assessment is the assumption that decisions can be made for one species (humans) based on studies conducted with another (animals). When a substance affects one or two animal species adversely, we can speak of a high probability that it may also affect humans. At present, however, the onus is on public officials to document specific agent-related human mortality, which means that it will take 20 years for adequate data to become available.

A proposed alternative to risk assessment relies on five principles of decision-making: (1) employing alternatives analysis instead of risk assessment; (2) making decisions by consensus, with the affected community represented; (3) ensuring that information flows in multiple directions among the persons and groups making the decision; (4) sharing information and roles among process participants; and (5) achieving a degree of cooperation among all parties that makes the whole greater than the sum of its parts. Nevertheless, risk assessment can be helpful. If risk assessment had been conducted on lead exposure, researchers would have been aware decades ago that low-level exposure is a great threat to childhood health.

Community participants urged scientists at NIOSH and other agencies to identify (1) which chemicals they would ban right now; (2) which chemicals they judge to pose the lowest risk to the community; and (3) how cancer, lupus erythematosus, and other harmful health effects are associated—if at all—with exposure to specific environmental toxins. They were concerned about how much exposure individuals receive during emission of benzene, which at a certain level causes leukemia, and about the problem of ignoring synergistic relationships, such as those between particulate matter and cigarette smoke as a cause of lung cancer. A trend to watch is an apparent increase in the prevalence of nonsmoking-related lung cancers, as noted in recent scientific reports. Los Angeles, CA, has an excellent tumor registry that could serve as the basis for studying the incidence of lung carcinoma in non-smokers. An accumulating body of evidence suggests that chemical carcinogens may be involved, to an increasing degree, in the development of lung cancer.

Another issue raised involved the problem of reaching the incorrect assumption that no further work on a suspected carcinogen is necessary. This scenario could happen if insufficient worker mortality data are available for a true test of the effect of a substance in the workplace. Then, despite a substance being identified as causing cancer in animals, human exposure to it is allowed based on false assumptions. Because of all the possible intervening variables and cofactors in human studies, we must have animal studies.

To explain why not everyone exposed to a chemical develops cancer, the scientific community is now looking for biomarkers—that is, biological evidence in the human body (blood, skin, urine, hair, and fingernails)—that show whether a change has occurred as a result of a particular environmental exposure. Biomarkers could be used to indicate susceptibility.

One attendee pointed out that a substance that causes cancer in animals will not necessarily hurt humans. Today, few toxicologists would say that saccharin, which was banned in the 1970s, causes cancer in humans. Another attendee commented that there is a big difference between absolute scientific proof that a substance is a carcinogen and some evidence that it can cause cancer. At the policymaking level, emphasis could be placed on primary prevention, increased frankness between scientists and communities, a reduction in the number of equivocal studies, a requirement that manufacturers prove in advance the safety of substances, and a reduction in exposure levels of substances of concern even before academic research on them is begun.

Another concern was that government sanctions against companies are often appealed and nullified, despite the fact that the intent of the sanctions was worker protection, particularly when polluting industries are clustered in the least advantaged communities. For many communities, the issue often comes down to electing legislators who “see the world the way people at this conference see it.”

Attendees also considered important the failure to link disabling conditions to occupational exposures and the need to study the link between the compensation system and causes of death. For example, data on silicosis from sandblasting, mining, and metallurgy show that after workers file for compensation benefits, many exhibit dramatic increases in death rates—specifically, from tuberculosis at a rate 50 times greater than the national average when adjusted for race. Yet, in one case examining cancer deaths for 509 people with silicosis, these workers had more than twice as much cancer of the intestine. Similarly, rates of cancer of the respiratory system, lung, and prostate were elevated. (Another presentation at this meeting showed a breakdown by industry of the causes of worker deaths from tuberculosis, respiratory diseases, cancer of the lung, and cancer of the large intestines. Risk rates vary by cause of death, as well as by major industry.) It appears that silicosis results in a variable risk of disease over time. For example, the risk for tuberculosis remains high for 10–20 years, then diminishes. Physicians need to be informed that when someone

is diagnosed with silicosis, the risk for tuberculosis is high soon after the disease is diagnosed and that risks for various cancers will grow over time.

BREAKOUT C

TITLE: CHEMICAL ACCIDENTS RESEARCH NEEDS

Dr. George Alexeeff of the California EPA called guidance levels the foundation of environmental safety in the community. Based on a chemical's impact on overall health and on morbidity and mortality, these values are used to determine the impact of a potential release of a specific chemical and give enforcement agencies the authority to act. Communities may use the Immediately Dangerous to Life or Health standard, which is defined in terms of the maximum concentration of a substance from which, in the event of respiratory failure, an individual could escape if exposed; the Emergency Response and Planning Guideline standard that was set by an industry-based group to protect "most individuals in the general population" (which is not explicitly defined); or the NAS standard for military personnel and some civilians, based on the wide susceptibility to each substance of people aged 18–25 years.

To be able to collect information about the impact of a chemical release and establish a relationship between exposure and any subsequent illness, communities, agencies, and CDC need methods to measure chemical releases in the first 24–48 hours after a release. The California EPA has used this kind of information to show that chemical-induced asthma may result from environmental exposure.

Scientists also need to know more about the impact of long-term exposures. Current standards do not test for the long-term impact of chemical residues, in part because equipment may not be able to detect small enough amounts of residual toxins to determine whether residue was left from a release, possibly trapped in walls, furniture, or furnishings. For example, 18 months ago, when a tenant died after reentering a fumigated apartment building, people first realized that substantial quantities of methyl bromide could be trapped inside the walls.

Robin Bryant, a refinery worker and union health and safety trainer, noted that people who work in chemical industries also generally live in nearby communities that are vulnerable to industrial emissions. The national Process Safety Manufacturing standards (PSMs), released in 1992, were designed to eliminate catastrophic accidents, such as the one in Bhopal, India, in 1984 and the Phillips explosion in 1989. The standards' 14 sections embrace every facet of plant operations and mandate employee involvement. To ensure that companies comply with this mandate and train

labor members to understand the standards, the Oil, Chemical, and Atomic Workers International Union (OCAW) developed its own action plan to implement the standards, as well as its own approach to training.

The 1992 standards call for a written plan that details employee participation. OCAW wants union representatives to be part of the plan, with the goal of having an equal number of union members and management work together on each committee that oversees the PSMs implementation steps. The standards also call for making process safety information available; identifying, evaluating, and controlling any hazards in the process; writing operating procedures that provide clear step-by-step instructions for safely conducting the activities involved in each process; ensuring that the training operator on each unit develops operating procedures that are reviewed annually, with input from the workers; training each operator in an overview of the process, as well as in any site-specific operating procedures; training others in their units by the first people trained, with regular retraining scheduled; similar training for contractors; performing a pre-startup safety review for new and significantly modified facilities; regularly maintaining, inspecting, and testing equipment for mechanical integrity; signing "hot work" permits signifying safety before welding, burning, grinding, or using an ignition source; and conducting investigations within 48 hours of any accident or near-miss.

A PSMs watchdog provision for compliance orders requires employee verification every 3 years that all required practices and procedures are being carried out. OCAW wants an ad hoc committee to develop a checklist to determine routine compliance on an annual basis. OCAW, along with the Labor Institute, has already developed a Jobs and the Environment curriculum that will be supplemented by a section on how to apply OSHA and EPA proposed rules. The curriculum can be used to train workers and people in the community.

In response to questions about time frames, Ms. Bryant indicated that they are different for different sections of the PSMs; 1996 is the target year for 100-percent completion. Companies that enacted safety measures before the PSMs came out have been allowed some leeway in achieving 100 percent compliance.

David Hastings of the Chemical Manufacturers Association (CMA) said that currently CMA represents 180 companies, or 90 percent of the productive capacity for basic chemicals in the United States. The Bhopal accident in 1984 was a wake-up call for the chemical industry to recognize the community's right to know and develop the Community Awareness and Emergency Response (CAER) program, which led to a coordinated emergency plan to deal with incidents at each facility. A 1988 study showing that the public had a negative perception of the chemical industry provided further impetus for change.

Key elements of the CAER program include several codes of management practices: distribution, product stewardship, employee health and safety, pollution prevention, and process safety (catastrophic accident prevention). Not all member

companies participate in the code of management practices, but the industry has established a voluntary initiative to exert internal pressure on member companies to do what is right. In many instances, CAER codes exceed current safety laws and regulations.

As part of public and employee participation, a public advisory panel meets regularly with CMA to serve as a sounding board and voice its concerns. For example, when the panel advised that a responsible CAER program needed to go beyond self-evaluation to third-party verification, the chemical industry began working with the panel to design a system that would allow for this aspect. The CAER code requires facilities to have employee and community outreach, a coordinated emergency response plan, regular evaluation of the effectiveness of these plans, and active participation in a local community-based advisory panel, coupled with a policy of openness that allows people to enter industry facilities.

CMA's involvement with EPA includes its support of the way the Clean Air Act extends process safety management (worker protection) to the community and combines process safety (prevention) with emergency response and hazard assessment, also extending them to community protection. CMA has a 1-year-old industrywide worker operations training program, involving a series of workshops, based on final OSHA regulations.

Mike Leedie, a board member of West County Toxics Coalition (WCTC), Richmond, CA, said that Richmond has been the site of several industrial accidents. These incidents include the explosion of the Chevron refinery, which dumped 60 tons of catalyst dust all over the community, and the explosion of the General Chemical facility. WCTC believes that both problems could probably have been prevented if a community technical advisor had been available to look at the issues, focus on concerns, and make recommendations. Further, when WCTC called for access to information, it found that the standards described earlier in this breakout session were not being reviewed with the kind of public scrutiny necessary.

Electronic technology offers opportunities for widespread data sharing with other communities while keeping costs low. Computers also permit networking among activists across the country. People in communities who have not previously had such access need training in this technology.

As the result of a California EPA regulation concerning the need to inform the public, WCTC receives a risk management prevention plan and an offsite consequence analysis of some facilities, but this material may be too technical for the general public. Consequently, enforcement is not strict enough. Further, current guidelines do not have adequate penalties for industries that do not comply nor are they specific enough to allow communities to control the public review processes that are part of risk management prevention plans.

An attendee mentioned monetary settlements paid by both Chevron and General Chemical to the Richmond community that were challenged by Chevron. WCTC worked with the community to get a number of conditions placed on Chevron's operating permit, including a \$60-million settlement package over the next 30 years that was earmarked for community involvement projects, including a community technical advisor. This condition was opposed by the company; Chevron eventually had the monetary award reduced to \$4.5 million.

Another attendee asked if the speakers thought that industries that pose health risks and are in or near residential areas have an obligation to contribute to their communities, even when there are no immediate and pressing health problems. **Mr. Hastings** answered that this obligation was part of the CAER initiative. He also noted that ongoing rulemaking by EPA will affect training and research, as well as 140,000 chemicals, and will cost the chemical industry \$10 billion to \$15 billion over the next 10 years, according to agency estimates. A third attendee said that EPA could make a big difference in worker and community participation—for example, by requiring a technology options analysis in which a facility would identify all potential ways of preventing a chemical accident—and that the role of State governments in overseeing industrial compliance needs to be considered.

When some session participants from West Virginia suggested management did not take community concerns seriously, **Mr. Hastings** said that CMA will soon be issuing new guidelines that restate the need for independence by community panels. Other queries concerned whether companies would be required to give panels technical assistance and access to detailed documentation about safety and whether primary prevention of accidents could be emphasized. **Mr. Hastings** agreed to meet with sponsors of a clause for the Accident Prevention Rule that would require manufacturers to describe their full technological capabilities to their communities and anticipated that CMA would submit comments to EPA within a week.

Other needs, as stated by attendees, included support by EPA of stringent public protection measures to inform people of risks in communities with plants that have catastrophic potential; to activate the Chemical Accident Safety Board; to require an offsite consequence analysis and equipment designed to minimize any kind of offsite release; to ensure more worker participation in unionized as well as nonunionized industries; to train workers of color, including non-English-speaking workers; and to make compliance mandatory.

An attendee from the Labor Occupational Health Program stated that she has no faith in voluntary compliance after an experience in which none of California's plating companies let her organization conduct training and one facility refused to spend a small sum so training sessions could be given in Spanish. Consequently, an untrained Spanish-speaking worker went into a confined space and passed out; 1 rescuer died and 16 other people went to the hospital.

BREAKOUT D

TITLE: SURVEILLANCE RESEARCH NEEDS

NIOSH defines surveillance as “the systematic, ongoing collection of relevant data and their constant evaluation and dissemination to all who want to know for the purpose of prevention.” The first goal of surveillance is to identify new opportunities for prevention. For example, nurses trained in occupational epidemiology have been placed in 10 State health departments to (1) find out what health problems exist; (2) tell NIOSH what the problems are; (3) collect pertinent information; and (4) act on the knowledge acquired.

An example of the role surveillance plays in identifying health problems was in an investigation of an outbreak of gastroenteritis among agricultural workers that turned out to be nicotine poisoning from cutting wet tobacco. Another example of surveillance concerned occupational burn injuries, such as getting burned by contact with hot oil from deep fat fryers in fast-food restaurants.

The second goal of surveillance is to define the scope of a problem. For example, 8 years ago only a few States required reports on adult blood lead levels; today, 30 States do. The data reveal that most individuals develop lead poisoning from occupational exposures, a few acquire lead poisoning from hobbies, and workers bring lead home from their workplace and expose their children to it.

The third goal of surveillance is to define trends; that is, are conditions improving, worsening, or staying the same? The fourth goal is to target prevention resources.

Among the surveillance studies ATSDR is conducting in minority communities, the first (and still ongoing) study was of a lead smelting operation open for about 50 years in west Dallas, TX. Not only were proper bag houses and insulation not in place at the facility, but the community was exposed to lead from the smelter. Five percent of children under age 6 years living nearby showed elevated blood lead levels in 1983. The first remediation steps involved removing contaminated soil from residential and public areas and replacing it with new soil and grass. Concerns arose, however, that the cleanup was causing further lead exposure among the children. In May 1993 the smelter site was added to the EPA's NPL.

Currently, the Dallas Health Department, along with EPA and ATSDR, does surveillance of children ages 6 months through 6 years who have been residents of west Dallas for more than 3 months. Some area residents have helped publicize the study, but they were not involved in its design. Additional surveillance activity is focused on blood lead levels of children in two communities with similar demographics but differing in their exposure to lead, based on air emission control monitoring. Possibly, the results will help EPA validate a mathematical model for predicting a child's blood lead level in regions with no surveillance, where health officials know the key independent variables, such as the level of paint, the existence of paint chips or dust, the level of soil contamination, and the tap water lead level.

With newly available measurement techniques, the west Dallas researchers can identify the amount of lead stored in the bones of children residing near the smelter. This important knowledge can be instrumental in considering effects on the children's health when they reach adulthood.

A second ATSDR project, in Texarkana, TX, involves a subdivision built on the site of an abandoned creosote wood-operating facility. This site was placed on the NPL in 1984. Soil and ground water were contaminated with aromatic hydrocarbons, benzopyrene, naphthalene, fluorine, and pyrene. A health study initiated in 1990, comparing residents with a control community, showed that the residents had three times as many skin rashes as the controls and more problems becoming pregnant. Study results, however, did not support the residents' perceptions that they had higher rates for cancers and adverse pregnancy outcomes. A limitation of this study was that investigators looked at self-reported symptoms that were not validated with medical data. Nor could the level of exposure be determined because the absorption of toxins into the skin could not be measured. To show relationships between adverse health effects and exposure, scientists need more reliable biological indicators capable of detecting the low levels of exposure that are likely to occur in residential communities.

Improved surveillance mechanisms are particularly important for low-wage workers, low-income communities, and communities of color—groups with higher risks for occupational disease than the general population, but for whom the available data on occupational disease are very limited. Moreover, the published evidence indicates that surveillance data do not adequately include these populations. For example, minority populations in New York are clearly underrepresented at occupational health clinics compared with their representation among the State's population.

Disease, disability, or untimely death that is likely to be work-related should make a physician consider and explicitly rule out occupational or environmental etiology in a particular patient. Such events are signs of a failure in prevention and suggest a need for substitution of a less toxic agent, engineering controls such as ventilation systems, or the use of personal protective equipment. Although physicians could play a critical role in surveillance research, they appear to be slow in respond-

ing, need better training in occupational medicine, and are unaware of how frequently their patients are exposed to toxins.

To one Iowa City questionnaire, three-quarters of the respondents reported exposure to at least one toxic agent and almost one-third of the respondents to at least four agents. Boston and New York City data also support the prevalence of occupational disease caused by toxic exposures and the low recognition of these problems by physicians, with the exception of Bellevue Hospital in New York City. Bellevue conducts occupational medicine case conferences; has started a physician-based outreach program; recently has added a Chinese staff member to help build an Asian community base; and is experimenting with outreach to community organizations.

There is a perceptual problem regarding community-based health research. Researchers often look at well-defined and limited problems, while workers and communities view sets of problems more globally. Bringing the two groups together with a facilitator might enable each group to air its respective viewpoint and thereby lessen the misunderstanding between the groups, as well as the anger and distrust that communities often harbor against well-meaning researchers. NIEHS should consider funding these focus groups.

Unions are now trying to have ongoing surveillance become part of OSHA standards, with requirements that employers conduct it and permit their interventions to be evaluated. In a parallel situation, surveillance activities might occur in school-based health clinics and other community-based sites, especially in low-income, minority communities. However, surveillance needs to go hand-in-hand with information dissemination. For example, how many of the 17,000 workers who are lead-poisoned in the United States are aware of the seriousness of their condition? The Labor Occupational Health Program at Berkeley, CA, has developed programs for low-literacy or non-English-speaking workers at small radiator shops and at "mom-and-pop" smelters, but project organizers have not yet been able to convince the owners of such establishments to educate their workers.

During discussion, an attendee challenged the speakers' emphasis on surveillance of sick workers rather than on surveillance of hazards. He also complained of the difficulty the public has in obtaining the data that the government and private sector have collected on exposed workers and asked for concrete recommendations based on the data. Others agreed that the data, even if flawed or incomplete, should be available to the community for evaluation and that it is easier to get access to community data than to occupational data. A panelist, who noted that in California only about 1 percent of workers who are exposed to lead are under surveillance, agreed that prevention may be more effective if it combines surveillance of exposure with surveillance of disease.

All speakers and attendees expressed consensus at this point that researchers should focus not only on mortality, morbidity, and biological markers but also on

prevention and intervention strategies. The problem, they concluded, is that the whole system for intervention needs more support.

The difficulty of establishing a link between a health effect and community exposure was again noted, using the example that researchers would never have found the benzene-leukemia connection had they looked only at the "Love Canals." The link was identified using occupational exposure data. In shoe factories in Turkey that used 100 parts per million of benzene, workers were getting leukemia. At this point, extrapolations to communities are necessary because, as mentioned earlier, the technology is still not available to document low-level exposures. To perform community studies now with inadequate tools is dangerous, because the results are liable to be misinterpreted as negative instead of inconclusive.

The primary problem in conducting surveillance and designing and testing interventions is a lack of funding. Attendees and panelists disagreed, however, on the source of funding. One attendee suggested that the government should pay for the additional studies that are being demanded. In turn, a panelist suggested that companies should pay for the studies but should not conduct them. An attendee noted that EPA's experience shows that getting industries to pay for studies can be a long-term process. Another attendee suggested that 10 percent of grant monies should go to community involvement and education.

A panelist commented that the symposium has focused on a new paradigm, one based on community involvement where the community works with researchers as an integral part of the team. To reach that ideal, he suggested that an effective means of community accountability be explicitly built and written into grants. When a grant team visits a community, it would bring not only molecular biologists and epidemiologists, but others who understand community participation and who would formally review how well a facility had related with the community, listened to its needs, and acted on them. He defined the paradigm in terms of process—specifically, a *modus operandi* that would integrate the community into the process, where the community helps to formulate any hypotheses, gather the data, interpret the results, and translate research into action.

Also suggested was that even basic science research that is not connected directly to community exposures should earmark part of any grant monies for community education. However, many bench scientists would find accepting this notion difficult even though the concerns of a community could potentially become a focus for their basic research.

BREAKOUT E

TITLE: MODELS FOR TECHNICAL ASSISTANCE: IDENTIFYING, ARTICULATING, AND DOCUMENTING PROBLEMS

Rose Augustine of Tucson, AZ, shared some of her experiences in obtaining technical assistance grants (TAGs) for remediation of Superfund sites. She asked other session participants to share their frustration and difficulties in obtaining these grants and their suggestions for making the application process easier for other communities. For example, the application process can take more than a year to complete, which often results in communities having to refile all paperwork.

Attendees asked how EPA was cutting through the Federal procurement requirements that often force groups to hire a consultant. Even if regional EPA staff provides technical support on a grant application, grants for community groups are required to follow the same procedures as those for other groups (e.g., universities). Reimbursable grants are another problem, because many communities lack the seed money to get started and cannot advance funds and wait for reimbursement... Expanding what a TAG award will fund (without taking money from the desperately needed technical experts) would enable groups to pay for someone to help organize the community, bookkeepers to help manage funds, and people to help them account for in-kind contributions.

In response to the suggestion that the 20 percent in-kind requirement be dropped, an EPA speaker gave the example of a group that had high in-kind contributions—a match of around 45 percent. Another community speaker reported that her group also had in-kind contributions, but lacked the mechanism to account for them. Further, although EPA provides for a waiver of this requirement for economically deficient areas, not all community groups are eligible for this waiver.

Three factors can help community groups successfully obtain funds. First, they should be familiar with the community and its leadership and resources. For example, groups can use adult education programs where there is money (as a result of the Economic Opportunity Act of 1964) and can very inexpensively use the media and the

“information highway.” They may have to build democratic involvement, especially in communities such as those of African-Americans, who have not traditionally been involved in government.

Second, community groups or individuals must be specific about their needs and be prepared to present hard data. They should approach decisionmakers for help, where necessary, and seek out ways to evaluate study procedures and findings. Groups must determine where to go to find the affected individuals.

Third, knowledge is power: Community members need to be familiar with every applicable statute, regulation, policy, and procedure. Put simply, if one does not follow EPA’s policies and procedures, one will not get money. Organizations or individuals other than EPA (e.g., Members of Congress or environmental groups) may be able to give assistance.

EPA representatives have implemented administrative changes to streamline the application process; expanded a technical assistance program to help prospective grant recipients understand EPA rules and regulations, relevant terminology, and site remediation needs; activated the National Environmental Justice Advisory Councils; expanded reimbursement programs in an effort to provide seed money—up to \$1,000—for out-of-pocket expenses; and assigned environmental justice coordinators (EJAs) to each EPA region. Changes made in the TAG application process now allow TAG funds to be used to hire a grant administrator to help with bookkeeping and management of grant funds. A revised, simplified TAG application comprised of two booklets will be available in the near future.

Speakers advised community groups applying for EPA grants to understand technical terms; understand and follow EPA rules, regulations, and procedures; be knowledgeable about the site; hire a technical advisor who meets the group’s needs; disseminate information widely through meetings, the media, newsletters, and electronic mail; and use nonprofit status to obtain in-kind contributions, such as donated supplies, volunteer telephone calls, bookkeepers, advertising, and free printing.

Alternative suggestions offered by attendees included that EPA develop a panel of environmental support personnel who are able to recommend community-friendly consultants; change or tailor rules, regulations, and requirements so citizens’ groups do not have to compete against other groups or organizations, such as universities, that generally have significantly greater resources, personnel, and expertise; establish and implement tasks for the newly forming Environmental Justice Advisory Councils (e.g., oversee a national list of environmental consultants and improve communication strategies between regional EPA offices and community groups); increase openness for dialogue and exchange between EPA, other Federal agencies, and community organizations; encourage government agencies to use advertising and newspapers to notify communities about cleanup efforts, training sessions, seminars, and such; identify one EPA staff member per region to serve as a community activist to work

with community leaders and help them access the system; remove the 20 percent in-kind requirement and initiate legislation to allow direct funding to citizen groups by EPA; increase EPA's commitment to involve and educate the community; and improve enforcement of existing laws, policies, and regulations.

One attendee noted that even though EPA has existed for 25 years, the majority of national changes come from regional coalitions. Region V, for example, has for years been the source of national toxic policy. Although individuals and community groups may work for change from the outside, change must also come from within EPA. EPA should consider why it has more guidelines on \$50,000 grants than on \$4-million cleanup projects. In order for EPA to change, its staff must play a crucial role.

BREAKOUT F

TITLE: AWARENESS/EDUCATION AND MONITORING COMPONENTS OF SUCCESSFUL MODELS OF COMMUNITY EMPOWERMENT

This session addressed both “what has worked” and “process” issues. **Maurci Jackson** of Parents Against Lead (PAL) in Chicago, IL, established this group after her daughter was poisoned by lead, once by accident, but again because of inappropriate in-house abatement procedures that education could have prevented. After difficulties with agencies in Illinois, she began to look elsewhere for information on lead-related issues. Her group’s mission is to tell people, especially the minority community, about the dangers of lead poisoning, including its specific adverse effects and its preventability. To educate, PAL uses the media, especially regular and creative use of television. Persistence and patience are important to get the media to respond. For example, it took 18 months to have aired a story on a child with blood lead levels nearly 11 times the safe level.

Responding to queries, the speaker said that her group’s next targets are obstetric units in hospitals and that she recommends seeking company donations of encapsulating paint. She also named three ways local health departments could communicate better: (1) have inspectors distribute relevant information to parents during a lead inspection visit to a home, (2) include information on proper lead abatement procedures and warnings for pregnant women when sending information to parents of affected children, and (3) provide parents with information on lead at city-sponsored events. Other session participants stressed the need to alert other residents when one child in an apartment house is treated for lead poisoning and to have wider spread inspections of the building.

Testing should be done immediately, because lead stays in the blood only 45 days before moving to the bones and organs, where it is stored. PAL helped pass a State law mandating testing before children enter school, but enforcement has been a problem. There are also problems of deciding whether to exclude children from school until they have the test and of ensuring that poisoned children are not stigmatized. With mandatory testing, the number of reported cases has increased.

Other advice given by the speaker is to leave intact walls alone and not to disturb or replace a suspect wall, and to let leaded water run before drinking or using. A water-testing kit can be bought. Greater attention should be placed on the dangers of lead, even in the presence of what appear to be more immediate dangers, such as rats. For questions about employment exposure, PAL refers individuals to OSHA.

Dr. William Sanders of EPA Region V commented on efforts of the Federal government to unite agencies on the issue of lead, the new availability of HUD funds for lead abatement in low- and moderate-income private homes, and on Chicago's progress, which includes testing more children and making more money available. New regulations require water suppliers to test drinking water, including that in the home. The attendees were reminded that abatements done incorrectly may exacerbate lead exposure and push lead levels in children's blood even higher.

Attendees expressed several concerns, including whether funded agencies collaborate with existing community groups; that the monies available cannot meet the needs; that initiatives to force lead manufacturers to take some responsibility for reparations are needed; that sludge from sewage treatment plants releases lead when incinerated; and that government bureaucracy makes grassroots organizations go through a great deal to obtain funding.

Monica Moore of the Pesticide Action Network (PAN) then spoke about pesticide reduction, noting that the key problem with pesticides is not a lack of information, but rather finding alternative products that perform as well. PAN works internationally on the issue of methyl bromide, an extremely toxic fumigant widely used in the United States for, among other uses, termite infestations and on strawberries and tomatoes. Its banning has been urged for years by labor organizations. Now listed as an ozone depleter, methyl bromide must be phased out by the year 2001. PAN has joined a coalition aiming to prevent replacement of methyl bromide by other toxic chemicals, even if they do not deplete the ozone, and to propose alternative methods that do not require chemicals.

PAN pools fundraising, administration, and other resources for its member groups. One example documenting the need for PAN was the December 1993 decision of the California EPA that farmworkers and rural residents were not required to be warned when methyl bromide was used, even though individuals exposed during structural fumigations would require notice. However, 90 percent of methyl bromide is used in agriculture.

During the discussion, a 1994 change in EPA's new and historic commitment in 1993 to pesticide reduction was noted. After bringing the U.S. Department of Agriculture into the planning process, EPA changed its language from "use reduction" to "risk reduction." With this change, EPA could use its authority to immediately ban, or at least phase out from the market in 3 years, known toxic pesticides and to stop the export of these chemicals to other countries when our own country stops using them.

Jill Guernsey-deZapien of the University of Arizona Medical School and Cancer Center spoke next of 7 years' work with Arizona communities, building model programs around various health issues, to which environmental health may be added. A basic model program is built on the notion of locally based community health advisors, who are trained in a given health issue during intensive, interactive sessions that result in both health providers and community trainees seeing a problem from a broader perspective, which helps them promote social change. This type of outreach is now underway in Nogales, AZ, a cancer cluster. The university is asking the NCI for money to expand the model to look at specific disease issues related to environmental health.

During the discussion, an attendee asked about experiences in combining labor and community groups into coalitions. **Ms. Guernsey-deZapien** observed that when the university has tried worksite programs, employers have not been cooperative, but community health centers, particularly in Yuma among the farmworkers, have provided support. The white environmental group that formed the basis of **Ms. Moore's** coalition was committed to involving more people and brought in labor and other interests. The Monterey, CA, pesticide coalition began as a community-labor coalition. It appears that groups with a sense of something to gain, and that can see change, ordinarily will stay with a coalition.

BREAKOUT G

TITLE: ENVIRONMENTAL HEALTH EDUCATION IN ACADEMIC SETTINGS: K-12 AND HIGHER EDUCATION

Dr. Marian Johnson-Thompson of the Office of Institutional Development (OID), NIEHS, proposed that the single most important element to address with regard to environmental issues may be education—not only of affected communities, so that people may understand what is happening to them, but also of young people, to encourage them to pursue environmental health careers. People of color and those in affected communities must be empowered to take control of their own situations. In addition, the public in general must be educated about environmental justice, so that society as a whole may take action.

Researchers at the OID, noting the small numbers of people of color who were pursuing scientific careers, realized that beginning scientific training at the college level was too late. They realized that parents and communities must become involved in education and that the Nation needs to encourage and provide education for minorities and disadvantaged populations to improve science literacy and encourage those who are interested in pursuing careers in environmental science.

Education and training are critical, and if the public wants to be heard, it must overcome an important obstacle: understanding the technical language used by government decisionmakers. For this reason, environmental education and training must involve a series of activities, from general public science literacy to training through the postsecondary and graduate levels to nonenvironmental professionals who make important decisions about environmental problems. Further emphasized was the desperate need for people from communities of color and affected communities to serve in positions of power.

Isiah Sewell, Director of the Environmental Education Division, Office of Technology Development, DOE, told how DOE seeks to ensure the participation of minority communities by developing an environmental consortium that solicits nationally from minority institutions. The consortium comprises 17 minority colleges

and universities across the country and has a broad range of activities, including outreach, precollege education, technology transfer grants, and research. Among its members are groups such as the National Congress for the Advancement of Minorities in Environmental Professions, industries, government agencies, and six community associations.

Milton Morris of Benedict College in Columbia, SC, described Benedict as a small minority institution and one of the few institutions of its size and status to have an environmental sciences program. The college's program, developed by the National Environmental Health Association, is designed to teach students the preventive measures needed to reduce both human and environmental exposure to harmful substances. The program was established in 1987 as part of a Title III initiative with 5 students; 17 students are currently enrolled, and more are interested. To encourage minority enrollment (99 percent of students are African American), the college's science faculty (50 percent of whom are also African American) go into communities throughout the State to promote the program.

At this point, an attendee questioned the need for formal training and education to participate in the decisionmaking process, noting that those in the community have their own education and wealth of knowledge. Further, for the people in her Native American community, the issues are simple: Their water—the lifeblood of the people—is contaminated, and it does not matter what scientific terms and what levels are used to explain the contamination. She continued that she does not need to be educated to know that the water is not safe to drink. Making scientists out of community people will not solve the problem; many individuals simply want to live on the earth in harmony with the environment.

The speakers responded that community involvement is often sparked through education. Further, primary and secondary education is a generally local activity. In both instances, the Federal government works with communities, which, in turn, determine what activities will be provided through their local schools and how they will be implemented. Attendees did express concern over the inability to find adequate or appropriate environmental education curricula for students or for the community. Programs for non-English speaking communities do not appear to be available.

Mr. Sewell noted that his Environmental Education Division has materials available for school districts. To begin to address specific educational issues, NIEHS has requested proposals from K-12 schools and has allocated funds to help schools introduce environmental health sciences education into existing curricula. NIEHS is not developing a curriculum but is relying on local communities to do so. Communities, in turn, may submit their curricula for funding to NIH, which, in conjunction with environmental organizations, community organizations, and individual consultants, will review the submitted curricula for feasibility and soundness.

NIEHS has also established centers in urban areas to address a protocol for treating lead-poisoned children; the cities included Baltimore, MD; Philadelphia, PA;

Columbus, MO; and possibly, Atlanta, GA. Another attendee mentioned an industry-funded curriculum for schools on radioactive wastes in North Carolina that stressed the safety of the wastes. In response to a comment that the school system itself can act as a roadblock to environmental education, it was noted that most agencies, such as NIH, have no mechanism for forcing curricula upon schools. However, people may petition their school systems for the inclusion of environmental education materials. Another option for community groups is to respond to NIEHS's Request for Proposals (RFP) announcements.

One attendee suggested that DOE send information on its curricula to school systems and libraries and also provide information on direct funding mechanisms for environmental tours, conducted by nonschool officials, to help educate children on environmental issues and enable children to take the information back to school and to their community. The Oak Ridge, TN, Associated Universities, a consortium of some 50 universities, has initiatives for implementing programs on laboratory research for high school students, environmental education, and training in environmental jobs.

Several attendees criticized the structure of RFPs, suggesting that the 1-month lead time is insufficient for a lengthy application process, particularly for community groups, most of which lack the resources, personnel, and expertise found, for example, at universities. Another attendee suggested involving community people beforehand, perhaps as proposal reviewers.

One attendee said that teachers must be educated by the people of the community, who, in turn, must participate in curriculum design. To teach environmental sciences, the curriculum must use community problems as case studies so people can identify with the problems at hand. While many universities send people to the community to collect information about local environmental problems, they never return to the community with help or information. A three-step process to address this issue was proposed: (1) Environmental studies should equip people to establish the causes of illness; (2) people can then trace these illnesses to specific polluters; and (3) policymakers can act on this information by requiring polluters to pay for cleanup activities.

One attendee also suggested the need for a broader understanding of people in the development of environmental studies curricula. For example, terms such as "ecofeminism," "deep ecology," and "biocentrism," that represent different ways of thinking about our environment, should be considered.

BREAKOUT H

TITLE: ENVIRONMENTAL HEALTH RESEARCH POLICY ACTION AND NEEDS: FOCUS ON DIOXINS, FURANS, AND PCBS

Pat Costner, Research Director of Greenpeace's U.S. Toxics Campaign, reported the EPA estimates that approximately 25,000 grams of toxic equivalents (teq) of dioxin are deposited each year over the continental United States and Alaska. An additional 12,000 grams of teq are released each year into the air. These deposits and releases should be compared with EPA's acceptable intake standard, by which 25,000 grams would be the acceptable lifetime—not annual—intake for 2.3 trillion people.

Primary and secondary sources of dioxin include the production of chlorine gas using graphite electrodes or mercury cells. In the United States, 15 percent of chlorine is produced by this method. The waste from this process contains high levels of dioxin and releases considerable amounts of the compound into the air. Other sources of dioxin include bleached and unbleached paper pulp, chloranil (an intermediate for certain dyes), and sewage sludge. Metal recycling, textile manufacturing, and the rubber industry (for example, the burning of tires) are also sources of dioxin emission, as are forest fires. Thus, virtually any time a carbon-based material is burned with a chlorine-based material, the emission will be harmful. Furthermore, there have been problems with PCBs and other materials mixed with home heating oils.

The health effects of dioxin (also called 2-3-7-8-tetrachlorodibenzo-p-dioxin, or TCDD) and other similar chemicals, including the benzofurans and some PCBs, are highly variable, according to **Dr. Linda Birnbaum**, Director of Environmental Toxicology at EPA. At very high doses, for example, dioxin is lethal. Before causing death, however, it causes a severe wasting syndrome, in which experimental and feral animals lose as much as one-third to one-half their body weight. Death is not quick and can take from 1½ weeks (guinea pigs) to as long as 8 weeks (rhesus monkeys). No evidence to date shows that dioxin has ever directly killed a human, most likely because humans have not been acutely exposed to sufficiently high doses. However, evidence shows that at lower doses dioxin damages the immune system and causes the

sinus glands to shrivel, liver changes, edema, and chloracne—a severe dermatitis that extends throughout the body and has been known to persist for 40 years in industrial workers. At still lower levels, dioxin can cause embryo and fetal toxicity and lethality in a number of species.

Dioxin also causes cancer at multiple sites in males and females of all species examined. At least 18 cancer studies—all showing positive results—have been conducted in rats, mice, fish, and hamsters. These studies provide strong evidence that dioxin may also cause cancer in humans. Although a direct cause-and-effect relationship for cancer in humans has not been established, five studies within the past 3 to 4 years have correlated dioxin levels in exposed humans with an increase in overall cancer rate and with an increased risk of lung cancer; cancers in the biliary system, thyroid gland, and blood; and certain kinds of lymphomas. Dioxin exposure may also increase the risk of soft tissue sarcoma.

The noncancer effects of dioxin in multiple species (rats, mice, rabbits, cows, dogs, guinea pigs, mink, fish, and birds) include mortality, embryo or fetal toxicity, low-birthweight animals with poorly developed immune systems and hemorrhaged gastrointestinal tracts, and gross birth defects (especially in mice) such as cleft palate and hydronephrosis (a defect of the kidney). Dioxin also retards the normal development of the sinuses. Unlike studies of PCBs, animal studies on dioxin do not conclusively show that it is toxic to the neural system. It is known that dioxin directly affects the developing genitourinary tract, leading to changes in the external genitalia. Scientists also have seen a decreased sperm count in male newborns, a permanent effect induced by prenatal exposure to dioxin. Further evidence has surfaced that male children born to women who were exposed to high levels of PCBs contaminated with dibenzofuran have micropenises when they reach puberty.

Dioxin may also increase the risk of endometriosis, a major cause of infertility, as well as a cause of painful menstrual cycles in women. The proposed link between dioxin and endometriosis is suggested in two recent studies of rhesus monkeys who were fed dioxin or PCBs at levels comparable (i.e., within a factor of 10) to the levels that humans encounter. EPA scientists have developed rat and mouse models for endometriosis in women and have performed preliminary experiments on dioxin exposure.

The conundrum in dioxin research, however, is that rats and mice respond quite differently to dioxin exposure. Mice are very sensitive to the immune effects of dioxin, but adult rats are relatively insensitive. Yet, developing rats that are born to dioxin-exposed mothers have major immune system problems. Consequently, the stage of immune system development at the time of dioxin exposure may be critical in determining dioxin's effects.

Dioxin also disrupts multiple hormone systems in the body. Not only can dioxin block or even mimic the effects of estrogen; it can also imitate the effects of

excesses or deficiencies of vitamin A in the body. In some cases, dioxin can even induce excesses or deficiencies of thyroid hormones.

Although the regulatory agenda for dioxin previously focused exclusively on cancer as an end point, recently scientists have begun to consider other effects (end points) that occur at lower body levels than those associated with cancer. Clearly, these effects demand attention, and future studies must focus on the critical populations: prenatally exposed children and women. Until now, almost all dioxin studies have focused on men. Because dioxin can affect the reproductive system, prenatally exposed children should be examined at birth, puberty, and menopause.

Dioxin belongs to a family of chemicals—all of similar structures—that bind to the same receptor protein and can cause the same spectrum of effects. This family of chemicals includes the dioxins, the benzofurans, the polychlorinated phenols, some of the polychlorinated naphthalenes (used during World War II to make teak decks water-resistant), and some industrial intermediates that are benzene-based. Because of their similar structures, all these compounds follow a similar path once inside the body (that is, the receptors in the body will interact with the chemical's molecules, and changes will happen accordingly). Dioxin's effects are, however, tissue-specific. The adverse effects of exposure to these chemicals also depends on where an organism is in its development—early embryo, fetus, child, or adult.

The toxic equivalency factor (TEF) measures relative potency. Dioxin is the most toxic chemical known to scientists, with a TEF value of 1. By contrast, other chemicals are given some fractional value. TEFs were developed on the basis of several different health effects. TEFs differ among species; thus, the TEFs developed for humans may not apply to other species and vice versa. TEFs are based on experimental animal studies using males and females of several species.

The World Health Organization recently established TEFs for dioxin and some of the PCBs by weighting the results of various studies. Absorption data indicate that the human body contains approximately 7 ppt of dioxin (as TCDD), 30 ppt of furans, and 50–60 ppt of PCBs. Meanwhile, environmental exposure to dioxins and furans for humans is 1–3 picograms per kilogram (pg/kg) of body weight per day. If PCBs are added, the total absorption of this family of chemicals comes to 3–6 pg/kg of body weight per day.

Katsi Cook-Barrero, a traditional Mohawk midwife (Wolf Clan), spoke about populations that have a much higher-than-average exposure to environmental contaminants, including subsistence fishermen, minority communities, Native Americans, and, particularly, nursing infants, who are exposed to toxicants 10 to 40 times more than average for a short period of time (depending on how long they nurse). The infants' rapid development and their position at the top of the food web place them in an especially sensitive position. Fish, dairy products, and beef are approximately equal sources of environmental contaminants in the U.S. diet. Research

suggests that the body burden in the general U.S. population is already at or near the level where adverse effects would be expected to occur.

Indigenous societies are in a unique position, because they are often encouraged to change or eliminate their traditions based on scientific findings. For example, a Native American community may accept the advisories not to eat fish; yet, fishing has always been their way of life, and fish have always been a major part of their diet, as well as a key part of their ceremonies. Therefore, complying with the fish advisories contributes to a decline in the collective ability of the Native American community to transmit Native American culture from generation to generation.

The St. Regis Mohawk Nation at Akwesasne, located on the U.S.-Canadian border in New York State, serves as an example. The community of 10,000 is situated on 38,000 acres of land along the Saint Lawrence River. Less than 100 feet to the west of Akwesasne, and within 1,000 yards of several Mohawk homes, is the General Motors Corporation Central Foundry Division, which is an inactive hazardous waste site. This site is included on the EPA NPL as a Superfund toxic waste site and is also listed on the New York State Department of Environmental Conservation's (NYSDEC) registry of inactive hazardous waste disposal sites as a Class 2 site, which means that it poses a significant threat to the public health and environment. For 25 years, sludge from the wastewater treatment system of this facility was contaminated with PCBs and disposed of in several lagoons and landfills on the property. Onsite soil and sludge samples contain up to 4 percent PCBs, and significant offsite migration has contaminated nearby sections of the St. Lawrence River and its tributaries. Some soil samples collected near a landfill contained more than 50,000 parts per million (ppm) PCBs, a level 1,000 times higher than that defining PCB-contaminated soil.

Also upstream from Akwesasne are the aluminum-processing facilities of Reynolds Metals, Inc., and ALCOA. These corporations have served as further sources of PCB contamination (as well as of numerous other chemical contaminants). These sites have been declared inactive hazardous waste sites by NYSDEC and are identified as local point sources of PCB contamination. The enormous magnitude of this PCB pollution has resulted in NYSDEC declaring the sediments and surface waters of affected portions of the St. Lawrence, Grasse, and Racquette rivers as inactive hazardous waste sites as well. Superimposed on these regional concerns is the generalized pollution of the Great Lakes-St. Lawrence River Basin with organochlorine pesticides, methyl mercury, and numerous other contaminants.

This chemical contamination has had a profound impact on the lifestyle of the Mohawks, who are threatened by the progressive poisoning of their land, water, animals, fish, and plants. The traditions and land-based culture of the Mohawks emphasize the interdependence of humans and their environment; indeed, many residents depend on local fish, waterfowl, and wildlife for food. The admonition not to eat fish marks not simply a dietary restriction for the Mohawk people but a negation of much of the culture's meaning. Thus, the impact of environmental

deterioration, not only on public health, but also on traditional native culture at Akwesasne must not be underestimated or ignored by the scientific community. The process of assessing and managing risk must be changed to include the cost of the loss of culture and tradition.

Unfortunately, community interaction with epidemiologists, toxicologists, hydrogeologists, and other professionals has generated more questions than answers—including those regarding the surprise finding of the enormous extent of contamination on the reservation itself. The impact of this contamination became evident when the skin of the people who washed with water from a stream near the landfill turned the texture of an orange peel (that is, burned and reddened) and when a heavy black fluid came from water taps that were turned back on after having been shut off for a time.

When women in the community concerned about health effects, especially in children, pressed for answers as to the safety of their breast milk, a study was undertaken by scientists from the New York State Department of Health to test for chemical contaminants in the breast milk of nursing Mohawk women. The Mohawk women were found to have the same levels of contaminants as women elsewhere in the country (that is, 26 ppb). The interpretation of these results was that consumption of local fish had declined significantly over time among the Mohawks, attesting to the concern of the mothers about the potential health effects of the environmental contamination at Akwesasne.

A previous \$1.2-million health study had been conducted in the late 1970s by researchers from Mount Sinai Hospital in New York. During the study, scientists drew blood samples, had residents fill out questionnaires, and hired Mohawk field-workers. Conducting the study became difficult, however, in part because of a lack of understanding of the cultural differences between the Native Americans and the researchers. As a result of this experience, the Akwesasne Mohawk community adopted an informal code of ethics, requiring that scientists whom they invite into their community increase their cultural competence so their research involves more than just data collection.

The major reasons for the current successful relationship between the scientists from the State Department of Health and the Mohawk community are their willingness to learn from one another and their common understanding of several general and interrelated principles that are critical to cross-cultural communication between scientists and indigenous peoples.¹ An understanding of these interrelated principles

¹ See the 1994 article "Communicating With the Public on Issues of Science and Public Health," by Dr. David O. Carpenter (Dean, School of Public Health, State University of New York at Albany, II University Place, Suite 310, Albany, NY), the principal investigator in an NIEHS-funded study of the Akwesasne situation.

of trust, respect, empowerment, and equity must be taught on a large scale, involving governments, scientists, and communities, in order to achieve environmental justice.²

During the discussion period, an attendee asked about the time range of studies on dioxin exposure. Included in the response was a description of one of the largest poisonings, which occurred in Italy in 1976 when an herbicide-producing factory exploded, spraying the area with dioxin. This year a team from the United States and the University of Milan will examine women who were children at the time of the explosion; these women are now 25 to 40 years old. The researchers also intend to look at the children who were in utero at the time of the explosion. In another case, a 1979 explosion in Taiwan involved thousands of people. A team from Taiwan and NIEHS has followed the children extensively for the past 14 years. Now that the children are reaching puberty, the team is continuing the followup. A followup of the adults involved in the explosion is also underway.

Other exposed populations have been identified. For example, in several areas of the former Soviet Union, where herbicide-producing factories were located, some residents have chloracne. Some children in these communities have chloracne because their parents brought the contaminants home from work on their clothes or through prenatal exposure. A difference between the occupational data from the former Soviet Union and Eastern Europe and the United States is the distribution of men and women who were exposed. Because equal numbers of both sexes worked in the factories abroad, equal numbers were exposed. In the United States, the data mostly cover men.

A pending study will investigate reproductive outcomes among women in North Vietnam, where there was no chemical spraying during the Vietnam War, compared with women in South Vietnam, where there was. Finally, among American Indian populations, researchers have looked at four tribes along the Columbia River in the northwestern United States. Looking at the fish consumption data from that survey, scientists concluded that Native Americans consumed, on the average, nine times more fish than the general U.S. population. Some people may even consume as much as 100 times more fish than the general population. Plans are underway to investigate what chemicals are present in the fish the tribes eat and any possible adverse health effects.

One attendee objected to the calls of scientists for yet more studies, stressing instead the need to protect and train workers to minimize exposure. Another speaker pointed out that contamination is a global problem and that the key to protection is prevention. With dioxins and PCBs, the bottom line is to go to the root of their industrial source: the chlorine industry. At every stage in the industrial chlorine cycle, the generation, release, and dispersal of persistent and cumulative contaminants occurs. These technologies must be replaced by safer methods and processes.

² This is an addendum to the proceedings by the moderator of this breakout session, Karen Medville, a Ph.D. candidate in environmental toxicology at Cornell University.

BREAKOUT I

TITLE: ETHICAL ISSUES IN ENVIRONMENTAL HEALTH RESEARCH AND DATA COLLECTION

Christina Roessler of the University of Texas noted that the consensus of a recent meeting of physicians and scientists to discuss risk assessment, biomonitoring, and the ethics of community-based studies was that the results of studies often are negative; that is, they seem to show nothing. In many cases, lack of effect may be real, or, perhaps more often, it may be due to poor or inappropriate study design, insufficient involvement of the community, insensitivity of the analytical or research methods to the problem, or an overall lack of scientific or medical knowledge of the impact of a toxic agent on the human body.

Acknowledging these drawbacks in environmental health research, the panel raised several ethical issues:

- What are the ethics of studying communities based on the principle of cause and effect, when we know otherwise that the cause is too complicated to prove?
- Is it ethical to study communities that have been exposed to hazardous chemicals without providing health care as well? And, what actions do these studies trigger? Is it ethical to reach conclusions on the alleged damage to a community based on studies that are incomplete (e.g., do not include all data, site visits, or interviews with individuals who have been affected)?
- Finally, how much proof is necessary before a causal relationship between exposure to toxins and the onset of disease is an appropriate determination? What role should common sense play? Is it the responsibility of physicians and scientists to promote the concepts of prevention and safety with regard to the use of chemicals and technology?

The panel decided on a precautionary approach, similar to that of the United Nations Environmental Program's Governing Council, which stated that to avoid

irreparable harm to the environment and human health, precautionary action should be taken wherever it is acknowledged that a substance could cause harm, even in the absence of conclusive scientific proof.

The concerns raised by the panel were addressed through specific examples given by this breakout session's speakers and attendees. In one case, **Elinor Blake** of the California State Health Department spoke of the ethical concerns that arose for the department when it found high levels of dioxin, generated from a junkyard incinerator located near an apartment building, in a rural, largely Latino community in the Mojave Desert. The department, believing that people had the right to know how much dioxin, if any, they had absorbed, offered residents blood tests. As department employees began to think further about the study and talked to other researchers, however, they perceived disadvantages to community testing. For example, dioxin is extremely carcinogenic for animals, but specific outcomes for any one human cannot be predicted, even if the level of dioxin in a person's blood is known. The department therefore established communication channels with residents to let them know both the benefits and the drawbacks. Ultimately, of 63 eligible individuals, only 3 decided to have the dioxin blood test. Department employees decided against further testing because they did not see any benefits, concluding that the place and timing of the tests were not barriers to participation.

Another study described by **Ms. Roessler**, conducted in 1990 by ATSDR, investigated mortality and selected morbidity among Native American firefighters after an April 1980 fire at the Russet Chemical Company warehouse, a facility that stored pesticides and other chemicals. The study was initiated after the community expressed concern that exposure to chemicals had increased the incidence of cancer among firefighters. The agency examined 26 firefighters, aged 28–65 years (median age, 40), and, finding that none had a medical history of cancer, concluded that the fire had not affected cancer incidence. At the same time, however, the authors cited several problems with the study, including a very small sample size and a lack of knowledge of the type or concentration of chemicals involved in the fire; they also acknowledged that 10 years was too short a time in which to ascertain the development of occupational cancers and that they knew nothing about the health or occupational backgrounds or the behaviors of the firefighters. Thus, the paper may have incorrectly given the impression that the community had not been harmed.

Another discussion focused on a 1987 study of PCB contamination and exposure at a Superfund site in Massachusetts, which was a pilot State for ATSDR at the time. The agency's mandate from Congress was to collect available health information, which, for most health departments, translates into death certificates, birth certificates, and cancer registry data—the kind of data that departments routinely collect. However, working with these data, researchers are hard-pressed to prove harm from toxins unless the exposure is extraordinary.

Echoing other presentations, another presenter from west Dallas, TX, pointed out that his community, which has a 50-year-old lead smelter in addition to 15 other

plants and consists primarily of poor people of color, had become resistant to additional studies after receiving essentially no assistance or support after a chemical spill at an asphalt plant and the closing of the lead smelter plant. Further, the community is situated on a Superfund site. After noting a high incidence of seizures in children, young women who required hysterectomies, and small children with swollen joints, the community requested help, including a clinic that specializes in testing the blood lead level and treating lead poisoning. EPA has investigated the area but failed to identify any problems within the community.

During the discussion, attendees strongly recommended that government agencies change their approach to entering communities and the way they conduct studies or assess results. The bottom line was for government agencies to involve the members of the public at the beginning of a study to allow them to help with study design, place on the table the questions they want answered, and become involved with the study. Further, researchers conducting health studies should use the resources of the community—resident experts who know who has died, who has been sick, and over what time period. Resources must also be placed at the community level for the kind of preparatory work needed to introduce the community to a study and to honor community requests for input. Otherwise, the community may reject health research studies that are imposed on it from the outside.

Recommendations and topics for a research agenda were given:

- Examine existing informed consent procedures to see whether they should encompass full disclosure of the pros and cons of testing.
- Examine the impact of biomonitoring on the community; that is, study results as well as any subsequent effects on the community after tests have been done.
- Examine other social and behavioral study outcomes for change in behavior. In other words, what is the good of these tests? And what might be the harm?
- Develop a list of available tests that expands upon the partial list of the National Research Council, with an overview of previous projects and consent procedures.
- Track forthcoming projects.

An occupational health physician from Brown University offered these guidelines:

- Agencies that fund studies should copy the approach of NIOSH. Briefly, no NIOSH study can go forward unless the people who will be the study subjects approve the methods.

- Each agency should have two or three levels of community participation for research; that is, a local, elected, community-based review group comprising 50 percent residents; perhaps a similarly constituted regional review group; and a national advisory committee, comprising more than 50 percent community representatives elected at the local level to advise on national and local studies. No study would proceed without the approval of all three groups.
- Because scientists may abdicate responsibility for ethical issues in their work, each agency should develop a handbook for its scientists. In turn, each researcher should have to pass a test on his or her agency's ethical guidelines.
- Each agency should be required to assemble a handbook for community people on ethical issues in language that is clearly understandable; culture-, race-, ethnic-, and gender-sensitive; and in multiple languages, where appropriate.

Other suggestions and concerns expressed by attendees included the following:

- Develop new and easily understood definitions, as part of the work of the community in partnership with professionals.
- Provide background levels to give people a sense of the distribution of exposure.
- Strive for a goal of zero tolerance for any kind of contamination of the body.
- Increase educational efforts concerning use of agricultural chemicals in developing countries.
- Reverse the current top-down model, in which a hierarchy of scientist to community exists; at the very minimum, a partnership should be developed.
- Increase education and research efforts on preventing pollution and on learning more about the effects of chemical mixtures.
- Locate polluting industries in isolated areas far from communities.
- Require agencies to calculate a cumulative risk, so when an individual company asks for a permit, the agency considers all other companies currently in the community.
- Substitute the term "alternative assessment" for "risk assessment."

The following addition to the above session summarizes prepared remarks by Linda-Jo Schierow, currently with the Congressional Research Service of the Library of Congress, which she was unable to present because of winter weather.

Ms. Schierow had participated in a research project at the Massachusetts Institute of Technology to determine the causes of angry confrontations in communities facing environmental health problems. She reported that in most cases, government's failure to communicate with the community, especially during early stages, was important and was interpreted by the community as disrespect and secretiveness. Decisions that appeared insensitive also angered communities; for example, in Love Canal officials agreed to evaluate pregnant women and young children but not the rest of the family. Although agency personnel showed stress because their desire to protect their jobs and reputations were not recognized as legitimate by citizens, the supervisors needed to recognize that communities tend to be self-absorbed and to help administrative staff and researchers with their responsibilities.

Along with communications problems, conflicting interests and value judgments cause controversies. Strategies to avoid conflicts include better communication, empowerment of residents, empowerment of agency personnel, protection of the independence of research staff from political influence, and full consideration of all options during decisionmaking. In applying these strategies, certain conflicts and problems must be identified at each stage of a study. The study stages consist of hazard recognition, decision to monitor, design of monitoring, conduct of monitoring, evaluation of results, dissemination of results, decision whether to act, and action (or inaction).

BREAKOUT J

**TITLE: ENVIRONMENTAL HEALTH RESEARCH POLICY
ACTION AND NEEDS FOR TRIBAL GOVERNMENTS
AND INDIGENOUS PEOPLE: REGIONAL EXAMPLES
OF CONTAMINATION, HEALTH EFFECTS AND
STUDIES, AND ECONOMIC INCENTIVES THAT
LEAD TO POLLUTION**

Participants of this session declined to be recorded. Thus, there is no official record of the discussion of this breakout group.

BREAKOUT K

TITLE: OUTREACH AND ACCOUNTABILITY: WHAT CAN WE LEARN FROM ASTHMA?

Marie O'Neill of the Indoor Air Division of EPA described EPA's Indoor Air Program on asthma, which is designed to help communities prevent asthma through environmental controls. EPA packages this information in a variety of media—in curriculum, guidance documents, and training courses—for communities to use to prevent exposure to indoor pollutants. EPA also targets specific groups—for example, building operators, who determine the maintenance and design of ventilation systems or who choose products to be used in a building. Recently, EPA has increased its focus on asthma as a disease end point susceptible to indoor air pollution. At the Federal level, as part of the Healthy People 2000 agenda, EPA staff have met with staff from other agencies to get communities involved in preventing environmental exposures that are linked to asthma. This marks the early stages of EPA's asthma outreach.

Some useful tools have already been developed through the Indoor Air Program. EPA, with the Institute of Medicine, funded a recently released report on indoor allergens that included a research agenda and recommendations for action. Another report—a guidance document—gives homeowners advice on how to reduce exposure to indoor pollutants (e.g., combustion appliances and biological pollutants), and another new brochure focuses on secondhand smoke. Further, in January 1994 EPA released a risk assessment study that ties secondhand smoke to cancer and other injuries to children's health, particularly to the health of asthmatic children. As a result, many facilities, such as day care centers, have acted to reduce children's exposure to secondhand smoke.

EPA also has given funding to the ALA to develop a school-based curriculum for children with asthma (the open-airways curriculum) that has been piloted in several cities. The curriculum is being evaluated on its effectiveness in helping children manage their asthma and reduce their exposure to environmental triggers, such as parental smoking. In addition, the curriculum uses practical advice to reduce dependence on inhalers. Currently, EPA expects to work more closely with ALA to

expand the distribution of the curriculum, particularly to inner-city schools. Finally, EPA is developing a guide for schools to help them improve indoor air quality.

Dr. Sydney Parker noted that the National Heart, Lung, and Blood Institute (NHLBI) has a long track record of training and outreach programs and a strong history of working with underrepresented minority populations. Many of the lessons of working with underrepresented populations are outlined in a 1992 conference report, "Health Behavior Research in Minority Populations: Access, Design, and Implementation." Publications on career development programs and on NHLBI-supported minority outreach research and investigation give further information.

The National Asthma Education program, also promoted by NHLBI, has targeted its first public education effort at minorities, particularly African-American families. Radio spots and print ads are thus pointing out the warning signs of asthma and urging people to see a physician. NHLBI regularly broadcasts a 60-second health-beat radio spot, which focuses on heart, lung, and blood diseases.

Four years ago, Johns Hopkins University in Baltimore, MD, joined with Clergy United for Renewal of East Baltimore (CURE) under an NHLBI grant to reduce smoking in the community. **Dr. Francis Stillman** of Johns Hopkins and **Reverend Herbert Watson** described this collaboration. The East Baltimore catchment area has 150,000 people and 235 churches (all of which are represented in CURE). Eighty-one percent of the population are African American; 41 percent have a high school education; and 12 percent have a college education. The average age of residents is 31 years, and 36 percent of residents are at or below the poverty level. More than 65 percent of the community attend church. On the health front, a high proportion of the residents have heart disease and cancer. Moreover, about 40 percent of the residents smoke, and the rate is on the rise.

The project, called "Safe and Smoke-Free," reflects the reality of residents' lives and their concerns with more than just tobacco. Further, the project includes people who currently smoke. Direct approaches to ridding the city of tobacco use include lobbying for legislation to ban billboards and advertising that promote tobacco use. Members of the research project also visit homes to test air quality. A community health center run by CURE community health workers, with support from Johns Hopkins, provides day-to-day support within the community.

Funding for the project goes directly to CURE, which decides how monies will be spent. In this way, the community has shaped the study. The project has given some residents jobs and training, such as gathering information for the study and interviewing respondents on the street and by telephone. Both the clergy and the researchers have directly benefited. Because of the link with Johns Hopkins, the clergy has become more educated about environmental issues, thus strengthening the partnership. Similarly, researchers have gained access to and an increased sensitivity to the community through the clergy.

Also discussed at the session was a new set of collaborative projects on minority health that were funded last year by NHLBI. One group of investigators from Columbia University, Presbyterian Hospital, Harlem Hospital, and the graduate school of City University in New York has come together to determine the causes of excess morbidity from asthma in African-American and Latino populations in north Manhattan. The group plans to design interventions that reverse this phenomenon and is studying whether frequent use of the emergency room by a population of predominantly Latino children is associated with the absence of an adequate continuing relationship with a primary care provider, severity of the disease, lack of adequate medical therapy to follow asthma at home, or knowledge to use that therapy correctly. The researchers also will test the generally held assumption that specialty clinics provide the best care for adults with asthma. In addition, national and local data on two inner-city communities—one largely African American and the other Latino—will be used to determine the independent effects of poverty, race, and community disadvantages on the increase in morbidity from asthma in adults and children and to identify social, behavioral, environmental, and health service factors that are amenable to intervention. The final component of this research program will evaluate the efficacy of an asthma self-management intervention program, using a trained family coordinator in helping children ages 4–19 years manage asthma.

In another effort, the State of New Mexico has joined the New Mexico State Children's Medical Services in a study to evaluate the effects of a new statewide program to enhance the identification, referral, and provision of care to rural families of Hispanic and Native-American children with moderately severe to severe asthma. All counties have been randomly assigned to an experimental or a control condition, and the project is expected to identify at least 300 children with moderately severe asthma. The children will be referred to the University of New Mexico for initial consultation. In turn, university staff will work with local providers to follow the patients clinically, with patients returning periodically to the university over a 3-year period for evaluation.

Gaps in our understanding of the relationship between the environment and asthma can be filled only through well-designed basic epidemiologic, clinical, and educational research. An NHLBI task force cited the following needs:

- More population-based, clinical, epidemiological investigations of the etiology of asthma, including genetic and environmental causes, to characterize asthma patients.
- More long-term investigations into the impact of breastfeeding, aero-allergen avoidance, and reduction in passive smoking in infants at risk for asthma.
- Evaluations of the efficacy and cost-effectiveness of measures to reduce indoor air pollution to prevent asthma among older children and adults at risk for asthma.

- Long-term studies to determine the mechanisms by which smoking promotes allergic sensitization to occupational allergens and leads to increases in airway responsiveness.
- Population-based studies to determine the effects of specific pollutants on the induction and aggravation of bronchial hyperreactivity.
- Behavioral research on asthma, with more interventions to improve management, particularly in low-income adults, older families, and families with children under age 7 years.
- Studies on the use of the peak flow meter, a home monitoring device.
- Evaluation of model programs that use schools as the setting to assist children and families in managing asthma.
- Investigation into the effects of stress, emotions, and psychoneuro-immunology on asthma, particularly among high-stress urban populations.

During additional discussion, one attendee stressed the importance of prevention—namely, eliminating indoor and outdoor pollution—emphasizing that minority communities should not simply become better consumers of medical care and drugs. Translation of information on prevention into clinical practice also was discussed. For example, many clinicians want children with asthma to lead as normal lives as possible and, as a result, tell children to stay inside on high-pollution days. However, there are a lot of triggers for asthma, of which pollution is just one. Studies have identified at least two additional important risk factors for asthma—tobacco smoke and nitrogen dioxide (poorly heated and ventilated homes that use gas stoves for heat have high levels of nitrogen dioxide). Thus, control of potential triggers in the indoor environment, including tobacco smoke, is critical, especially if an asthmatic child is in the house. Communities can also participate in or lead efforts to control the outside environment (for example, shutting down a polluting factory).

The paucity of minority professionals trained in asthma research was discussed, and meeting participants were encouraged by one attendee to lobby Congress for more training for minority researchers. The questions that challenge Federal agencies include the following: (1) Should real community participation be required? (2) Should mechanisms be designed to evaluate community involvement in research programs? Answering these questions will require building an infrastructure to examine grant applications.

BREAKOUT L

TITLE: POLLUTION PREVENTION THROUGH ECONOMIC EMPOWERMENT

Elmer Chenault of EPA Region VIII said that the environmental legacy of the Federal government's mission has been felt throughout all the Nation's communities, particularly minority and low-income communities. The estimated annual cost of cleanup for Federal facilities alone in the country is more than \$400 billion, and the process most likely will extend into the next century. An EPA Region VIII investigation revealed that more than \$300 million for FY 1994 has been budgeted and funded for cleanup at Federal facilities; at least nine other regional offices have similar budgets. The EPA study discovered, however, that under the Installation Restoration Program, minority contractors had been excluded from cleanup activities.

Another study conducted in Brooklyn, NY, showed that for every dollar spent there, 80 cents was recirculated within the community. In contrast, every dollar spent in a wealthier nearby community generated \$8. That gap was larger than the income gap between the two communities. Thus, a core issue is control; that is, the control of the circulation of wealth within a community is as important as the income coming into it. Therefore, simply infusing dollars into low-income communities is not necessarily enough.

With this backdrop, the speakers at the breakout session noted that pollution is a symptom, and prevention addresses that symptom. In turn, community and economic empowerment represent long-term solutions. With these assumptions, it is possible to link the concept of community and economic development to "environmental racism," thus paving the way to understand why some communities lack the expertise and infrastructure to handle a cleanup. Balancing community activism with economic development is a tremendous—but necessary—challenge.

Dr. Curtina Mooreland-Young of Jackson State University noted that improving the overall economic and environmental status of communities and individuals is a high priority in Mississippi. According to the "Green Index," published by the Institute of Environmental Studies, Mississippi ranked 47th among all 50 States in terms of environmental health; 49th for premature environmental

deaths; and 50th on its congressional voting score on environmental issues. The State also has consistently ranked between 47th and 50th in per capita income. In addition, between 35 percent and 40 percent of the population are people of color, although the official figure may actually be higher. Some argue that, as a poor, minority State, Mississippi—with attributes and laws that tend to favor the location and practices of certain businesses—is a prime target for chemical industries and pollution.

At Jackson State University, a historically black university, officials have developed a three-pronged approach to solve the State's long-term problem through the empowerment of communities of people of color. A fundamental precept of the program is the reality of environmental injustice and racism. A primary goal is to educate practitioners of color who may someday, for example, lead EPA.

One prong of the university's program is student and faculty development. The university has developed two curricula: one in environmental management, planning, and policy, and a second in community and economic development. Both master's and doctoral degrees are offered. The two curricula are integrally linked: Students specializing in community and economic development must take environmental courses and vice versa. At the same time, faculty have tried to instill an ethic of service in students.

The second prong of the program centers on faculty and administrators. Efforts are focused on increasing the knowledge and changing the mindset of university faculty, who were not educated in the dual issues of environmental and economic justice and for whom these issues were not linked.

The third prong involves community outreach. Among the university's accomplishments is sponsorship of a congressional hearing on environmental health, economic development, and racism. The university also provided forums to link civil rights and environmental groups together, such as the Fannie Lou Hamer forums. Students and faculty are working with the Mississippi Black Caucus to help draft environmental justice legislation, are involved in a comparative risk project that includes economic and crime issues, and participate in outreach programs for students in middle schools in the poorest parts of Jackson, MS. Long-term efforts include developing mechanisms and action-oriented research toward sustainable development projects in Mississippi. The university is planning an environmental summit with grassroots organizations, hoping to develop a directory of State-based environmental groups as a resource guide. Funding for the program, which comes from HUD and EPA, supports a minimum of 20 students at the graduate level.

In another forum—a minority contract conference titled “Environmental Justice Through Economic Empowerment Workshop”—the issues of economic empowerment through pollution prevention were examined. The workshop, held in December 1993 after activist Tom Godwin asked EPA for help, was designed to attract minority contractors into the arena and to encourage these contractors to pursue Federal dollars

that were slated for cleanup projects; pollution prevention provides another opportunity for minority businesses.

Historically, minority contractors have not been awarded remediation jobs for a variety of reasons: no work history, inadequate bonding and insurance, and questionable capacity. In many cases, the reasons were justifiable enough, because the contractors had never been allowed to get jobs before—but this is a vicious cycle. Workshop speakers stressed that minority contractors need to get into the system, work with it, and learn how to win contracts. In Colorado, for example, minority business sectors, including the Asian, black, Hispanic, Indian, and women's sectors, united in an effort to break into the environmental cleanup business.

The economic empowerment workshop illustrated the crucial need for teamwork. Attendees included staff from EPA, the Air Force Center for Environmental Excellence, 16 prime contractors, 30 minority businesses, and 4 community leaders. Meeting participants addressed the Federal Facilities Compliance Act, which requires that individuals learn how to set up community planning and ombudsman programs. Attendees also focused on how to work together to overcome environmental problems, with each party presenting its own expectations and desires: Prime contractors were interested in sharing problems, whereas small businesses were interested in education and training to learn the system.

Initial 30-day evaluations disclosed that the prime contractors, who were the most pleased of all the attendees, were interested in identifying minority contractors. The workshop evaluation comments also indicated that prime contractors were looking for ways to help each other, to subcontract within the community, and to improve the overall process. A 3-month evaluation is planned.

The last speaker, **Dennis Livingston** of Baltimore, MD, stated that over the next few years, the Federal government will spend \$120 million per year for lead abatement. Yet, minority and other contractors in low-income communities continue to face barriers: difficulty in obtaining insurance, lack of sufficient capital and cash flow, and lack of contacts among the networks making contract decisions. Two ways to overcome these barriers would be to require municipalities to help build the capacity of community-based contractors by giving preference to local contractors and to help develop consortia of local contractors to share technical and business resources, space, capital equipment, and bulk purchasing.

Overall, according to **Mr. Livingston**, the environmental justice movement is one of the most exciting in decades because (1) it understands the balance between community economics and activism and between natural and human environments, (2) it can work with government agencies to keep money within communities, and (3) it is a movement of, and led by, people of color.

During the discussion, one speaker noted that "environmental justice" may be considered an elusive term; some view it as a topic involving the location of

hazardous wastes in communities of people of color, while others perceive it as involving the selective enforcement of environmental regulations in all communities. Still others see it as involving issues of economic development and empowerment.

An attendee from the University of Massachusetts at Lowell, who is working with the Toxic Use Reduction Institute, noted that toxic reduction may put some people out of business. Ironically, if toxic substances do not enter the environment, the need for the management or cleanup of such substances is eliminated.

The following suggestions were offered as means of achieving pollution prevention (not pollution control or cleanup) over a long period:

- Develop “sustainable” models to ensure jobs for environmental managers to protect our environmental legacy.
- Substitute toxic materials with nontoxic or less toxic agents (which also addresses the potential loss of jobs).
- Accept individual responsibility for stewardship of our environment.

One speaker reminded the audience that (1) in discussing pollution prevention, it is important to remember that workers, like communities, have much to contribute to dialogue about change and (2) cleanup workers must be protected. The absence of representatives from OSHA was noted.

An attendee asked about the best approach to training workers who do the actual cleanups. The bottom line, speakers noted, is that workers be trained as technicians and supervisors, not just as laborers. Simply put, minimally trained workers will remain laborers. Additional training offers opportunities for further advancement. Such training probably will be expensive, but communities should expect funding from the Federal government. It was noted that the total cost of a training program for 2 years is the same as the cost—\$300,000—for one 10-year jail sentence.

BREAKOUT M

TITLE: RADIATION EXPERIMENTS ON U.S. CITIZENS

The first speaker described the efforts of DOE Secretary Hazel O'Leary and others in the Clinton administration to open up the Department, halt any destruction of records, and provide access to previously secret information on nuclear tests, radioactive materials, and past illegal radiation experimentation. The President's Human Radiation Interagency Working Group was established in January 1994 to ask ethical and scientific questions, determine whether laws and regulations were violated and whether existing legislation is adequate to deal with these issues, give a full accounting, and consider possible types of compensation. There is concern, however, that disclosing the names of subjects or of their next of kin would constitute an invasion of privacy and add insult to the harm to which they have already been subjected.

The types of radiation experiments conducted on human subjects included effects on various organs, systems, and tumors, use of radioactive tracers to study biological processes, and dispersion of radiation through the biosphere after intentional release. Two particularly troubling aspects were the apparent lack of informed consent from subjects and the selection of subjects who were clearly vulnerable, including people of color, people with little education, patients who were already sick or dying, and pregnant women.

The Working Group's independent advisory committee is focusing on all radiation experiments conducted since 1944 that did not involve therapeutic or diagnostic uses of radiation. Its goal is to make recommendations on the adequacy of existing research guidelines, review experimental procedures, and provide advice concerning lapses in scientific and ethical standards. When a session participant asked if the committee would examine whether health care workers were adequately protected when dealing with radiation technologies, the speaker said that he would convey that concern.

The speaker noted that the first step is to obtain an overview of the problem. Persons who suspect that they or a family member were unwilling subjects in medical

or government experiments should phone 800-493-2998, which logged 1,000 calls per day in the first few weeks of operation.

The second speaker, a physician, said that his investigations of these unethical government-sponsored experiments have been impeded by government officials withholding information. He also said that the government's claim of protecting the victims' right to privacy is specious, since many victims and their families have requested their own medical records without success. In the case of a railroad porter whose injured leg was injected with plutonium, observed, and then amputated, the General Counsel of the DOD still holds the medical records requested by the family.

The speaker criticized the failure to use scientific principles and methods as well as the lack of informed consent. For example, the investigators in the case of the railroad porter did not know exactly what they had injected or how much, and they did not follow up on the subject. Experiments between 1940 and 1975 at the University of Cincinnati concerned with the health effects of wartime radiation on soldiers had similar flaws, used lethal, not therapeutic, doses of radiation on poor blacks with cancer, and killed at least eight people. Samples of new, untested isotopes were sent from the Oak Ridge, TN, research facility to Charity Hospital in New Orleans for injection into unknowing, indigent blacks.

Besides lack of true treatment for their disease, subjects were denied treatment for radiation-induced nausea and vomiting, and written instructions forbade nurses from asking about symptoms of nausea and diarrhea. In a truly scientific inquiry, such details would have been considered important.

Other issues raised by the speaker included the competence of current personnel to conduct these investigations; the past use of review boards whose members all had special interests; and the guilt that should be shared not only by government agencies, but by the universities that received funding, the journal staff and readers who did not object to the research when results were published, and the contractors who also destroyed records. The claim that the experiments were important for the purpose of learning how to protect workers is specious since the DOD and DOE still do a poor job of worker protection. Even today's researchers are not exempt from blame, because none have stepped forward to help investigate these cases.

Participants mentioned other concerns about the routine releases of radiation into the environment at the Savannah River nuclear site in South Carolina; the need to follow up veterans who were exposed to atomic bomb testing; and the current lack of adequate protection for workers cleaning nuclear weapons production sites. They were told that 250,000 soldiers, sailors, and residents of the Marshall Islands will be studied and that they should file Freedom of Information Act requests to obtain health and personnel records of friends and family possibly involved in suspect incidents and procedures.

Participants showed a great deal of emotional upset throughout this session, about past experimentation, alleged continuing coverup, and lack of cooperation by offices and staff of the Federal government.

In closing, the first speaker commented that beyond dealing with the shock that these experiments even occurred comes the important task of making sure it never happens again.

BREAKOUT N

TITLE: ENVIRONMENTAL AND OCCUPATIONAL HEALTH RESEARCH NEEDS TO ELIMINATE RESPIRATORY DISEASE

Dr. Diane Gold of Brigham and Women's Hospital discussed three types of respiratory diseases that disproportionately affect people of color or the socioeconomically disadvantaged—lung cancer, tuberculosis (TB), and asthma. Lung cancer causes nearly a quarter of all cancer deaths and is attributable mainly to cigarette smoking; its rates are down for white males, but not for white females or black males and females. Furthermore, tobacco advertising targets the disadvantaged, and occupational exposures are likely to be important although data on these exposures are too few to be sure.

TB, which has always had a high incidence among socioeconomically disadvantaged people and is nearly 50 percent fatal when untreated, decreased steadily in the United States until 1985, then rose in association with HIV infection and the increase in multiple-drug resistant TB. Prevention and detection are crucial, requiring intense efforts.

With rates increasing, asthma affects 10 million to 20 million persons in the United States, including more women than men. Blacks are affected more than whites and Hispanics. Related factors include cigarette smoking, low birthweight, a large family, small house size, scant maternal education, residence with only one parent, and extreme poverty. Since outdoor air pollution does not differ among groups with different asthma rates, indoor factors need more study.

David Coultas of the University of New Mexico said that it is important to know how environmental agents interact and how to intervene to prevent lung diseases, such as by eliminating certain exposures. Major risk factors for minorities include cigarette smoking, indoor and outdoor air pollution, and occupation, such as laborer and farmer. Minorities are also likely to have greater exposure to dust, fumes, and other pollutants than persons working in managerial and professional areas.

In the 1989-1993 survey that **Mr. Coultas** conducted of nonmalignant lung diseases among Southwestern miners, a higher rate (14 percent) of silicosis (a totally preventable disease) was found in Native American miners, compared with 7 percent in non-Hispanic whites and 6 percent in Hispanics. Native Americans, who had worked as miners for more than 20 years, had a greater incidence (28 percent). Copper mining, open pit mining, and potash mining increased the risks. Ongoing surveillance of workers is needed to detect early disease and prevent deaths.

Dr. Peyton Eggleston of Johns Hopkins University described a national cooperative asthma study of eight inner-city sites begun by NIAID to assess why asthma problems are rising among inner-city poor black and Hispanic children and to test interventions. Potential causative factors include inadequate medical care, stress, intrinsic problems of the affected population, and environmental exposures. Children's exposure to cigarettes will be measured by detecting cotinine, a breakdown product of nicotine, and through a questionnaire on smoking at home. Nitrogen dioxide, an irritant from excessive burning of gas stoves and kerosene (for instance, as heating supplements), is also being monitored in the children's homes and appears to precipitate asthma attacks.

When looking for differences between poor and middle-class homes regarding the presence of allergens from cockroaches, dust mites, and cats, the major difference was elevated cockroach antigen in many of the poorer homes. Since this factor seems to cause increased daily symptoms and emergency room visits, **Dr. Eggleston** recommended focusing the study's intervention phase on cockroach eradication to ease asthma symptoms. The intervention phase will use a model called "Case Management by an Asthma Advocate."

During the discussion, it was pointed out that studies of genetic factors and interventions to correct poorly constructed housing are beyond the scope of this project and that there is evidence that removing a child with asthma from his or her environment can result in improvement.

BREAKOUT O

TITLE: ENVIRONMENTAL AND OCCUPATIONAL HEALTH RESEARCH NEEDS TO ELIMINATE PESTICIDE EXPOSURE PROBLEMS (AND COMMUNITY ISSUES)¹

A Hispanic woman told of working in California for many years in the presence of pesticides without ever seeing a warning label. In 1986 she worked on the same farm where 96 persons were poisoned by pesticide spray after they had been told to enter a field while a plane was spraying pesticides or else they would lose their jobs. Despite publicity about the poisonings, the system has not changed. The farm's owner has connections to the governor. The speaker, who views U.S. Federal agencies as worse than those of Mexico, made available an article she had helped research on the problems of the farmworkers.

Dr. Angus Wright of California State University-Sacramento then spoke about farmworkers and pesticides, suggesting some research ideas and taking into consideration the back-and-forth movement of peoples between Mezo-America and the United States. These farmworkers suffer from so many health, economic, and social problems that they rarely describe pesticides as their number-one health problem. Pesticide studies that presume the subject is otherwise healthy have little applicability to this situation.

The United States needs to recognize that the number of migrant farmworkers is rising. While the signing of the NAFTA presents an opportunity to research transborder life and health issues, farmworkers will never be fully protected except by developing organizational strength. Other factors that may help are to develop a healthy agriculture based on policies for increasing safety and reducing pesticide use and to adopt crop strategies that permit employment of workers on a permanent, rather than seasonal basis. Organic agricultural operations, in particular, are employing permanent workers. The health of these

¹ The second tape identified as recording this session deals with community issues unrelated to pesticide exposure, the official topic of this session.

workers could be compared with that of the migrant workers. (One participant suggested that the government help maintain farmers and farmworkers during a 3-year transition period to organic farming.)

Dr. Wright urged health researchers to acquire a greater understanding of political realities. As an example, when researchers looking for areas of greatest agricultural risk pinpointed areas with high reports of pesticide poisonings, those areas turned out to be ones where organized labor unions were making sure that the reports were made.

Martha Moreno of the Committee on Agriculture in California described frequent spraying of excessive amounts of pesticides and other chemicals on grapes and dates and reported on several incidents in which women showed direct effects, such as fainting, and were not given proper care. She knows also of human miscarriages and deformed chicks. She asked for better inspections, enforcement of correct spraying and materials handling, and availability of basic hygienic care. She fully expects to be fired because of her activism.

Comments during the discussion included a recommendation to advocate organic farming, while remaining aware that farmworkers can be exploited there, too; a reminder that farmworkers are exposed to greater levels of chemicals than consumers; and a plea to work for political power rather than relying on scientific proof of problems. One professor of agricultural medicine termed farming the most dangerous occupation in the United States, with pesticide poisoning ranking 10th among causes of immediate farm deaths. He recommended including chronic disease to change the ranking for pesticides. He also cautioned that researchers can lose their objectivity, whether or not they work for chemical companies.

Other discussants asked (1) for a model of agriculture that does not exploit people; (2) whether community members should validate their own suspicions by looking into the health system to find a pattern that physicians and hospitals do not recognize; and (3) whether a community-based system is sustainable in the face of economically targeted investors. One suggestion was to use scientific information as a political tool and health as a moral issue.

A participant then reported that the statistics concerning pesticides as a cause of death are much worse for farmworkers than for farmers and said that 5 to 13 percent of workers have been reported clinically poisoned in various examples. There is also evidence of chronic neurologic effects. Furthermore, reports on mortality can misdiagnose causes; in a Philippine study, deaths related to organophosphate pesticides were attributed to strokes.

Sylvia Herrera, a participant in People Organized for the Defense of Earth and Her Resources (PODER) in Austin, TX, described how this organization became involved in two community issues and also mentioned its aim of dialoguing with high-tech companies about potential problems and why local

people were not winning jobs in the industry.² Her own involvement started with reading a public notice about the potential expansion of an oil company facility. Concerned about emissions, PODER organized the community, gathering information (such as data on prevailing winds), encouraging publicity, and insisting on a cumulative look at the emissions from all sources in the area. PODER discovered and began to monitor lead contamination as well.

The county government and the State health department provided some cooperation, but the city, including the fire department, initially presented impediments. The Federal government did not provide assistance except for a 70-page EPA report. Even the way the Federal government provided data on cancer incidence was not helpful. The community is still trying to get a handle on the health effects. However, a research team from the University of Texas Medical Branch was of little help except for doing some tests.

Eventually, all the oil companies shut down their facilities. The last one, Exxon, did so only after an extensive PODER campaign. The companies should have provided public notification and buffer zones from the outset. PODER is still in litigation to recover property damages and because the remediation process was unsatisfactory.

Noise pollution and concerns about electromagnetic fields from the oldest local power plant led PODER to participate in another community effort, establishing a citizens' monitoring committee, preparing brochures, and working with city and county employees.

The next subject discussed at this session involved issues relating to lead levels in Alameda County, CA. Concerned about tests showing high lead levels in the environment and lead poisoning in 60 percent of 500 children tested, PUEBLO, an Oakland community group, succeeded in getting the local cities and county to set up a benefit assessment district, in which every home built before 1978 is assessed \$10 per year.

Steve Schwartzberg of Alameda County's Lead Pollution Prevention Program discussed additional issues involving lead, plus another issue in which the government appeared to use lead as a distraction. In the case of a park (built on an old battery manufacturing site) with "yellow ooze," which was later identified as arsenic and zinc, the city concentrated on lead pollution, possibly to avoid the potentially more serious problems of arsenic and zinc. However, the blood tests to measure lead levels of community children were not scheduled until a time when the lead would have cleared the bloodstream and moved into the children's bones.

Besides remediation of the park, supervised by Oakland's environmental health department, positive steps include enlisting an outreach worker to hire

² As noted earlier, the rest of this session does not deal with pesticide exposure.

six local persons to conduct door-to-door interviews. The interviews will serve as a tool to enter the homes in order to refer people to community services such as prenatal care clinics.

The high level of lead in the houses, soil, and ambient dust that occurs in the area is illustrated by the results of environmental samples taken from the play area of a school near this park. Lead levels of 2,000 to 6,500 ppm were discovered, indicating conditions 100 times worse than those in the park. The children in day care who use the play area need to be supervised for careful handwashing before they eat.

A California Proposition 65 lawsuit against the importers of leaded pottery and tableware has led to a settlement fund that is supporting a conference of Latino leaders to help alert the community to the dangers of leaded pottery. Some cultural sensitivity is being shown by having the government sponsor stay in the background. However, one plan for publicity may not work because the planned ad resembles a ploy sometimes used by the Immigration and Naturalization Service.

BREAKOUT P

TITLE: HOW TO CONDUCT COMMUNITY-BASED HEALTH SURVEYS

Carol Roos, a school social worker, reported on a Tucson, AZ, community study that revealed a high rate of cancer in children and adults exposed to trichloroethylene (TCE) through the water supply. The first step was when she noticed that several school children had the same rare type of cancer. Another crucial step came when reporter Jane Kay recognized that the disease incidence could be linked to TCE from an old aircraft-cleaning facility that was seeping into a local aquifer, a major community water source.

A specialist from NCI helped with an exposure study that revealed various cancer cases and a testicular cancer rate 6.7 times that expected. Despite a 30-mile spread of the TCE plume, the health department was uncooperative. A class action suit against the U.S. Air Force, Hughes Aircraft, and the City of Tucson, including its airport authority, was needed to produce a cleanup.

A woman from the Environmental Health Network added that the network could help prepare communities to do their own environmental studies by assisting them with training, surveys, registries, and workshop development.

Antonio Diaz of PODER, a community organization in east Austin, TX, reported on work done by people of color on environmental issues in that community, including their detection of health effects linked to a tank farm and a power plant. Tests detecting contaminants in the air, water, and soil and anecdotal reports of health effects in the neighborhood of a tank farm led PODER to use health questionnaires in affected neighborhoods. Besides gathering information, the questionnaires served as an instructional tool. Eventually, all six oil companies having tank farms in the area agreed to move out and remediate by cleaning up the ground water.

Concerns about whether a nearby power plant also had adverse health effects led PODER, with others, to conduct a survey within three blocks of the power plant, using a questionnaire on health problems. The health problems

that were identified potentially correlated with proximity to the power plant. Eventually, the city announced it would close the power plant within 2 years.

A current PODER concern is the growth of the electronics industry in east Austin. PODER's overall focus is helping to find safe alternatives to hazardous conditions, for which it wants EPA's help.

Subjects mentioned during the discussion included the usefulness to communities of disease registries, the failure of government to support disease registries and include community assistance in its epidemiological studies, and the dearth of physicians trained in public health.

A disagreement arose as to whether ATSDR has the authority to support community health clinics, but general agreement was reached on the need for community clinics and for better health care for people living near Superfund sites.

At the end of the session when one participant protested that the session subject, how to conduct health surveys, had been neglected; another participant offered to provide information to him.

BREAKOUT Q

**TITLE: ENVIRONMENTAL HEALTH RESEARCH POLICY
ACTION AND NEEDS FOR TRIBAL GOVERNMENTS
AND INDIGENOUS PEOPLE: SETTING STANDARDS
AND ADDRESSING INSTITUTIONAL BARRIERS
WITHIN AND OUTSIDE TRIBAL GOVERNMENTS**

According to the tape record, no discussion was convened at this session.

BREAKOUT R

TITLE: RIGHT TO UNDERSTAND AND RIGHT TO ACT: EFFECTIVE RISK COMMUNICATION AND WORKER TRAINING (FOCUSING ON WORKERS' RIGHTS)

Michele Gonzales Arroyo of the Berkeley, CA, Labor Occupational Health Program (LOHP) spoke of the importance of providing health and safety training in a format that workers who deal with hazardous wastes could understand. Realizing that many workers have difficulty reading and writing, LOHP, with NIEHS support, explored how to link literacy with health and safety training. From talking with workers enrolled in literacy programs, LOHP first learned that most were not immigrants but had grown up in the United States and had attended high school and even, in some cases, community college.

The suggestions of the workers included that trainers go to job sites and ask workers about what topics to cover, what educational materials to use, and preferred training approaches. They also suggested that written materials be easy to read and visually appealing and that workers be asked to do periodic evaluations of training programs. Consequently, LOHP developed visual aids, such as a diagrammed T-shirt and local risk maps, and games for tasks such as reviewing Department of Transportation labels.

Ms. Arroyo stressed in summary that outreach to involve workers or a local community is crucial and that technical information can be taught without complete reliance on reading and writing.

The next speaker, a labor activist and representative of the OCAW then stated that his main message is that the power to ensure environmental safety and health lies within the communities and the workforce together. When he trains workers for occupations in the environmental sector, he tries to include community members as well. Within small groups, a real exchange of information can take place, and community members, as well as workers, can learn about safety and health and their rights.

The speaker also pointed out that industries are playing "toxic roulette" when they do not inform workers and community members of the dangers; that

OSHA is only as effective as its enforcement; and that simply moving toxic dumps to new sites is not a good solution.

A session participant who represented Communities Concerned About Corporations, a coalition of 90 local groups from across the country, stressed that the power of corporations is the real issue, rather than specifics about how to improve environmental safety and health, and that nothing will change until workers are educated and organized into democratic trade unions that are responsive to the community.

Alluding to a worker who was unknowingly exposed to toxins in a Haitian shoe factory, another participant emphasized the importance of educating people who are just entering the workforce so they will understand their rights. Someone else pointed out that workers in the public sector need safety training, too; another discussant noted that worker training programs frequently fail to explain OSHA's right-to-know regulation. This person proposed educating management about the savings involved in good training, which lowers medical costs, workers' compensation, and turnover rates.

Also mentioned during the discussion were the advantage of having strong family and community ties, as immigrants do; the possibility of using environmental safety issues as a vehicle for advancing occupational issues; the need for communities to understand that local production facilities must be improved to remove toxins from their environment; the necessity of involving OSHA in conferences like this one, especially when its standards are considered 10 times less strict than EPA's; and the possibility that communities resistant to labor unions may be willing to accept safety training as long as the word "union" is avoided.

BREAKOUT S

TITLE: MODELS FOR ACADEMIC RESEARCHERS AND INSTITUTIONS TO PROMOTE COMMUNITY PARTICIPATION

The moderator proposed that research partnerships focus on health problems and that research include the interests of the community. Then, **Grover Hankins** of the law school at Texas Southern University and previously a Federal government lawyer, mentioned his past involvement in a suit that led to lower lead level standards for the States to use in determining acceptable exposures. He is now seeking funds to mobilize a team of experts and activists to work for environmental justice.

A current case shows how he would like to conduct his studies. Community members are suing a foam rubber plant in Odessa, TX, whose emissions—including styrene, benzene, and toluene—usually blow toward a minority community that has many health problems. When previous lawyers, who would have received 40 percent of the settlement, wanted the community to settle the nuisance part of their lawsuit without considering the adverse health effects, **Mr. Hankins** became involved. If funds can be obtained, **Mr. Hankins** already has four institutions willing to cooperate on a health effects study and community members who are ready to be trained to do a survey. Other community members are likely to accept a new one-page survey as opposed to the eight-page document the previous lawyers could not get people to respond to.

Dr. Beverly Wright of the Deep South Center for Environmental Justice at Xavier University described the center as a consortium of four universities that is guided by a board composed of university and community representatives. The project was a mutual university-community arrangement from the beginning and was developed by 22 people at a 2-day meeting. Besides research, the center's mandate includes environmental education. The funds that are raised are split between the universities and the community. Currently, the center has some private foundation support and two research projects, which are funded through the Environmental Equity Office of EPA. One project is to develop a means of communication to gain the trust of communities that do not trust EPA.

An example of the problems of trust can be found in a community near New Orleans that was built on a landfill. One Federal study reported no problem; however, the community only recently learned (through an anonymous contact) of a 5-year-old ATSDR study that disclosed problems, such as high lead levels in the soil. Although **Dr. Wright's** center has facilitated meetings between EPA and the community, how can there be trust when Federal agencies have known for 8 years that the people were living on top of a hazardous landfill that catches fire in the summertime?

Dr. Wright also mentioned that Texas Southern University has a useful resource, a federally funded center of toxicologists, epidemiologists, and others with the expertise needed to conduct research and quickly provide health test results.

The Xavier Center would like to expand beyond its two-person staff and conduct training but has not received the needed grants. **Dr. Wright** observed that universities seem to be favored to get grants and also noted that anyone interested in applying for a grant should realize that since environmental equity counts seven points in the scoring, developing a citizens' advisory board would give an application seven additional points.

When one session participant asked how to interest her university in advocacy, the suggestion was made to involve not just the university's leadership but also students, through fellowships and internships. Stressing community service is another approach. One way to get started in community work is to contact the NAACP.

Other discussion topics included the following: the gap between physical and social scientists, with the former likely to behave arrogantly; the usefulness of approaching a community through the social worker model, stressing community needs rather than one's own agenda; the need to involve local health departments in delivering services; and suspicions about scientists not doing promised research and State governments favoring industry.

BREAKOUT T

TITLE: MODELS FOR LOCAL AND STATE GOVERNMENTS TO PROMOTE COMMUNITY PARTICIPATION IN ENVIRONMENTAL HEALTH EDUCATION FOR ELECTED OFFICIALS

Steven Schwartzberg, M.P.H., Director of the Alameda County, CA, Lead Pollution Prevention Program, emphasized involving the community in the planning process of environmental health education and taking a broad view, instead of concentrating only on lead poisoning or any other single concern. A special aspect of his program is that it combines housing and health staffs. At first, in his example, community education and involvement were neglected. The problem concerned a yellow powder seeping out of cracks in the basketball court at a park in east Oakland built on the former site of a battery manufacturer.

Although tests eventually showed the powder to be arsenic and zinc, the city aroused the community by claiming the presence of lead in the park. **Mr. Schwartzberg** found this ironic because lead-contaminated housing is a much more serious problem in Oakland. When blood lead levels of children from a nearby school were measured to check for possible lead exposure from the park, delays in testing made any tie to the park meaningless. The levels detected were in the normal range for all but 6 of 626 children tested. For those six, the problem turned out to be high lead levels in their homes. An irony is that a school play yard near the park had 100 times the lead level of the park.

Some more recent positive steps are that the city is paying to train 15 to 20 community people to work on remediation of the park, other community persons will do door-to-door interviews regarding lead in the community and access to health care, and the community will form a health and environmental safety committee that will be a resource and teacher on community needs. **Mr. Schwartzberg** hopes to replicate this process elsewhere.

BREAKOUT U

TITLE: CHILDREN AS SENSITIVE POPULATIONS: RESEARCH NEEDS

Dr. Joan Cranmer of the University of Arkansas Medical School addressed how toxic materials affect children, from embryo through adolescent. Many chemicals cross from mother to fetus through the placenta, especially low-molecular-weight and lipophilic materials, and the fetus lacks detoxifying enzymes and ways to excrete toxins. The rapidly multiplying fetal cells, including brain cells, are targets for toxins. Damage can include malformations, overall growth retardation, fetal death, and subtle functional and behavioral changes evident only after birth.

Children are likely to receive greater toxic exposures than adults because of their higher respiration rates and proportionally greater surface areas and intakes of fluids and food. Furthermore, their barriers to toxic absorption and detoxification systems are still not fully developed. Some are exposed to pesticides when accompanying their farmworker parents to the fields.

The three body systems most at risk from toxic exposure—nervous, immune, and endocrine—initially compensate for the exposure, with latent effects manifesting later. In **Dr. Cranmer's** research on methyl mercury exposure in fetal rats, a silent toxicity occurred: The exposure caused the rat brain tissue to develop less dense than normal. This damage showed up only much later in life when the symptoms of degenerative diseases appeared in the aging adult rat. Similarly, in one human population that ate a great deal of fish containing mercury, the children appeared all right, but older members of the group showed problems.

The list of chemicals (including estrogenic pesticides) known to affect the endocrine system is growing, as are rates of breast and uterine disease, infertility, miscarriage, and premature puberty. The rates of neurodegenerative disorders are also increasing.

When session participants asked about testing farmworkers and their children before and after pesticide exposure, the speaker said that such

monitoring, which is required but not implemented, would show only the effects of low-level exposure whereas high-level exposure is the issue. Furthermore, 20 years ago, scientists predicted what is happening now.

The conditions for conducting research are another problem: Usually, as with the pediatric research grants available now, no provision exists for fixing the problem once the study is completed—such as by education or prevention of exposure, addressed in a culturally sensitive way. A farmworker in the audience corroborated that there was no help for her after she was studied for toxic exposure. Participants agreed strongly that research must include helping affected persons and giving them a voice in how research money is spent.

Joy Carlson, M.P.H., Director of the Children's Environmental Health Network (CEHN) in Emeryville, CA, told how this national network was formed 1 year ago to meet the need for data on other toxic exposure besides lead poisoning in children and for emphasizing the field of pediatric environmental health. Last year CEHN and NIEHS held the first national workshop on pediatric environmental health research.

Two needs are medical training in pediatric environmental health and special regulations on toxic exposure in children. One approach is to work toward including on medical board examinations questions concerning environmental exposures in children, because medical schools would then be more likely to teach the subject, for which a curriculum is available.

CEHN wants to make environmental health a part of primary health care and to change research from focusing on the cellular effects of toxic exposure to targeting pollution prevention technology and land use planning. The environmental justice movement could help by encouraging research and training collaborations between medical researchers and environmental scientists.

BREAKOUT V

TITLE: POLLUTION PREVENTION AND INTERVENTION: THE ELECTRONIC INDUSTRY GOOD NEIGHBOR CAMPAIGN: THE ACCOUNTABILITY MEASURE FOR SEMATECH AND OTHER SEMICONDUCTOR INDUSTRIES¹

Focusing on ways to clean a house, particularly to rid it of lead, session participants considered the use of water and trisodium phosphate (TSP). Participants also looked at problems with limited research and education on cleaning methods and outright misinformation from government officials. One experienced attendee preferred scrubbing well with pure water to using TSP. Clean rags should be used for rinsing, and rags and mop heads should be discarded. Use of squeegees is undesirable because contaminants remain in the sponge. Concerns about TSP included the fact that it is a corrosive material and that using phosphates can damage waterways.

Regarding research on cleanup methods, an attendee faulted one existing study for unrealistically testing solvents on stainless steel, which is not a major component of homes. Regarding education, one parent reported having been given the impractical advice to damp-mop her house daily—a difficult task for a nursing mother with toddlers. Someone else agreed that this advice was an impossible burden and called it a “blame the victim” strategy.

A mother with a 10-month-old infant who had high blood lead levels recounted a tale of bad advice from a State official who told her to use a heat gun and abate the problem herself. Because the advice did not include a warning to contain the lead dust caused by using the heat gun, the result turned out to be higher lead levels in the house and the infant.

Attendees wanted to provide this session’s information to the conference’s core groups.

¹ Only a fragment of this session was recorded on the session’s tape.

BREAKOUT W

TITLE: RESEARCH NEEDS TO ADDRESS MULTIPLE RISK FACTORS

Contrasting the “Eurocentric” view, which tries to identify the effects of each single toxic chemical, with the holistic Native American view, the first speaker declared that our system will have to change, because the knowledge we are gaining about multiple toxic chemicals is on a collision course with our environmental laws, regulations, and policies that focus on single chemicals.

The speaker said the term “multiple exposures” includes exposure to (1) mixtures of chemicals; (2) multiple chemicals that all target a single receptor or system; (3) chemicals entering by multiple routes, e.g., inhalation and ingestion; (4) toxic chemicals that worsen the existing burden of chemicals the body is already carrying; and (5) anything new affecting someone who already has a compromised immune system as a result of a medical condition, the use of drugs, or previous exposure to toxic chemicals.

Several approaches contribute to the current, single-chemical view. Risk assessment studies are done one chemical at a time. Thus, instead of phasing out all chlorine-containing chemicals, EPA prefers to “ban, cancel, or suspend specific chlorinated compounds that exert a deleterious and widespread environmental impact.” Moreover, proof is needed of a cause-and-effect relationship between a single chemical and a single health effect before action can be taken. Thus, the evidence that dioxin in Columbia River fish interacts with other substances and kills bald eagles has not led to action to help the Native Americans nearby, who eat 15 times the amount of fish that was used in the dioxin study.

Further, the requirement that a single “bad” chemical must be identified before any action is taken against a hazardous substance leads to such situations as the inability to ban the herbicide 2,4-D, since its association with cancer might be attributable to other chemicals present in small amounts in this herbicide preparation or to other chemicals the subjects had been exposed to throughout their lives. Yet, risk assessment studies assume that the people who

are being studied start off as clean, healthy organisms, an unrealistic assumption.

Instead, we must base our policies on the broad reduction of the use of toxins that will potentially affect our health. These policies would lead to laws reducing the use of toxins, particularly pesticides, and to mandatory recovery plans. We must also recognize that because of differences in biological susceptibility and in previous toxic exposures, we can never know how much of a given chemical is safe.

Rather than risk assessments, we should conduct mandatory alternative assessments for the least possible discharge of toxins into the environment, asking which technological, social, and economic options avoid the use of toxins. Examples include closed-loop production processes, total removal of previously deposited toxics, and banning the production of toxic wastes. Research must find ways to protect people from toxins that remain in the environment.

Before participating in research, communities affected by environmental toxins should find out whether any action will be taken to help the community if environmental damage is found. Research should not serve as an excuse to delay action, and researchers must take more responsibility for preventing exploitation of study participants.

The second speaker's thesis was that studies are needed on the role of environmental factors in the development of asthma. She described asthma as a multifactorial disease, saying that children with asthma who are poor are more vulnerable to air pollution and other environmental insults than children with asthma of other socioeconomic backgrounds and that it is difficult to distinguish environmental contributors to asthma from other risk factors.

Millions of people are affected by asthma (the most common chronic respiratory disease), including 15 percent of all children. Billions of dollars are spent each year on health care related to asthma, with nearly half spent on indirect costs, such as days missed from school or work and premature mortality.

Both morbidity and mortality rates for asthma are increasing worldwide for white and black females and black males, with blacks having an overall mortality three times higher than whites. Air pollution (ozone, sulfur dioxide, aerosols, and particulate matter) is definitely associated with symptom worsening. Children are more vulnerable to these effects than adults because children spend more time outside, are more active, and are more likely to breathe through their mouths, bypassing nasal screening mechanisms.

The reasons that poor people are more vulnerable to asthma, although not fully understood, are likely to include episodic health care; limited health education about asthma; use of gas, kerosene, or wood stoves for cooking and heating; exposure to mold, dust, and cockroaches; and lack of air conditioning to ease symptoms.

Session participants noted that black communities are concerned about the causes of asthma; every player on many urban Little League teams has asthma; CDC research in Los Angeles showed a clear relationship between ozone levels and symptom severity in children; and as asthma increases, the factor that has changed over time is air pollution. One participant speculated that the difference in incidence between blacks and whites might be attributable to the fact that so many blacks live in urban, air-polluted areas.

The third speaker, an environmental engineer for EPA, described how the engineers and technicians who were EPA's first employees in 1970 turned to technology to clean up the water and the air. They were not helped by health departments because the medical professionals who ran those departments were not interested and had no training in environmental health. Now the removal of the last 5 to 10 percent of heavy pollutants will cost the same as did the removal of the initial 90 percent.

During general discussion, one session participant emphasized how poor people and people of color are more likely to be affected by environmental degradation because of their generalized susceptibility. He also mentioned the initiator-promoter cancer model; that is, certain chemical exposures initiate cancer and other chemical exposures promote its growth.

When asked what to do for communities instead of research, the first speaker proposed that the most important question is how to remove the problem from the community. One participant agreed with the speaker that research must address multiple exposures, citing the example of an industry releasing multiple harmful materials in its emissions. Another participant said that feasibility studies must include the costs of adverse health effects and shortened lives in the community affected by a proposed industry. Someone else called for adequate health assessments of communities impacted by multiple facilities, such as Alton, MS, where there are 11 different waste facilities.

Other questions included the following: Who should be responsible for ensuring that safe substitutes are found for hazardous chemicals? Why don't hospitals recognize their responsibility to provide asthma education. When will EPA focus on what enters the pipe instead of cleaning up at the other end? (EPA staff said the law required their end-of-pipe focus.)

Session participants also noted that despite EPA's accomplishments, various chemical uses have increased, and air pollution has worsened in some communities.

BREAKOUT X

TITLE: OUTREACH AND ACCOUNTABILITY: WHAT CAN BE LEARNED FROM THE LEAD POISONING PROBLEM

Lucy Billings of Bronx Legal Services urged activists and people endangered by lead exposure to work for legislative action on behalf of tenants exposed to lead paint and for regulatory action to make landlords comply with lead exposure regulations. Regulators appear to be unwilling to enforce compliance and do not, for example, impose penalties.

Furthermore, weakened Federal statutes no longer require total abatement of lead paint once it is detected. Abatement is now required only when a housing unit is rehabilitated using \$25,000 or more in Federal funds. Moreover, current regulations allow for containment of lead paint rather than total removal and do not specify that the landlord is responsible for getting the work done, which methods of containment are permitted, or the time frame in which containment must be undertaken.

As an alternative, many activists are turning to public nuisance ordinances or to local or State statutes that require the immediate correction of hazardous conditions in housing. Impoverished persons needing representation can use city, county, or state legal services programs even though program staff may have been previously unfamiliar with lead problems.

Dennis Livingston of the Baltimore Jobs in Energy Project told the session that he was motivated to conduct lead poisoning abatement work when he realized that the weatherization activities his company carried out could cause lead exposure. He recommended against development of a lead cleanup industry, favoring instead a holistic approach that takes into consideration not just lead paint, but the moisture that can damage the paint. The holistic approach requires examining a building's heating and cooling systems and air exchange, which are skills a "weatherizer" acquires over a long time. A weatherizer can quickly learn lead containment and abatement procedures and can test for and treat all types of toxicity—carbon monoxide, radon, asbestos, and lead.

Weatherizing companies are also community-based and can monitor the cleanup for years. They can hire and train residents to be technicians and supervisors in a new trade. They would be sensitive to working in a way that minimizes displacement of residents, who cannot afford alternative living quarters.

Marty Sonnenfeld of Innovative Empowerment Strategy explained that the beneficiaries of lax regulations concerning lead exposure include landlords who do not have to pay for proper and safe abatement—government agencies must pay for abatement work when landlords fail to do so—and the real estate community. To counteract this opposition to enforcement, community members need to organize around as many relevant issues as possible, including public health, education (since lead poisoning causes learning disabilities), housing, children's rights, and civil rights.

Mr. Sonnenfeld used New York City's 12-year experience with a strict lead poisoning control law as an example of problems and successes. When health department staff were hostile and racist toward poor people and when they initiated programs without consulting the community using poorly prepared pamphlets and procedures, children continued to be poisoned. The speaker and his associates developed effective literature, worked with local organizations, and met parents at local day care sites, all of which helped promote successful community programs. One sad note is that one city mayor, who had advocated lead poisoning control, opposed and delayed a legal case that would have advanced such control. The mayor's opposition presumably was because of the cost to the city if it admitted liability.

During the general discussion, one EPA staff member worried about how to make the issue understandable to disadvantaged parents. He also noted that HUD has an enormous task, inspecting all housing units built before 1978 to detect whether renovation is needed to eliminate lead paint. In reply, a session participant said that the housing movement must get organized: Basic outreach programs can make the issues understandable, and community involvement is essential. One example is a community where children testifying before the city council swayed the vote.

Participants mentioned other problems: Residents do not want to consider whether their beautiful old homes are full of lead; the thought of having to renovate an entire home panics people; when some community activists tried to obtain funding to educate people, they were told that only industrial hygienists or biologists were qualified to do that; and the regulations requiring all pediatricians who accept Medicare patients to do lead screening are not enforced (many young children use emergency rooms rather than pediatricians anyway). Another issue is that the official figures on lead poisoning are misleading because too few children are being tested.

Suggestions included that organizers should spend a lot of time with people in affected communities; members of Attention Deficit Disorder (ADD)

advocacy groups (many children with ADD are victims of lead poisoning) should be invited to participate; and veterinarians should be alerted to the possibility of lead poisoning in pets.

Another session participant provided one last demonstration of government insensitivity to community involvement, reporting that HUD is supposedly drafting new guidelines on inspections, abatement, and risk assessments, but several leaders of community groups at this conference have not been contacted and do not know of anyone who is participating in the formulation of these guidelines.

BREAKOUT Y

TITLE: OCCUPATIONAL EXPOSURE PREVENTION

First, **Dorothy Morris** from the Toxic Victims Assistance Corporation in New Mexico described health problems related to her former employment in the electronics industry. Later, several audience members spoke about their own experiences also as workers in the electronics industry. One participant described an incident 10 years ago in which more than 200 people working in one electronics plant with certain chemicals came down with similar respiratory and neurological symptoms. Another participant reported that she had used solvents that she now knows are associated with permanent neurological problems. Someone else reported feeling "high" and hallucinating after exposure to chemicals, behaviors that could endanger other persons as well as the workers themselves.

Dr. Bruce Chin of the University of Michigan said that since the symptoms of the 200 workers did not match those known to be linked to single-chemical exposures, they might be suffering from a multiple chemical syndrome. Doctors could try to establish a link between the chemicals and the symptoms and inquire whether the workers felt better away from the work site. In the actual situation, results of a case-control study conducted by toxicologists were sealed and not shown to the victims. The person reporting on this problem had been told that the chemical she was exposed to is still in her body and that any significant change in her metabolism could exacerbate her lingering symptoms.

It appears that some of these companies were not in compliance with OSHA's guidelines for permissible exposure levels for solvents and were not using well-known correct handling practices. Poor recirculation of air by industries and in airplanes aggravates indoor air pollution.

Another exposure problem at work sites results from a combination of certain medications with certain workplace chemicals, according to one session participant who pursued a lengthy lawsuit against her employer without the cooperation of her doctor. Another worker suggested that the difficulty of finding doctors who understand occupational exposure to toxins could be overcome by creating clinics that also serve as research sites. California's Silicon Valley, with its concentration of high-tech industries, would be a perfect location for such a clinic-research center combination.

With regard to protective clothing and chemical residues, **Dr. Chin** noted that showers should be provided for the workers and work clothing should not leave the work site. Another session participant said she regularly took such clothing home and now wonders if her two grandchildren's birth defects are related to the resulting chemical exposure that her family received. (The woman added that the company now has a policy of requiring workers to change into their own clothes before returning home.)

Dr. John Sheehy of NIOSH mentioned that the idea of an entitlement fund is being adopted widely and any new industries that arise must set aside such a fund to be used in case workers are injured.

In a presentation on lead exposure in the workplace, **Dr. Sheehy** noted that standards to protect workers from lead poisoning have been in place for years, but one California study found that 85 to 90 percent of businesses involved in lead exposure did not comply with these regulations and had not suffered any consequences for noncompliance. A contrasting report of the lead reclamation industry found that companies spend an average of \$15 million to revamp their workplaces and improve their ability to protect their workers.

Bridge repair work represents a growing new industry in which lead exposure is a potential hazard, and NIOSH is looking at several new systems designed to minimize exposure to lead paint on bridges. NIOSH also was able to help a Colorado radiator shop where workers using lead solder were found to have high blood levels of lead. NIOSH designed and built a relatively inexpensive device that draws away fumes and circulates fresh air.

Dr. Sheehy noted that the job was only half finished when the device proved successful; it was equally important to publicize its success so that other businesses could provide the device to their workers. This was done by developing an easy-to-read workbook and contacting the trade association and medical personnel through relevant publications.

BREAKOUT Z

TITLE: POLLUTION PREVENTION AND HEALTH INTERVENTION

Elmer Chenault from EPA first provided from his own experience a classic example of a community 6 miles north of Denver, CO, that took action against its pollution problems. Home to a 100-year-old lead smelter, a rendering plant, an electric power generating facility, and an abandoned public housing site with soils contaminated with heavy metals, the community is also close to 5 of Colorado's 15 hazardous waste sites and bisected by two interstate highways that greatly affect air quality. All residents of the small community are poor or people of color or both.

A 1991 environmental equity workshop provided the community with up-to-date knowledge on relative risks, options for reducing those risks, and pointers about accessing the government for help in fighting its pollution problems. Subsequently, EPA hired an independent contractor to help the residents, who did not trust any level of government.

The lead smelter, producing lead, arsenic, and cadmium, was shown to be a major cause of environmental pollution despite its installation of high-efficiency collectors. Ground water and garden soils were highly contaminated with heavy metals. In 1993 the community was awarded \$27 million in its lawsuit against the lead facility—the largest amount ever awarded in an environmental case in Colorado—and the State health department now has a suit pending.

The community's case also led to a medical monitoring program to screen both current and former residents for lead poisoning. Both the monitoring program and the contractor who was hired to clean up the site must comply with the court's ruling to employ residents in that effort, if residents so desire.

Cadmium production at the smelter has been halted, primarily for economic reasons, and the company owning the smelter is attempting to reduce the use of other hazardous chemicals in its extraction process.

Dan VanderMeer from NIEHS asked participants to advise NIEHS on how to apportion its funding (\$264 million this year). Funds can be allocated to NIEHS research on the relationship between people and the environment, training of researchers, and communication of research findings to the public. Human research studies (such as epidemiological studies and clinical trials) are the most expensive and time consuming. Toxicology and basic biology studies can be useful even though they may not appear relevant to lay people. A panel of experts helps NIEHS rank proposed research projects.

Calling for balance among studies, the speaker gave an example: Removing dioxin from the environment could take many years and cost billions of dollars, whereas quick, inexpensive research in basic biology might uncover a way to prevent cells from absorbing dioxin, saving people from toxic exposure. He stressed that NIEHS needs to explain such choices and on the whole communicate more with the public.

One session participant then commented that risk assessment studies are all too often based on unsubstantiated data. Another asked about availability of NIEHS data; the speaker said the entire toxicological database will be made available to any users of certain computer networks. A third participant suggested that a new criterion for funding research should be that the studies must involve health effects in communities impacted by pollution problems.

Dr. Sylvia Tesh of the University of Michigan spoke of the benefits of community participation in environmental issues—such as furthering the cause of democracy, allowing community activists to become experts in their own defense and in environmental issues, and providing decisionmakers with important perspectives and values that they would not otherwise get. However, she also cautioned that community groups should not formally participate with government agencies, saying that it may be better to stay outside the process and organize, protest, and lobby the real decisionmakers to make the right choice.

Dr. Tesh's reasons for not participating include the following: Formal participation of the community can be a means to legitimize decisions that the community opposes. Community groups can never have power equal to that of government agencies. Community groups open themselves up to the charge that they do not really represent the entire community. Then, if several different groups must participate, this dilutes community power even further. In addition, community participation sets a precedent by having people who were not elected take part in decisionmaking and represent others instead of having elected officials, answerable to their constituencies, make the decision.

One participant disagreed with **Dr. Tesh**, saying that communities must be involved early in the process of fighting an environmental injustice, that communities are not helpless, and that in many cases they can have an equal voice.