

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



*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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PREFACE

The following executive summary and recommendations were developed by grassroots, academic, government, labor, business, and community leaders attending the historic Symposium on Health Research and Needs to Ensure Environmental Justice. We, the Protocol Committee of the Symposium, urge you to read and use these recommendations to implement the Presidential Executive Order on Environmental Justice.

Environmental Justice encompasses more than equal protection under environmental laws (environmental equity). It upholds those cultural norms and values, rules, regulations, and policies or decisions to support sustainable communities, where people can interact with confidence that their environment is safe, nurturing, and productive. Environmental justice is served when people can realize their highest potential, without experiencing sexism, racism and class bias. Environmental justice is supported by clean air, water and soil; sufficient, diverse and nutritious food; decent paying and safe jobs; quality schools and recreation; decent housing and adequate health care. Environmental justice is supported by democratic decisionmaking and personal empowerment; and communities free of violence, drugs, and poverty and where both cultural and biological diversity are respected.

Symposium participants should be applauded for the time, energy, and commitment for making this event a successful one. Although written within a three-day period, these recommendations flow from years of painful experiences embedded in struggle for survival. This Symposium allowed stakeholders to sit at the table, discuss differences and similarities, and recommend strategies to improve the quality of life of high-risk populations.

Within the spirit of environmental justice, we encourage you to use these recommendations as the basis for the development of strategies within and between federal and state agencies. Please use them as you work to increase the participation of communities. They should also aid you in increasing the efficacy of your work for addressing the problems of low income and minority communities.

People of color and low income communities have not only borne the brunt of contamination, but they have been isolated from those mandated to serve them. Environmental justice is a challenge to "right" long-overdue "wrongs." With commitment, we can make a difference. We can improve the quality of life for all and

bequeath to future generations a livable and an environmentally just society. Let us continue the progress made towards building partnerships between those most affected by pollution and those most committed to its alleviation.

Respectfully yours,

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Executive Summary of the Recommendations
from Health Research and Needs to Ensure Environmental Justice

INTRODUCTION

On February 10-12, 1994, six government agencies with the support of community and academic leaders convened the first federal symposium on environmental justice. This Symposium on *Health Research and Needs to Ensure Environmental Justice* was a working meeting. Its goal included formulation of recommendations by: community leaders, workers, business and academic representatives, diverse government personnel, and people from the broader scientific community.

More than a thousand Symposium participants worked in small core groups that met three times throughout the Symposium for facilitated discussions. These groups provided opportunities to discuss substantive issues raised in breakout groups and plenary sessions and answer specific questions related to health research and needs. Core group discussions also provided opportunities for individuals to share different experiences and to debate, integrate and summarize key Symposium issues. Within core groups, everyone shared expertise or information from plenary and breakout sessions and from personal and professional experiences. The core group format allowed each person to become teacher and learner, and increased the level of participation.

A major theme of the Symposium was the importance of involving grassroots organizations in education and research activities in their communities, and in making sure that communities benefit from these activities. Another major theme was the need for federal agencies to work together and avoid contradictory policies and duplication of services.

Core groups recommended that the Federal Government and other environmental justice stakeholders empower communities, increasing their self determination and enhancing their interaction, collaboration and communication with a more responsive, reinvented government. Specific requests included:

- I. Conduct meaningful health research;
- II. Promote disease prevention and pollution prevention strategies;
- III. Set up new ways for interagency coordination;
- IV. Provide outreach, education and communications; and
- V. Design legislative and legal remedies.

Executive Summary of the Recommendations

from Health Research and Needs to Ensure Environmental Justice

Sections I through V of this executive summary provide an overview of recommendations crafted by Symposium participants. The appendices to the executive summary provide specific recommendations and other Symposium products.¹

I. Conduct meaningful health research in support of people of color and low-income communities. Preventing disease in all communities and providing universal access to health care are major goals of health care reform. Effective preventive measures cannot be equitably implemented in the absence of a targeted process that addresses the environmental health research needs of high risk workers and communities, especially communities of color.

1. Develop new models for occupational and environmental science research that involve high risk communities and workers as active participants in every part of research, including:
 - a. making and testing of hypotheses,
 - b. planning and putting into action creative research strategies and methodologies,
 - c. interpreting and communicating research results, and
 - d. translating research results into disease prevention and pollution prevention action.
2. Assure that new models include examination of the ethics and social responsibility of research, standards of evidence, and the history of worker and community involvement in research and policymaking.
3. New models of studying people must be developed that address:
 - a. exposures and diseases among only small numbers of people,
 - b. exposures to low levels of a hazard,
 - c. exposures to many different occupational and environmental hazards over a short period of time and over a lifetime, and
 - d. the knowledge and experiences of community members and workers about their diseases and exposures.

¹Appendix A identifies questions posed to each core group, specific recommendations based in part on these questions, and recommendations from more specialized caucuses and environmental justice networks. Appendix B describes the difficulties and rewards of the core group process. Appendix C summarize the evaluation of the symposium by its participants. Appendix D contains a letter from federal sponsors of the symposium regarding these recommendations.

Executive Summary of the Recommendations

from Health Research and Needs to Ensure Environmental Justice

4. Target the development of new molecular technologies and tools to serve the at-risk workers and communities. These technologies and tools should serve the community in risk assessment, disease etiology, and policy formation.
5. Federally funded research centers should prepare well-thought out plans for partnerships with local communities of color. (These plans should be made available to community groups on request.) Community and worker representatives in these partnerships must be active participants in all stages of research, and partnerships must lead to timely and effective public health actions. The plans and results of the partnerships and public health actions should be evaluated in the same peer review and site visitation process as the more traditional research parts of the project.
6. Where high risk workers and communities are underserved, create new local/regional occupational and environmental health research centers.
7. Community-based research needs to be conducted in ways that strengthen ties among community-based organizations, public health agencies, and educational institutions.

II. Promote disease prevention and pollution prevention strategies. While treating disease and cleaning up environmental problems are essential, long-term solutions must rely upon truly preventive approaches.

8. Build a stronger base for occupational and environmental health.
 - a. Increase the emphasis on occupational and environmental health in curricula and training programs for health care providers. This should include training to gather information on occupational and environmental exposures as part of medical histories.
 - b. Increase clinical studies in affected communities to provide people at risk with effective surveillance, monitoring and treatment of adverse health effects.
 - c. Initiate where necessary and fund birth and disease registries for all states.
9. Increase Department of Health and Human Services funding through the Public Health Service (including ATSDR, CDC, NIEHS, and NIOSH) for prevention research that addresses occupational and environmental disease problems in communities of color and other high risk populations.

Executive Summary of the Recommendations

from Health Research and Needs to Ensure Environmental Justice

10. Direct a major part of ongoing and new NIH disease prevention research funding through NIEHS for prevention of environmental and occupational disease in communities of color.
11. Promote communities that have been successful in eliminating or reducing pollutants from the environment as models for research on disease and pollution prevention.
12. Use tax and government buying policies to promote sustainable and safer technologies that improve product stewardship.
13. EPA should support regional pollution prevention networks involving government, community, and industry associations to investigate, develop and put in place alternate, less polluting technologies.
14. Funds should be available to help workers and communities make transitions when plants temporarily or permanently shut down for purposes of improving technology. Use military conversion to stimulate new technology for preventing pollution in the future.

III. Promote interagency coordination to ensure environmental justice. While at risk communities and workers are most threatened by occupational and environmental hazards, government agencies (federal, regional, state, local and tribal) are also important stakeholders. Unfortunately, environmental problems are not organized along departmental lines. Solutions require many agencies to work together effectively and efficiently.

15. Educate stakeholders about functions, roles, jurisdictions, structures, and enforcement powers of government agencies and the needs and concerns of low-income and people of color communities. Research projects must identify environmental justice issues and needs in a particular community, and how to meet those needs through the responsible agencies.
16. Establish interagency working groups at all levels to address and coordinate issues of environmental justice.
17. Agency attitudes need to change and agency staff need exposure to the community's perspective.

Executive Summary of the Recommendations

from *Health Research and Needs to Ensure Environmental Justice*

- a. Agencies should actively provide information about the government's role as the community identifies short- and long-term economic and environmental needs and health effects.
- b. Train staff to support inter- and intra-agency coordination, and make them aware of the resources needed for such coordination.
- c. Government agencies should make available staff who are trained in culturally appropriate language and communication.
- d. Tribal, local, state and federal governments need to recognize and rectify problems when other levels of government are not effectively doing so.
- e. Support research agencies operating in the public interest by increasing or protecting their budgets.
- f. Hold workshops, seminars and other meetings to develop partnerships between agencies, workers and community groups.

IV. Provide effective outreach, education and communications. Findings of community-based research projects need to be produced and shared with community members and workers in ways that are sensitive and respectful to race, ethnicity, gender, and language, culture, and in ways which promote for public health action.

18. Government agencies, including ATSDR, CDC, EPA, NIEHS, and others, should visit affected communities and workers, and provide information about: (a) research goals, objectives and policy, (b) the organization of each agency, and (c) the specific agency's mandate. Such visits should also promote a better understanding of worker and community needs.
19. CDC, DOE, EPA, and NIH should develop and/or increase funding for community/academic research partnerships (such as the NIOSH Education Resource Centers) in order to provide research services to address environmental justice concerns. They should review existing community/worker research partnerships and develop guidelines to be used in forming partnerships at federally funded centers. Make environmental justice issues part of the curricula of Schools of Public Health. Include environmental justice in the accreditation process of institutions of higher learning. Assure that environmental justice is an integral part of any ATSDR, CDC, DOE, EPA, NIEHS and NIOSH research and training grant.

Executive Summary of the Recommendations

from Health Research and Needs to Ensure Environmental Justice

20. Recruit, retain and promote people of color and members of affected communities in scientific research and education. In particular promote scientific research and education at Historical Black Colleges and Universities (HBCUs) and other Minority Institutions.
21. Design and carry out education efforts tailored to specific communities and problems. Increase the involvement of ethnic caucuses, religious groups, the press, and legislative staff in resolution of health and environmental justice issues.
22. Train workers and communities to understand the links between health and pollution and to pose meaningful questions to researchers.
 - a. Expand the NIEHS hazardous waste worker training program to include other workers and communities. Make disease and pollution prevention part of the training curriculum.
 - b. Fund community training programs through a portion of pollution permit fees.
23. Assure active participation of affected communities in the decisionmaking process for outreach, education, training and communication programs - including representation on advisory councils and review committees.
24. Revise EPA's Superfund Technical Assistance Grant procedures to eliminate federal procurement requirements for those grants and to establish federally-funded, state-based, community coordinators to promote and facilitate community participation.
25. Encourage federal staff to change bureaucratic processes to be more responsive to community needs and to provide training to enhance environmental justice awareness.

V. Design legislative and legal remedies.

26. Incorporate private attorney rights-of-action clauses into regulatory laws, making it easier to bring suits and, if successful, to recover costs and attorney fees.
27. Strengthen whistleblower protection laws so that agency staff can identify problems and initiate actions to protect affected communities.

Executive Summary of the Recommendations

from Health Research and Needs to Ensure Environmental Justice

28. Government agencies should use Title 6 of the Civil Rights Act of 1964 in their enforcement of environmental justice.
29. Enact, strengthen and/or enforce legislation such that it provides equal protection of the law to all people against environmental problems.
 - a. Increase civil and/or criminal penalties for violators.
 - b. Strengthen legislation (such as the Federal Insecticide, Fungicide and Rodenticide Act which regulates pesticides, the Clean Water Act, the Clean Air Act, and the Superfund law) coming up for reauthorization in 1994 to protect vulnerable or at-risk populations.
 - c. Redefine "action levels" to accurately reflect the needs of sensitive subpopulations, such as children and communities exposed to many different hazards and/or exposed at many different times and places.
 - d. Authorize and appropriate funds to address issues of environmental justice (e.g., prevention, clean-up, and health care), and make grassroots participation mandatory.

Appendix A

Questions: CORE GROUPS 1-3

How do we conduct meaningful health research in support of people of color and low-income communities to ensure environmental justice?

1) What are the barriers to overcome in order to be able to conduct meaningful research on topics central to environmental justice? 2) What needs to be established to provide true community input on an ongoing bases to agencies? 3) How do we identify meaningful research problems and needs? 4) What are meaningful research problems and needs (i.e., data, techniques, technology, research projects, training, etc)? 5) How do agencies gather data from communities on their needs and how data are translated into research, and programmatic areas? 6) What do communities wish to do that requires research assistance from federal agencies? 7) Define what resources are needed? 8) What are delivery systems that maintain community control? 9) How can we overcome barriers to change? 10) What is the role of community-based organizations? 11) What is the role of laboratory science? 12) What is the role of government agencies? 13) What is the role of academic institutions? 14) What are the funding mechanisms for agencies, institutions, and community-based organizations to conduct more meaningful research? 15) What are the specific recommendations to be brought forth in the plenary session?

Recommendations from CORE GROUP #1

Co-facilitators - Stephanie Anthony
Heidi Klein

Overall Summary

Out of frustration, people's concerns for environmental injustice and blatant degradation are being voiced loud and clear at meetings such as this Symposium. Our core group's needs assessment would logically include the following:

1. Strategies for community involvement, including specific emphasis on a conflict resolution process.
2. Scientific recommendations.
3. Health recommendations.
4. Education.
5. Consideration of economic factors.

Obviously, beyond identifying needs, immediate action is required. A fair and equitable process needs to assimilate the input of various groups, uniting for one common goal: To eliminate the effects of all environmental hazards on people's health, both physical and emotional.

Overall Recommendations

- o Get all parties, including polluting businesses and government agencies, together to develop an agreement in principle.
- o Government needs to stop "accepting" the situation; the government should take a stand, be an advocate, educate community leaders.
- o Local/regional research centers should be created that include local expertise and resources: the community should control this institution, should determine type of research, how it is to be conducted, and the amount of money to be spent on the projects.

- o Community residents/workers are being harassed and made fearful of raising environmental concerns--these incidents need to be documented and brought to the public's attention through the media.
- o Because many community experiences with public health officials have been of mixed benefit, future work needs to document the past history of interactions and create a new record of promises and performance which can be used to hold officials accountable.
- o "People's Epidemiology" can be an important tool to get attention to a community's health problems; communities that document their health problems can use this information to push for full health studies.

Community Perspective and Recommendations

Survival is key to many communities. To involve the community, one must first know the community. Patience and understanding are essential for community work. Once a community trusts you, you can accomplish many objectives.

- o Approach the community with dignity and respect.
- o Use the knowledge and skills that the community already possesses.
- o Going house to house helps a community get to know you and also helps you understand their multiple needs.

One of the problems of research (academic research) is the imbalance of the links with other partners in society. Currently links are strong within academia itself and between academia and industry. Research is costly, and, so far, communities haven't had the resources to support research (at least on a large scale).

- o Taxpayer's money should be made available to support community-oriented and sponsored projects.
- o Stronger links between academia and surrounding community should be developed.
- o Community members should be directly involved and trained in health research or pollution remediation.
- o Develop local research centers that involve members of that community at all levels.
 - use existing facilities and/or develop new local research facilities
 - take advantage of local expertise and resources
 - further develop local expertise with training activities
 - further develop local understanding with appropriate and accessible information
 - modify funding processes to include specific language that requires community involvement---Money talks
 - include community at the grant funding and project identification processes
 - include community representatives on institutional review boards to instill accountability

establish community resource centers to provide emotional, technical, financial, and other support

- o Include cultural and community awareness training in researcher training and as an enforceable requirement of funding to minimize the tendency for elitism, condescension among "outside" researchers.
- o Develop affirmative outreach activities for workers populations, particularly injured workers to combat industry intimidation.
- o In any research activity, develop avenues and material for appropriate, effective communication and education on the project and its results.
- o Shift focus from assessing health and environmental damage to preventing such damage.
 - develop strict standards
 - develop effective means for enforcement
- o Require industry to be involved in funding fair, unbiased research on the potential health and safety and safety issues associated with a new facility **before** placing it in a community.
- o Develop strategies to link industry and government funding with oversight that includes academia and community representation.
- o Adopt strategies which are meaningful including educating the community about fairness issues.
- o Be sure to reach out to others and still adopt/keep the focus of choice.
- o Have a consensus-building process.
- o Involve experts (both local and outside).
- o Get government involved early and in a meaningful way.
- o Identify resources needed, including tax money.
- o Adopt check and balances for the decisionmaking process.

Scientists, Professionals and Government Role

Communities can't depend solely on scientists, lawyers, politicians and bureaucratic professionals alone. Community action will result in change only when the impacted community takes active participation, not turn over to scientists and lawyers to provide solutions for them that is disempowering.

- o The scientists role then is to recognize this and work to educate community leaders at the grassroots level in lay terms; disassociate their research and policy from industry influence; and guarantee impartial regulatory agencies in order to gain credibility as a governmental agency

with the public's interest as its mandate within the communities it serves. Researchers should listen more to those who know first hand what's going on...VICTIMS!

- o The message needs to be heard by the NIEHS and other governmental agencies that are considering collaborating with industry on testing of chemicals and they must maintain the integrity of public interest and avoid the appearance of any conflict of interest.
- o There must also be a statement that the privatization of public agencies, and contracting out public interests to the private sector requires strict oversight and accountability to assure that the community does not get coopted for a maximization of profit and therefore may not be the most effective approach and should be avoided if at all possible.
- o The agencies established for public health need to stand behind communities that are trying to clean up the hazards in their neighborhoods. The existing structures have allowed science to be used against communities even when the overwhelming consensus of the staff would conclude otherwise.
 - Government agencies should reject the paradigm of accepting solutions offered by industry purely because of economic arguments and need to be willing to make sacrifices.
 - Use "People's epidemiology" to draw attention to issue and document health problem.
 - Scientists should provide data--community itself should keep the power.
- o Government should develop and distribute a directory that lists various agencies and other resources, what they do, and who to contact for assistance.

Scientific Recommendations

Currently, the burden of proof rests with communities. Need community to be behind scientists and support efforts to shift the burden of proof. Goal is clean, sustainable environment and economy. In some cases there is already a body of research data available. Even though cause and effect may be 100% conclusive there is a critical mass of information to ready a logical conclusion about health impacts.

- o Data needs to be translated to the community-based organizations in a language that is in lay terms so that an understanding of the impacts can be addressed by the community and they can be empowered to mitigate the targeting of industrial toxic polluters in their community.
- o To address the issue of environmental justice, sustainable mechanisms are needed to ensure that the results of research lead to effective public health action.
- o Where conclusive evidence of health effects of specific environmental toxins exists already, immediate action must be taken to develop effective regulations to control these exposures and prevent the adverse health effects.
- o This will require development of a "New Paradigm" for environmental science research which includes communities as active participants in the research, including hypothesis generation, planning, conduct, interpretation and ensuring that the results of the research are translated into appropriate public health action whenever possible.
- o Prevention of disease in all communities and universal access to health care are major goals of health care reform. However effective preventive measures to ensure environmental justice

cannot be equitably implemented in the absence of a targeted process that addresses the environmental health research needs of communities of color.

- o Specifically, a major portion of ongoing and new NIH prevention research funding should be channeled through NIEHS for initiatives targeted to the health research needs for prevention of environmental disease in communities of color.
- o Moreover, the HHS should commit substantial new funding to NIOSH and ATSDR, to develop initiatives targeted to health research needs for prevention of occupational and environmental disease in communities of color.
- o NIH- and CDCP- funded centers should incorporate requisite, verifiable plans for partnerships with their local communities of color. Such partnerships must demonstrate active participation of community representatives in all stages of research as well as reasonable mechanisms for ensuring timely and effective public health action. The success of the community partnerships and public health actions should be evaluated in the same peer review, site visitation process as the scientific components of the project.
- o Establish accountability vis-avis quality of community participation as a requirement for research center grants.
- o As part of the accreditation process, environmental justice should be incorporated into the curricula of Schools of Public Health, NIEHS, NIOSH training grants.
- o Where regulations exist to limit exposures to specific environmental and occupational toxins, these regulations must be equally and effectively enforced in all communities without regard to race, ethnicity, and socioeconomic status. We applaud the commitment of the EPA, clearly stated at this Symposium, to enforce existing environmental laws and call on the EPA as well as other regulatory agencies including OSHA to fulfill their mandates in the interest of environmental justice.

Health Recommendations:

- o Define the site community as the affected population as well as the geographic community.
- o Put members of the affected community on the public health assessment team from the beginning to the end of the process.
- o Include community members in technical meetings between EPA, ATSDR and other related agencies.
- o Environmental regulatory and public health agencies should send information on site specifics to the effected communities in advance of a site visit to provide community members with the background to ask more informed questions.
- o Affected communities should be involved in the cooperative agreement program with state health departments. Further, grant cooperative agreements to qualified community groups.

- o Involve communities at the grassroots level by using local health and environmental agencies and affected community groups.
- o Direct more resources toward involving poor and people of color communities.
- o Use public service announcements and community service programs (radio and television to disseminate information to communities using alternative and community media in appropriate languages of the affected communities).
- o Communities should be provided financial and technical resources to participate in agencies' activities.
- o Provide guidelines to communities on how to follow up with Congress on issues of environmental public health.
- o Conduct workshops for the community on health data gaps, sources of information, and standardization. Information should be understandable to affected youth.
- o Communities should be informed of all environmental and public health agencies' activities, recommendations and actions.
- o Establish a process for affected communities to set priorities of funding for environmental justice issues.
- o Immediately develop health based standards for all pollutants on the hazardous materials index.
- o Set universal standards for emissions of particulate matter at 10 or below.
- o Prioritized funding for research of alternative processes and hazardous materials in the workplace.
- o Prioritized funding for prevention or exposure of toxins in children.
- o Take immediate action to remediate, provide health services and notification where identified clusters of cancer, disease and poisoning already exist without waiting for the burden of proof.
- o Ensure corporate accountability by providing compensation to affected individuals and communities, and assessing criminal penalties and mandating clean-up.
- o Immediately notify affected community of federal, state and local regulatory violations.
- o Track federal, state and local regulatory violations and clean-up processes.
- o Include a mechanism for community participation in the development of Environmental Impact statements (EIS) at the beginning of the process.
- o Incorporate socioeconomic considerations in the development of the EIS.

- o Provide Technical Assistance Grants (TAG) to communities to hire experts or other advisors to review decisions regarding permitted discharges for facilities, including military facilities.
- o Enforce environmental racism violations as civil rights violation.
- o Require the Department of Justice to apply civil and criminal penalties if corporate practices results in sickness and death. It would be discriminatory not to pursue both, civil and criminal remedies against corporations.
- o Abolish the Warner Amendment (Doctrine of Sovereign Immunity).
- o Require federal and state governments to conduct appropriate research on environmental justice issues. Failure to do so is violation of civil rights protection.
- o Require federal and state agencies to conduct a comprehensive inventory of all pollution sources (air, water, etc.) in high impact communities. This data should be used for new permitting decisions so that cumulative effects are considered. This process should include notification to affected communities.
- o Identify environmental racism as a form of institutional violence that contributes to the degradation of the community.
- o Government contracts generated under Superfund and others statutes should be available to affected communities to review.
- o Recognize, protect and respect indigenous sacred sites and territories as vital to spiritual health.

Recommendations from CORE GROUP #2

Co-facilitators - Michele Gonzalez Arroyo
- Valerie Jackson Jones

Note: Core Group 2 broke the 16 questions into four major categories. These categories are listed below. Category 1 consists of questions 1,4,6,7 and 9. Category 2 consists of questions 2,3,5, and 8. Category 3 consists of questions 10-14. The final category, which consist of question 15 was addressed singularly.

How do we increase community input/involvement?

- o Pollution prevention policies and legislation are needed. Too much money is spent on clean up and litigation; focus should be on pollution prevention.
- o Polluters should be charged with criminal activity and fined/jailed. Fines should exceed the cost of compliance. Fines are too lenient.
- o Researchers should include community as an integral part of the research design and the development of research methodologies.
- o Researchers should educate community about the limits and benefits of research.
- o Researchers should provide findings to community in an understandable manner and bilingually if necessary.
- o Community people should be able to speak for themselves. Consultants should not be paid to speak for community.
- o Government agencies should provide a flow chart or an organizational chart that demonstrates which agencies and at what levels of government people can turn to. Too many times agencies pass the buck to other agencies or to other levels of government and no one wants to assume responsibility for the problem.
- o There must be a systematic, user friendly way to interact with agencies.
- o Resources should be put into community education about the hazards that they face instead of into consultants and researchers. Community can help to educate other members of the community.
- o Data should be gathered by communities and neighborhoods and not just political groupings like congressional districts.
- o Community realities should be validated. Who is the government to tell the community that what they are living or experiencing is not really what is happening to them.
- o Money should be used to deal with the health related concerns of community people that are caused by environmental problems.

What are the roles of all of the various participants in this meeting in order to get meaningful community research?

- o Cooperation amongst all: CBO, research scientist, industry, government agencies, social scientist.
- o Community needs to be educated about the research process.
- o Community-based research with extensive community outreach is needed.
- o All participants need to have an investment in community-based research.
- o Grants need to be made more easily available to CBO.
- o Industry money should be included.
- o Community needs to be a part of the research design process. Community needs to be both subject and object of the research. Community should be involved in the development of methodology.
- o Grants should mandate legitimate CBO representation be included in the process.
- o Research priorities need to emphasize prevention not just intervention. Research should be proactive.
- o Institutions need to have community liaison that represent community.
- o Need to define "meaningful research." We need to avoid the duplication of research questions that have all ready been answered.
- o Research needs to address what are most effective modes of educating, preventing and intervening to solve problems quickly.
- o National Standards that demand Environmental Impact Statements/Reports on all projects. No negative declarations.
- o Need to train minority researchers and environmental policy analysts.

Funding Mechanisms for Community-Based Organizations

- o Create an industry tax to be used for community projects, i.e., health care and youth programs.
- o The penalties and fines placed on industry and government by outside regulatory agencies should be given back to the communities affected.
- o The Federal Government should provide more money to community-based organizations.
- o Simplify the process to respond to an RA.

- o There should be a mechanism for outreach and technical assistance to communities so that they can respond to an RA.
- o Have the government farm subsidies go to farm workers to provide for health care.
- o Ensure that community advisory members are placed on industry planning committees and funding bodies.
- o Ensure community involvement in selection of planning/zoning committee members.
- o Inform community-based organizations about EPA's \$50,000 grant which is available for environmental justice issues (available now).
- o Call Regional EPA Offices to get on mailing list so that community-based organizations be informed about any RFAs.

What are the problems and barriers to doing meaningful research?

- o Lack of realization that problems exists.
- o Unable to get funding of long-term studies.
- o Community ambivalence because of difficulty dealing with government bureaucracy.
- o Need a better definition of "meaningful research."
- o Lack of communication by government with communities.
- o Additional funding needed.
- o Infrastructure in the community is needed to address health problems of the community.
- o Elimination of political conflicts of interest.

Recommendations from CORE GROUP # 3

Co-facilitators - Teresa Stickels
- Bill Redding

- o There is a need to support and legitimate community and worker collaboration in environmental and occupational research from the design through the implementation, interpretation, and notification. This needs to be accomplished through:
 - determining the final research questions that need to be researched.
 - greater worker and community control over funding of research.
 - Funding of NIEHS and EPA Centers should require an outreach and training component with a mandatory review committee that includes the affected communities and which would have the authority to review and approve funding.
- o Researchers need to take a more global approach to their subjects.
- o The level of qualifications and requirements for cooperation must be increased for investigators from EPA.
- o Workers and communities should get funding for ongoing data collection, surveillance and analysis. Specifically,
 - funds should be available through Superfund reauthorization or other federal legislation.
 - funding should be sufficient to allow communities and workers to either hire or train technical support people.
- o Request that CDC establish a "community" Health Hazard Evaluation process (similar to NIOSH program for workers). The program should require report back to affected community in a reasonable time period.
 - Put "800" number on bottom of MMWR.
 - community involvement in entire "Community HHE" process should be required.
- o Disseminate final Environmental Justice executive order to all conference participants by 4 PM Saturday. Implementation working group for Executive Order must include community members.
 - "Public participation" should not just be a "buzz" word but must genuinely involve the community.
- o EPA and other agencies need to change the complexion of the agency through recruiting.
 - EPA and other agencies need to provide internal education/training for all staff.
 - All EPA staff must be held accountable for their interactions with affected communities.
- o Provide resources and funds necessary to sustain the environmental justice movement.
- o Respect, listen to and learn from, the knowledge, wisdom and culture of indigenous peoples. Western science, including medicine, needs to learn from traditional ways.

Questions: CORE GROUPS #4-7

What are new models for pollution prevention to ensure environmental justice?

1) What are the barriers to overcome in order to be able to create new models of pollution prevention? 2) What are the clearly defined areas of responsibility for government agencies? 3) In what ways do government agencies hinder or facilitate pollution prevention? 4) What are issues or requests that go beyond agency mandates, resources, limitations or time constraints? 5) What are agencies doing in terms of prevention that needs to be altered? How can we overcome barriers to pollution prevention? 6) What is the role of community-based organizations? 7) What is the role of government agencies? 8) What is the role of workers and businesses? 9) What is the role of laboratory science? 10) What are the funding mechanisms for agencies, institutions, and community-based organizations to conduct more meaningful research? 11) What are the specific recommendations on pollution prevention to be brought forth in the plenary session?

Recommendations from CORE GROUP # 4

Co-facilitators - William Fontenot
- Karen Medville

Responses to the Question: What are new models for pollution prevention to ensure environmental justice?

- o Look at the products we use every day -- become earth conscious consumers.
- o Government procurement policies push sustainable, safe technologies.
- o Redirect Federal and State environmental control agencies staffing to emphasize community role (jobs for affected) "seed bureaucracy."
- o Change product and production choices to eliminate pollution and poisons before it begins.
- o "Fence-line" communities need a fair and just option to move away.
- o We need to value the "natural state of things" in decisionmaking.
- o Develop mandatory health and science education programs for K-12 on environmental justice.
- o Push laws and regulations that make our Nation's economy "natural and sustainable."
- o Different "permitting system" that recognizes that certain chemicals should not be produced. No permitting on "acceptable risk."
- o Form a real labor-community partnership to hold corporations accountable for safety.
- o Criminal penalties and confiscatory fines and accountability from national environmental groups.
- o Invest in basic environmental education.
- o Advocates to assist public in bureaucratic maze.

- o Educate workers about dangers in the workplace and "take home" toxins.
- o Regulation writers consult grassroots workers and community members to close loopholes.
- o Community organizing to ensure citizens voice is heard, facilitated by government.
- o Manufacturers must prove the products they manufacture are safe (burden of proof is on the manufacturer).
- o Increase RFA from \$500,000/year (an insult) to \$20 million.
- o Document the REAL TOTAL pollution costs and make the information available to ALL Costs (per product/alternative).
- o Larger fines for perpetrators.
- o Implement change necessary to focus from health treatment to disease prevention (e.g., in medical and veterinary institutions, public health programs, etc.).
- o Universal screening of hospital patients for exposure to certain toxic substances.
- o Add questions to census to provide exposure and health data.
- o Provide training and support to communities to make them "chemical independent."
- o Promote product stewardship.
- o Move government functions to the communities and downsize big government.
- o Public health research branch **must** involve community input component. Train to support this initiative.
- o **No phoney "staged" environmental justice.**
- o There **must** be affected community participation in any and all development projects.
- o Form pollution prevention network; EPA should be involved.
- o State/industry/community partnership on Toxics Use Reduction Inventory. Use forum to get reductions by focusing efforts to get industry responsive to community concerns.
- o Evaluate government programs **at all levels** for environmental racism and justice issues.
- o Develop and organize around political agenda.
- o Employer neutrality for toxic workers to organize.
- o Mandatory citizen access to TV networks for sustainable message.
- o Ban/outlaw most dangerous chemicals and all classes of known toxics.

- o Field personnel empowered to shut dangerous facilities.
- o REAL whistleblower protection for workers who report environmental health problems in industry.
- o Education issues address environmental justice issues.
- o Write regulations to be responsive to community concerns.
- o High regard for chemically injured population as an environmental warning.
- o Include and support community representatives in environmental justice process.
- o Federally funded cancer and birth registries in every state.
- o Work to remove segregation from housing patterns.
- o Improve quality of life for those already affected by environmental injustice.
- o **Require human impact statements.**
- o Why are corporations so absent in our discussions???

Recommendations from CORE GROUPS # 5 AND 6

Recommendations from these core groups were not received.

CORE GROUP # 5 - Co-facilitators - Robert L. Ford
- Tracy Easthope

CORE GROUP # 6 - Co-facilitators - Manuel Gomez
- Mildred McClain

Recommendations from CORE GROUP # 7

Co-facilitators - Grover G. Hankins
- Diane Wagener

Needs for Effective Pollution Prevention:

Legal

- o Private attorney general clauses need to be introduced into regulatory laws making it easier to bring suits and, if successful, recover costs and attorney fees (responsible groups: EPA (federal and state), ?DOE, ?DOT).
- o Need to be able to get compensatory relief, including attorney fees and costs (responsible groups: EPA (federal and state), ?DOE, ?DOT).
- o Need better whistleblower laws so staff of agencies can identify problems and help government get out of the way. These are needed at all levels of government.
- o Grants should be available to help communities hire the help they need to obtain information (such as health and exposure information) needed to bring suits and initiate action.
- o Federal agencies should have ombudsmen with right of review and veto.
- o Title 6 and Civil Rights Act of 1964 should be used by all government agencies in the enforcement of environmental injustice.
- o An international agency should be available so that when the US goes into another country, potential victims should have a mechanism to bring suits. This forum should be able to supersede international agreements. At the present time, the UN is the only forum that exists, but more legal authorities are needed for such a superagency.
- o A supercourt in the US should be established for toxic insults perpetrated by US companies and multinational companies in the US.

Consciousness Raising

- o Both people and companies need to have their consciousness raised. Companies are the biggest offenders, therefore, their accountabilities need to be raised by:
 - Need accountability for companies, this means repeated offenders are punished. Pollution is a violent crime and needs to be treated as such. Companies have been sheltered.
 - Make CEO's accountable, this means CEO's and senior management are not sheltered from liabilities.
 - Make CEO's accountable, this means making CEO's and senior management give community service.
- o People need to be aware of impacts of choices they make as consumers, need new education initiative to demonstrate this to kids and adults.
- o Pollution needs to be raised to a spiritual, ethical, moral and patriotic issue.
- o Need to involve press, local and national. Organized public campaigns need to be conducted, like the anti-smoking campaign. (Responsible groups: Department of Health and Human Services)
- o People become involved when jobs are on the line; make information available about how changes can be made without losing jobs.
- o Direct civil obedience is needed to prevent new pollution in local areas, in part because cannot show people who have already had adverse health effects.
- o Need to get social groups involved, such as ethnic caucuses and religious groups.

Education:

For People

- o "Environmental Justice" needs to be a household word so voters are educated and new public officials are elected...it should be clear that pollution is a violent crime and both companies and individuals are responsible.
- o Education needs to be tailored to the specific community and to the problem. Need to educate heart and spirit as well as the mind.
- o Materials should be distributed widely throughout the community, through stores, local media, libraries.
- o Need a readily available list of what guides and pamphlets exist.
- o Citizens need to know How, When, and Where to report concerns.
- o Don't need more guidelines, need pamphlets geared toward the specific community, the specific community concerns and the specific problem, written in the right language.
 - People in the communities should produce these pamphlets, not the governments.
 - Funds need to be available to communities to develop these materials and local campaigns.
- o Retain Public Service Announcement capabilities to encourage companies to sponsor educational spots in the media.

For Communities

- o Agency sponsored training of leaders and representatives from the community to understand the potential links between health and pollution and how to frame the questions for the researchers.
- o Extend the NIEHS worker training model to other workers who handle toxic materials in communities. Experienced community workers need to have resources available from government agencies to train other communities on effective pollution prevention, intervention, and remediation.

For Medical Personnel

- o Improved guides and pamphlets are needed for medical personnel.
- o Training of medical personnel regarding environmental health during their schooling and after (CME).

Economic Incentives:

- o For people: Need to demonstrate savings by making the total cost to society and to the environment of specific consumer products widely known...the true cost should show up at the cash register.
- o For community: Make economic incentives attractive for the community by training local workers to be able to maintain and repair technological improvements to buildings, cars, factories.
- o For people: Encourage alternative materials through tax incentives, through rebates.

DEMONSTRATING THAT PROBLEM EXISTS:

- o Public laboratories should be available to community representatives for the purpose to make the testing of samples possible and affordable by the public...these samples are needed to demonstrate problem exists and often are collected and processed by the polluter, and hence are likely to be misleading (responsible parties for funding: ATSDR, CDC, EPA, State agencies).
- o Funds for such public laboratories might be made available from taxes on production of toxic chemicals.

STRATEGIES FOR ENGAGING GOVERNMENT AGENCIES:

- o Need to get social groups involved, such as ethnic caucuses and religious groups, to help identify which government agencies should be approached and how. These groups should be involved in contacting the agencies.
- o Need to approach government agencies at all levels simultaneously, that is, approach local, state, regional. Need to keep working until locating an official willing to listen.

INTERACTIONS BETWEEN GOVERNMENT (NATIONAL, STATE, AND LOCAL) AND THE PEOPLE:

- o Governments should facilitate face-to-face meetings between the community and polluters; this should help the problems of mutual understanding.
- o Governments should provide monies to communities to train community members and obtain important information needed by the government to identify problems...funds could come from industrial taxes or fees.
- o When working with establishments, the government should involve workers, not just management, in the resolution process.
- o Governments should look at the totality of the problem, not single aspects of the problem.
- o Groups need to be created in each region consisting of government, community, and industry for the purposes of investigation and implementation of viable new alternative technologies.
- o Emergency response teams involving representatives from several different agencies and departments of the government should be available. These should include emergency, technical and laboratory experts to give analysis capabilities to the problems that exist.
- o Partnerships should be formed between labor and government representatives and between the community and government representatives to improve existing documents and develop new document formats that can be understood more easily by the community.

INFORMATION NEEDS:

- o Need questions on Current Population Survey (or Census) that provide information on extent of pollution concerns. The results from these questions need to be published.

- o Health monitoring units are needed to follow up the community over an extended period of time because some health effects are expressed over long periods of time and because pollution is not cleaned up immediately.

IMPROVED TECHNOLOGY:

- o Just like road bridges, the standard for companies dealing with toxic materials should be to over-engineer for the sake of safety.
- o Economic conversion needs to be made the norm, not the hardship. It should be clear that what we are doing is not working, so we should move forward enthusiastically to world friendly technologies.
- o Funds should be available to help communities make transitions when plants shut down or plants are temporarily shut down for purposes of improving technology. Information on the Economic Worker Dislocation Assistance Funds should be more generally available. But funds are also needed to relocate non-workers.

REMEDATION:

- o As part of the remediation process, government agencies need to be forced to answer how the pollution got started and what conditions allowed it to continue. This will improve the understanding of the current situations for other sites.
- o Need emergency fund for removal of victims. These funds should be available from EPA Regional offices so they can be released quickly, without several layers of approval.
- o Part of the fines should be plowed back into the community for health services and other needs identified by the community.

INCREASED MANPOWER TO ADDRESS REMEDIATION AND DEVELOPMENT OF IMPROVED TECHNOLOGIES:

- o For new jobs and jobs conversion, environment should be a priority. In contrast to the current programs that emphasize export-related jobs, we need more jobs that are related to environment and clean-up. More workers and jobs are needed to accomplish this...perhaps these could come from military conversion.
- o Use military conversion to stimulate new technology for preventing pollution in the future.

Questions: CORE GROUPS 8-11

What are new models of disease prevention and intervention to ensure environmental justice?

1) What are effective models of disease prevention and intervention? 2) What are new models of disease prevention and intervention or issues or requests that go beyond agency mandates, resources, limitations or time constraints? 3) What are the barriers to overcome in order to create effective disease prevention and intervention models to ensure environmental justice? 4) In what ways do government agencies facilitate or hinder new models of disease prevention and intervention? 5) What are agencies doing that needs to be altered? 6) What are clearly defined areas of responsibility for government agencies? 7) How can agencies find ways to work with communities that are multicultural and multilingual? 8) What is the role of community-based organizations? 9) What is the role of workers and business? 10) What is the role of laboratory science? 11) What is the role of government agencies? 12) What are the funding mechanisms for agencies, institutions, and community-based organizations to conduct more meaningful research? 13) What are the specific recommendations to be brought forth in the plenary session?

Recommendations from CORE GROUP #8

Co-facilitators - Adrienne Hollis Hughes
- Grace Boggs

- o That communities, governments, scientists, and other academicians cooperate and work together to structure the funding, proposal design, implementation, and use of data to be gathered in order to meet the needs of each community.
- o That all involved in cooperative research efforts recognize community knowledge and experience as guidelines for the use of scientific methods of data collection. This is in order to mitigate proper assessments of impacts to social, economical and cultural aspects, and to eliminate adverse impacts to any proposed projects, etc.

The community is not limited to officials; it includes grassroots activists and educators. The community is everyone.

- o Find ways to stop the process of both the production and the disposal practices for hazardous waste.
- o Find ways to bridge the communication gap that exists between communities, government agencies and academia.

Disease prevention/intervention will occur when:

- o Researchers critically examine the assumptions, values, attitudes, questions, etc. implicit in their research.
- o Research must be done more holistically - in the context of the moral and ethical dimension. The definition of research must be expanded to include social responsibility. The domain of research must extend to more than data collection - it must include an analysis of applications. "How data may be used" should be asked.

- o The legitimate non-western European research being done by grassroots communities must stand side by side with "mainstream western scientific research."
- o In those instances when information from "mainstream western scientific research" is simplified for common folks, this is to be done so that it can be used as a tool for the people's struggle. However, great care must be taken to see that it is not unthinkingly (uncritically) accepted as valid before it has been subjected to interrogation by communities at risk to identify its hidden agendas, values, assumptions, etc., if it "fits them" it is to be used -- if not, discarded.
- o Researchers must join in shattering the conspiracy of silence surrounding people's knowledge and folk ways of knowing. People across this nation are crafting meaning from their local experiences. This must be honored and incorporated in decisionmaking by governmental agencies -- not silenced and delegitimized.
- o Participatory research and participatory action research (qualitative critical ethnography) are models of research that must be used for a new research paradigm.
- o Researchers should ask: Who is the information for? Who will use the findings? What kinds of information are needed? and for what?
- o Researchers should be clear about their research: it should be visionary, transform society and promote social change that honors the dignity of plants/animals/humans.
- o We (grassroots communities) must be careful to not depend ultimately on research or research-based decisions. The reality is: governmental decisions are political and economic. The reality in America is: Governments are saying to us: "You grassroots communities want justice? How much justice can you afford? Justice will only come through direct action, by us, now! We can't wait."

Recommendations from CORE GROUP #9

Co-facilitators - Vernice D. Miller

- Tirso Moreno

What do we need in our communities to solve our environmental health problems?

- o Less research, more action.
- o More accountability/more enforcement--compensation, education, fines.
- o Cabinet level environmental position.
- o Elliot Laws needs to meet/dialogue with environmental justice community.
- o Funds should be provided to community for information to identify environmental health problems/diseases.
- o In occupational surveillance work closely with unions. Less risk assessment, more studies.
- o Chemical research should be done prior to exposure. Risk assessment has many disadvantages.
- o More lead research.
- o More protection for lead workers because of take home lead residue that exposes family at home.
- o More federal funding for lead work in community groups.
- o Need for parity in medical intervention in child lead poisoning.
- o Primary prevention should be the reduction or elimination of toxic chemicals, including pesticides.
- o Higher fines for agricultural industries.
- o More research on African-Americans regarding stomach/digestive cancer.
- o Classify wood as a carcinogen.
- o Federal government should set aside money for cleanup in affected people of color communities to employ people of color clean-up contractors and that the communities have control over the economy of those funds.
- o Re-examine the use of the word term/label "minority." Use term "people of color" instead. Use terms such as the oppressed ethnic group."
- o Majority of further research in lead poisoning must be focused on evaluating effectiveness of hazard reduction efforts.

- o As asthma prevention
 - provide plastic covers for children's beds to control dust mites.
 - assistance in venting nitrogen oxides out of homes with gas heating
 - rat and pest control assistance.
 - current research paradigms are much too costly, and require too much time to comply while the results are usually inconclusive. The millions of dollars that are spent on research should be shifted to potential prevention and exposure.
- o We need more medical specialists who can diagnose and treat poisonings, such as pesticide poisonings, including short-and long-term health effects. These specialists must also know how to prevent poisoning to protect workers and others.
- o Doctors must be honest with farm workers. Farm workers must have the right to go to their own doctor of choice because company doctors don't give farm workers correct information about their cases.
- o There must be more training on occupational safety and health for farm workers. For example, farm workers need to know they must wash their hands before going to the bathroom so that they remove pesticide contamination.
- o Government officials--especially enforcement officials--must get out into the fields to really see what is going on.
- o Farm workers must have a national right to know what hazardous substances they work with.
- o Farm workers must get training about their rights in the workplace.
- o There must be more public information--in many different languages--to teach people about the damages of pesticides (e.g., on TV, magazines).
- o There must be a national right to unionize for farm workers.

Minority Environmental Association as a non-profit environmental organization comprised of minority businesses and professionals recommends:

- o That EPA join with other agencies such as HUD, Agriculture, DOE to have a non-partisan bases liaison (representative) to exclusively present environmental issues. This national environmental coordinator should not be of employee status, but serve as a complement to organizations such as Ben Chavis of NAACP. This representative should be funded to appoint advisory committees for the regional recommendations to EPA, DOE, etc. The ability to speak the languages of industry and feel the emotions of the community is a requirement. An upper level is required to impact the middle management and career employees of EPA and others who quietly undermined the good intention of President Clinton. This position should have access and availability to employer and inform the Black Caucus and other such power bases.

Recommendations from CORE GROUP #10

Co-facilitators - Ivette Perfecto
- H. Gwyn Smalls

To the Conference Organizers:

- o We will not leave this conference without a firm statement on why we were brought here and what the sponsoring agencies will (not just proposes to) do with the information we provided them.
- o The organizers should draft a report which should be distributed to all participants for comments. All comments should be included in the final draft.
- o Need follow-up conference. Must include--through democratic process--community representation involved in the coordinating planning process.
- o Send out survey form to participants of conference to solicit comments/recommendations about next conference.

To Government and Government Agencies:

- o The Executive Order should state that "the right to a clean environment is a fundamental human right." There should also be a Constitutional amendment stating this.
- o The Executive Order should state that everyone has the right to generate and access information regarding the condition of their environment.
- o Resources should be made available to the communities to ask the questions they want answered, and to the non-regulatory agencies to ask the scientific questions that inform prevention and intervention.
- o The U.S. Government must sign the International Convention on Children's Rights mandated in Geneva in 1993.
- o An EPA-citizen task force must be established to, within six months, rewrite Superfund Technical Assistance Grant procedures to eliminate Federal Procurement requirements for those grants and to establish federally-funded state community coordinators to help set up and guide community overview organizations.
- o Agencies should develop a mechanism by which community-based organizations can provide direct inputs back to the agencies regarding issues that affect the community. This mechanism should be easy and be made known to all citizens and public participation must be financially supported where public input is requested and/or required.
- o Lack of data should not be used as an excuse not to act.
- o Strongly encourage EPA staff to take the initiative to change the process from within to be responsive to community needs to provide training on environmental justice awareness.

Related to the Role of Communities and Community-Based Organization:

- o Related to #3 under "Recommendations to Government and Government Agencies:" Communities must control their own study funds. Allocations of funds should be on a per capita basis and 50-50.
- o Communities, by referendum, should be able to limit or shut down any source of pollution in their community.
- o Community-based organizations should educate the community about the connections ("what doesn't go into our backyard goes into someone else's backyard.").
- o Community groups have the responsibility to provide input to government agencies concerning their health and the health of their environment.
- o Provide financial support for community groups to participate in the process through attendance at meetings and conferences.
- o Community groups should collaborate with scientists in doing research (participatory research).
- o Community organizations should document success stories.
- o In doing research, citizens (as well as scientists) should be up front with articulating their bias.

Related to the Role of Scientists and Academics:

- o Agency scientists and consultants must be trained to recognize and articulate the *intrinsic* (structural) bias in the question(s) asked, focus of the study conducted, methodology employed and the "science" produced.
- o Scientists have the responsibility for connecting health protection action to their research.
- o Scientists should collaborate with communities and help them do "science by the people."
- o Scientists should continue collecting needed data, but with more input from the communities.

Related to the Role of Worker:

- o Workers should be responsible for enforcing OSHA regulations.
- o Labor should form coalitions with other groups (for instance, environmental justice, housing, etc.).

Related to the Role of Business:

- o All businesses should make public a written analysis of their technology options for not using/producing toxic chemicals. These plans have to explain why the business is not using appropriate (non-polluting) technology.
- o Corporations operate under a public charter to serve the public welfare. When a corporation violates their principle of their charter, they should lose their charter to operate.

- o There should be some tax incentives for companies that incorporate non-polluting technology, and penalties for those that pollute.

With Respect to Effective Models for Disease Prevention and Intervention:

- o Communities that have been successful in eliminating or reducing pollutants from their environment should be used as models for research on disease prevention and intervention.
- o Research on disease prevention and intervention should focus on children.
- o The focus should be on the elimination of toxics rather than the treatment of the diseases caused by the toxics and ways to get rid of the toxics once they are in the environment.
- o Post World War II local health departments developed a universal testing program for VD. With the approval of the communities, this system could be used as a model for disease prevention and intervention in environmental health.
- o These models should operate under the principle that the health of human beings is more important than the profits for corporations.

Recommendations from CORE GROUP #11

Co-facilitators Florence T. Robinson
 - Jose Morales

Legislation

- o Enact, strengthen and/or enforce legislation such that it provides equal protection to all people against environmental degradation.
 - Increase civil and/or criminal penalties for violators.
 - Strengthen legislation (such as FIFRA (pesticides), Clean Water, Clean Air, and Superfund) coming up for reauthorization in 1994 so that vulnerable or at-risk populations will be protected.
 - Redefine "action levels" to accurately reflect the population as a whole.
 - Legislate funding to address issues of environmental justice (e.g., prevention, cleanup, and remediation) with mandatory participation as necessary.

Reparations

- o Compensate all those affected by exposure to environmental and occupational hazards.
 - Create a "Superfund" for workers who lose their jobs because of environmental technologies or innovations.
 - Provide job training and opportunities for people who have lost jobs because of environmental technologies or innovations.

Community

- o Comply with partnership models in all government interventions. Decisionmaking authority must be in the community's hands. Involve communities in every step of the decisionmaking process, from the definition of the problem to its resolution.
 - Establish a training program for community individuals so that they can effectively represent their communities.
 - Fund the community training program through a portion of the permit fee.
 - Involve the community training program through a portion of the permit fee, environmental change or risk that would affect the community.
 - Ensure parity through majority community participation (at least 51 percent).
 - Bestow final veto and revocation power in the community over all permits of and for industries that affect the community. This must apply to all lands, including Federal trust lands.

Health and Science

- o The scientific community must consider, first and foremost, the health and occupational effects resulting from exposure. The health and scientific communities should recognize the community's expertise in health and environmental matters. Shift the burden of proof from the victims and onto the hazard itself.
 - Provide greater emphasis in health care provider curricula and residency training programs in environmental and health education for primary health care providers (such as medical doctors, nurses, midwives, social workers, opportunities for active health care providers).

Undertake more clinical studies in affected communities. The studies must provide the people with (health and environmental) monitoring diagnosis, and treatment of adverse health effects, as well as provide a source for data on environmental health effects. Include environmental related questions in all medical histories. Adopt a more holistic approach (which will look at the total body and the environment rather than just limiting treatment to a compartmentalized organ-based approach) when teaching health care curricula and in treatment patients.

Recommendations from CORE GROUP # 12

Co-facilitators - Anne Sassaman
- Goro Mitchell

Role of Academic Institution

The first session of this core group was devoted primarily to looking at broad issues relating to research and the role of academic institutions with communities in this effort. The following general principles were put forth:

- o There is a need for involvement of the community in design, implementation, and analysis of research.
- o Pursuit of knowledge doesn't have to be incompatible with needs of the community.
- o Academic institutions should make resources available to community and provide training as needed.
- o There is a need for dialogue between academic institutions and community, with both partners having equal status.
- o Research should be relevant to the needs and concerns of the community; research should be designed on the basis of need for solution to problems.
- o Community-based organizations can take the lead in research, being involved from beginning to end. Researchers need to take a back seat, be sensitive to language barriers and to cultural differences and values.
- o There is a need for funding/fiscal arrangement so that community has power (matter of trust). The parties can then talk about realities on both sides--researchers and community members--as communication increases.
- o Communities can design and implement their own studies--government and academia can/should provide facilitation and expertise.
- o It is important to recognize specific talents and contributions of Historically Black Colleges and Universities (HBCUs) and other minority institutions.
- o There is a need to change perspective of academic institutions and government from working FOR communities to working WITH communities.

Funding

The second session was focused on issues of giving locus of research to community and community-based organizations (CBOs). (Definition of CBO: Inclusive and representative of people most directly affected by environmental degradation.) At this point, the recommendations became more specific.

- o Utilize CBO's capabilities to allow them to manage government grant monies; include leadership development as part of program.

- o Remove reimbursable provisions (especially in technical assistance grants) and provide more flexible granting procedures.
- o Work with historically Black college and Universities to develop graduate programs to environmental sciences.
- o Have CBOs generate criteria for granting agency's programs.
- o Develop community oversight committees to oversee funding and research process.
- o Write legislation and regulations to mandate inclusion of CBOs and affected communities in process.
- o Expand grant programs in environmental justice.
- o Involve communities in planning and prioritization in budget process.

Education

- o Provide education on environmental issues at all levels and ages in settings within high risk communities and neighborhoods.
- o Use resources of existing programs to accomplish educational goals (e.g., NIOSH Educational Resource Centers); expand mandate and structure of these resources, if necessary.
- o Increase the political literacy of communities. Federal and state programs should utilize community resources, including colleges and other academic institutions to increase political literacy of communities, including how to access and work with the "insider" political process.
- o Expand health professional education and training about environmental health issues and community concerns and cultures.

Empowerment

- o Include community participation in decisionmaking, including permitting process and EIS.
- o Set research priorities in communities.
- o Assure language accessibility in all programs.
- o Assure access to information.
- o Encourage ability to turn information into action with enforcement.
- o Increase enforcement power within communities.
- o Stop all permitting until affected communities are involved.
- o Make all public participation provisions, existing and new, mandatory and implement at earliest phases of planning and development, carrying throughout process.

FINAL RECOMMENDATION

There should be an organized CBO follow-up structure to take action on recommendations and report to participating organizations.

Recommendations from CORE GROUP #13

Co-facilitators - Jerome A. Strong
- Nina LaBoy

How do community groups coordinate with agencies to ensure community input on research, policy and projects?

- o Create Pressure
 - for change
 - to get credit for ideas
 - to get agency personnel to take personal responsibility and see themselves as conduits for community concerns (agency personnel and policies should reward such behavior)
- o Create Friendships
 - with information couriers
 - with people in power
 - with other groups that can aid efforts
- o Create Win-Win Situations (when possible)
 - brainstorming sessions w/agency
 - help agencies do their work investigating options
- o Know Thy Agency
 - past history of interaction with community groups
 - specific reasons/issues to trust and distrust
- o Maintain Pressure
 - accountability hearings
 - community hires
 - agencies should include meaningful community participation in grant planning and project development and review
 - develop "best policies and practices" guide
 - place "burden of proof" on agency/industry, not exposed people
 - ensure support, funding of true representative groups selected with community input
 - call for quality of life concerns to be guiding criteria rather than traditional cost/benefit criteria

Community groups should pressure universities, academics, scientists for information on university policies (e.g. assigning toxicologists to community groups) and demand responsiveness (e.g. inclusion on board; access to state/federal funding).

Recommendations from CORE GROUP #14

Co-facilitators - Don Villarejo
- Monica Moore

Role of community-based organizations

- o Since communities have awareness of problems (may be just individuals) - are ones who are affected:
 - Often 1st to know of problems.
 - Can be ones to form organizations.
 - Can inform agencies & motivate them to take action.
- o Ideally, agency would identify problem(s) & inform community.
- o Community can demand accountability, monitoring & action.
- o Full partnership in studies, research, planning, etc., from beginning, including setting goals.
- o Should have access to & educate scientific & research community.
- o Existence of Community organizations provides forum for action & empowerment; can or should be responsible for identifying concerns.

Ambiguity sometimes arises: WHO represents "community"? What organization is truly representative? Often workplace may be the "community", or labor unions.

Role of government agencies

- o Agencies should keep track of what is going on in the communities & inform them accordingly.
- o Enforce laws & regulations: inspections, and act on results.
- o Develop laws & regulations to supplement or replace those that leave gaps.
- o Fully release information to targeted individuals, i.e. affected and interested parties, in accessible (user friendly) format, e.g. lead poisoning of child in one apartment, but residents of other apartments not informed.
- o Fund training of community & labor groups.
- o Require that all studies include cross sectional representation, i.e. gender, ethnicity unless fully justified.
- o There should be interagency and cross-jurisdictional & regional (local, state, tribal, federal) cooperation.
- o Government should aggressively support/seek alternatives, e.g. to toxic & hazardous products, rather than just be concerned with permitting & licensing - be more future oriented, such as through
 - funding of research to develop alternatives.
 - tax breaks.

- remove subsidies to companies that produce hazardous or toxic materials (pesticides, tobacco ---).
- o Work to educate congress (include congressional staff) & other lawmaking bodies regarding:
 - environmental justice
 - discriminatory impact of current laws
 - negative impact of some current economic incentives
 - potentials for positive economic incentives
- o Provide protection of every worker (worker's compensation, OSHA) independent of documentary status.
- o Hold polluters responsible.
- o Staffing & leadership in agencies should reflect diversity (ethnic, cultural, language) of populations & communities served.
- o Include genuine involvement of affected communities in decisionmaking process, e.g. representation on advisory panels & review committees.
- o Agency personnel should spend time in the field.
- o Explicit accounting for time spent with interested industrial reps and balance with community reps.

Role of Academic Institutions

- o Integrate occupational & environmental health in educational programs in medical schools.
- o Ditto in other science curricula.
- o Implement goal of having student & faculty representative of the population, hence recruit and support traditionally underrepresented populations: focus on retention (compile & publicize successful programs-AAAS?).
- o Include environmental justice (information, analysis) in environmental studies programs.
- o Ditto science education programs.

Recommendations regarding future Environmental Justice Conference, esp 1995

- o There should be regular conferences on environmental justice movement, accessible to community representatives, gov agencies, academics, scientists.
- o More practicing health scientists should participate.
- o List goals & targets year to year, evaluate on yearly basis.
 - were targets met?
 - if not, why not?
- o Agency heads (or top echelon staff) should be present throughout the conference.

- o Broaden & improve outreach (many communities were not informed, invited or contacted).
- o Let communities themselves select their representatives to attend.
- o Arrange for translation (e.g. to Spanish).
- o Make location accessible & friendly to community representatives (but don't lose gov & academics!).
- o Ensure more & better advanced notice.
- o Congressional representatives (or staff) should attend.

Action Plan: How these recommendations should be followed through

- o More for a community testimony process at local and regional level as a beginning point with scientists and government listening to coming together groups, agencies at national level.
- o Link with government employee ethics organizations (e.g. Forest Service employee group). Link with community action groups to develop and present demands at fora with consequences for not following through.
- o These processes require more money and resources than are now allocated. It is essential to identify and reallocate, and to create new sources, both from within existing agency budgets (e.g. DOE funds) and from industry (earmarking and creating new fines and taxes).

Recommendations from CORE GROUP #15

Co-facilitators - Jessie Deer-In-Water
- Charles Griffith

Three classes of recommendations were brought together by the group: (a) those pertaining to community-based organizations, (b) those pertaining to agencies, and (c) those pertaining to individuals, companies and others. In general the group was in favor of a very broad definition of the task of the Core Group Cluster 12-15, but specification as to whether the question should read, "...effective ways to {communicate with, work with, assist, help, empower} populations overburdened..." could not be settled. One participant (a minority?) disliked the question structure, agenda, etc. The majority in this core group were from community-based programs. The group had few scientists, only two people from agencies, and only one person from industry.

Community-based organizations

- o Stronger/more diverse cross-sections of the various publics (community groups, professional organizations, industrial associations and individual companies) [not just sell outs] need to be included in all agency scoping processes and reviews.
- o Funding is needed by community groups for their own technical assistance and training. Cut corporate subsidies and redirect that money to community/justice organizations.
- o Provide funding for joint worker/community training on common Health and Safety issues. Expand existing training and funding through existing approaches for the USEPA-approved RMPs (Risk Management Plans) rules and OSHA PSM (Process Safety Management) rules to increase worker, community environmental protections.
- o Promote access to and use of federal and state agency data to advocate for community groups and communities to be either remediated/relocated. Public health service agencies must advocate, not just collect data.
- o Obtaining better coordination within and among agencies requires mechanisms for communication, organizational simplification, and mission clarity.
- o It may be necessary to change the manner in which agency management is selected, developed, evaluated and rewarded for progress in the above activities. The management essentially has to be more responsive and responsible/accountable.
- o Better integration of agency efforts should be achievable in the environmental area, in terms of regulation, permitting, enforcement, and planning.
- o The ideas of Total Quality Management should be emphasized in terms of objective measures of effectiveness, how well the public is served, and how efficiently resources are used to these ends in agencies and companies.

Individuals and others

- o Many problems would be apparent to agencies and companies if managers had to live in the impacted area, so those responsible for decisionmaking should: (a) at least visit the area on a frequent or sustained basis or, better yet; (b) stay in the community, drink the water, breathe the air, etc., for an extended period.

- o Key issues are funding control, priorities and effectiveness. Little is available at the community level where small amounts of funding can be especially effective.
- o Multi-lingual oral/written communication and materials for all groups in the affected area. Simple plain language must be used at all times.

Questions: CORE GROUPS 16-17

What are new models for interagency coordination to ensure environmental justice?

1) In what ways can the community coordinate with various agencies to ensure community input on research, policy, and projects? 2) How can government mechanisms be created to coordinate their work with affected communities to make sure such work is not fragmentary or contradictory? 3) What are the barriers to overcome in order to facilitate interagency coordination to ensure environmental justice? 4) What are the clearly defined areas of responsibility for government agencies? 5) What are interagency coordination issues or requests that go beyond agency mandates, resources, limitations or time constraints? 6) What are agencies doing that needs to be altered? 7) How can we overcome the lack of interagency coordination? 8) What is the role of community-based organizations? 9) What is the role of government agencies? 10) What is the role of workers and businesses? 11) What are interagency funding mechanisms for institutions and community-based organizations to conduct more meaningful research? 12) What are the specific recommendations to be brought forth in the plenary session?

Recommendations from CORE GROUP # 16

Co-facilitators - Helen Kim
- Hubert Dixon

What are new models for interagency coordination to ensure environmental justice?

Overview

Communities and workers are those people who are most impacted and affected by the situation at hand. The other stakeholders are the layers of government agencies: federal, both national and regional, state and local and tribal. There needs to be mutual education about the functions, roles, jurisdictions, structures and enforcement powers of the government agencies and the needs and concerns of the community's constituencies. There is a need to design a research project that identifies environmental justice issues in a particular community, and how to meet those needs with the various agencies that might be involved. We need priority funding to implement the recommendations.

- o Establish an intraagency forum at all levels to add issues of environmental justice.
- o Community involvement must be strengthened.
 - Affected communities should have an equal place at the table from the beginning.
 - The community, not government, should decide how it will be involved in decisionmaking and information dissemination process. The community will decide its own representatives. Also, the community sets the agenda for meetings, not just agencies.
 - Communities need resources to hire technical and organizing experts to work with them on strengthening their ability to effectively participate as decision makers on a more level playing field with government and polluters.
 - Communities need a legally enforceable right to participate, and opportunities to seek grants to get the lawyers assistance.
 - There needs to be local community involvement in emergency response including identification of potential emergency needs, design of protocol for emergency services and training of community representatives.

- We need community input at all stages; this includes community control over the permitting and enforcement process of currently operating facilities and community control over the identification of, selection for cleanup of sites endangering the community. The community should have the right to participate in decisions about how currently operating facilities should be regulated and how old sites should be cleaned up.

o Government must be more responsible and responsive to community needs.

One of the key problems is that each individual agency (and indeed oftentimes individuals or departments within those agencies) only see the community through tunnel vision from where they are seated. The community is surrounded by tunnels, but no one in any of the agencies attempts to connect those tunnels, identify the needs of the community at the end of the tunnel or meet those needs.

There is a perception that agencies and polluters are locked in smoke-filled rooms cutting deals about issues which affect the lives of the community.

- Agency attitudes need to change and they need to learn about the community perspective.
- The government should proactively solicit community input into the design, dissemination and evaluation of health surveys.
- We need community based health registries and medical monitoring.
- Agencies should identify other agencies that might potentially be useful or helpful to the community.
- The agencies should proactively make that information available to the community as the community identifies its needs, short and long term economy, environment and health affects.
- There needs to be better staff training on resources available for inter- and intra-agency coordination.
- There needs to be a commitment on the part of management to ensure that this actually happens.
- More 1-800 numbers for agencies also need to be actively distributed in the community (e.g., supermarkets, community centers and schools) - oral and written forms that are currently available must be culturally appropriate and disseminated in a proactive manner to break down language barrier.
- Agencies must be adequately staffed and competent in culturally appropriate language and communication.
- Greater resources to agency to do things like give staff time to spend in the actual community (with the community deciding when and where) so that they better understand community needs.
- Need to know where to go to complain when community has a problem with a particular person or agency, and how to change those departments with overlapping responsibilities between agencies and where community needs go unmet.
- Federal government needs to protest when states are not doing a good job.
- Regulatory agencies should take action where a hazard clearly exists without continuing to study the problem before taking action.
- Research agencies operating in the public interest, i.e., health and environment, should not be subjected to political budget blackmail.
- Democratically unionize all federal workers so that individual researchers are not so easily muzzled, and the agencies can operate in solidarity with the communities.

Government agencies, including DHHS, EPA, NIEHS, ATSDR and others, should come into affected communities to do workshops to provide information about: research agendas and policy, the organization of each department and potential for evaluation.

Recommendations from CORE GROUP # 17.

Co-facilitators - Antonio Diaz
- Ted Meinhardt

Goals: Address the total environment (air, water, soil, workplaces) of the affected population.

Emphasize:

- Recognition of environmental contamination as environmental racism and civil/human rights issues
- Prevention of future exposures
- Intervention to stop present exposures

Through:

- Education at all levels
- Information dissemination
- Direct prevention activities
- Strong regulations with enforcement
- Prosecution of violators of civil rights of affected populations
- Improved surveillance of illnesses and biological indicators and hazards

Process

Who should be involved?

- o All activities should be coordinated by the affected communities (including Native American nations) and all relevant agencies.
- o All affected populations should be involved in all phases from the beginning to the end. Native American nations, people of color and the poor should not be left out. Established community groups should be included.
- o All relevant governmental agencies at the Native American nation, local, state, and federal levels should be involved. Local health and environmental agencies, and local zoning boards should not be left out. Include appropriate federal departments or agencies such as Housing and Justice, Urban Development (re housing), Labor (workers), Commerce (economic issues), Agriculture, Fish & Wildlife, Interior, and Soil Conservation Service.

When should affected communities and local agencies be involved?

- o At the beginning, before agencies begin to develop plans or programs and throughout the process until resolution of the problem.
- o This principle should be followed in carrying out Principle 8 of the Executive Order on Environmental Justice, before strategies are developed and not after strategies are printed in the Federal Register (for comment with 15 days).

How should affected communities be involved?

- o Democratic process.
- o Leadership development and training should be provided to community members.
- o Develop mechanisms for meaningful community involvement, such as citizen advisory groups.

- o Affected communities should be involved in all activities, such as the following:
 - Decisionmaking.
 - Prioritizing actions to be taken.
 - Public health assessment teams.
 - Technical meetings, including interagency meetings.
- o Outreach to affected communities should be constant and ongoing for expanded involvement.

What information should be available to the community and when?

- o Site-specific information should be sent to the affected communities before the site visit to provide community members with the background to ask more informed questions. The information should be sent well in advance to allow the affected communities adequate time to prepare for what regulatory agencies are asking of them.

Language

- o The site community should be defined as affected population rather than geographic community.
- o Materials must be in language understandable to the affected populations, such as printed materials in languages spoken by the affected population, alternate media resources (such as videotapes) for nonliterate individuals.
- o Eliminate technical jargon from all federal documents.

Information Systems and Clearing Houses

What should be included in the repository?

- o All relevant toxics information that could be useful to the affected communities. Information relevant to the total environment, including air, water, soil, and workplace, should be available.
- o All reports from all relevant agencies. Reports should be full reports. Report summaries should be in lay terms and in all appropriate languages understandable to the affected communities.
- o Access to computer networks for information dissemination and sharing.

Where should the central repository be located?

- o At a local office accessible to the affected communities.

Who should have access to this information?

- o All relevant organizations in the affected communities.

Who should staff the central repository?

- o Scientific and technical staff, such as toxicologists, environmental health specialists, etc., from the community.
- o Support staff from the community.
- o People who are knowledgeable and sensitive to cultural issues and communication needs of the affected community.

Local telephone hotlines

- o Purpose: For all community members to be able to:
 - obtain information.
 - report problems that can be referred to the appropriate governmental agencies
 - obtain assistance.
- o Callers should be able to remain anonymous.
- o Number should be something easily remembered, such as "1-800-Citizen." (Comment: The word citizen may be perceived to exclude non-American citizens even though all people are citizens of their communities.)
- o Hotline should be well publicized.
- o Hotline numbers should be readily available, such as on the inside cover or first page of the telephone directories (similar to emergency numbers).
- o Models of such hotlines or information sources should be looked for at local or state levels (such as system in Texas and the Ohio Ombudsman for Migrant Workers).

Environmental resource telephone numbers

- o Telephone numbers should be listed in an easily accessible place in local telephone directories.

Radio and television

- o Public service announcements.
- o Community service programs.

Guidelines on how to access and engage the Federal Government

- o Workshops in the community on health data gaps, sources of information and standardization.
- o Education at all levels (children and adults) on multiple relevant issues.

Projects

- o Demonstration projects with community and interagency involvement at selected sites.
- o Cooperative agreement programs between qualified community groups and state health departments.
- o Target hazardous industrial or community sites based on reports from the community level and other information available to government agencies.
- o Look for good existing programs to use as models for demonstration projects. Look for programs with community access to government agencies, community-involvement programs, consolidated programs or consolidated agencies (such as Chicago lead advisory group).

Funding

Uses

- o All levels from the community level to the federal level should be funded to carry out these programs. Priority should be given to affected community groups, especially Native American, people of color, and the poor.
- o Leadership development and training.

Potential sources

- o Reallocation of resources.
- o Decrease duplication of effort among agencies.
- o Fees from sources of contamination, such as manufacturers and waste handling firms.

What the Federal Government Can Do

Communication

- o Maintain contact with the affected communities.
- o Inform affected communities of all agency actions.

Resources to empower affected communities

- o Information.
- o Funding to provide the financial means for community development.
- o Grants to qualified community groups to pursue cooperative agreement programs with state health departments.

Interagency cooperation

- o To address the needs of the whole community, that is, look at the total environment, not just pieces of it.
- o To eliminate duplication of efforts.
- o To eliminate barriers to interagency cooperation, such as conflicting jurisdictions.

Training for federal employees

- o Interactive workshops to educate federal workers in cultural and communication issues to be able to sensitively and appropriately respond to the needs of the affected populations.

Regulations: Chemicals should be considered "guilty until proved innocent."

- o Require that all appropriate testing of untested chemicals be done by companies.
- o Require that consensus of safety be established before chemicals can be manufactured in order to prevent exposures to workers and communities.

Questions: CORE GROUPS 18-20

Outline a new and effective research paradigm for health research to ensure environmental justice.

1) What are effective research paradigms (past and current) that should be documented? 2) What are new and/or effective federal research activities that will be of value to communities? 3) What needs to be established to provide true community input on an ongoing basis to government agencies? 4) Define and describe how agencies gather data from communities and how this data is translated into programmatic areas? 5) What do communities wish to do regarding new and effective research paradigms that require research assistance from federal agencies? 6) Define what resources are needed? 7) What are research delivery systems that maintain community control? 8) How can we overcome barriers to change? 9) What is the role of the community-based organizations in creating new and effective health-research paradigms to ensure environmental justice? 10) What is the role of government agencies? 11) What is the role of workers and businesses? 12) What are the existing and new funding mechanisms for agencies, institutions, and community-based organizations to ensure the development of new research paradigms? 13) What are the specific recommendations to be brought forth in the plenary session?

Recommendations from CORE GROUPS #18, 19, 20

Co-facilitators -(#18) David Hahn-Baker
Sherry Milan

(#19) Pat Bellanger
Claudia Samuels

(#20) Rebecca Head
Joseph Hughes

A new paradigm for health research rejects several tenets of the "old" research paradigms.

- o It recognizes that science is a tool for people and people are not a tool for science, or government, or researchers. The limits of scientific knowledge and the value of other ways of knowing are valued and utilized in this new paradigm.
- o The new paradigm recognizes that research needs to serve the needs of the community. It recognizes the abuses of the past, that is, the use of research to delay, stall, or simply do nothing. Too often research has been designed to prove nothing, as an excuse for government inaction.
- o It is needed in which the purpose of health research is examined, made explicit, and critiqued.
- o It is grounded in the principles of community-based health research. These are as follows:
 - The purpose of community-based research projects is to enhance knowledge and promote change in ways which benefit the community.
 - Community-based research projects need to be designed in ways that empower rather than exploit the principal participants in the process.
 - Community members need to be integrally involved in all stages of the research from problem definition, research design, data gathering, use of the results, evaluation.

- Community-based research needs to be conducted in ways that strengthens collaboration among community-based organizations, public health agencies, and educational institutions.
- Community-based research projects need to produce and disseminate the findings to community members in ways that are sensitive and respectful to race, gender, and language, and in ways which will be useful for community action.
- Community-based research projects need to be conducted according to the norms of partnership: mutual respect; recognition of the knowledge, expertise, and resource capability of the participants in the process; open communication; and joint ownership.

A critical point in this new paradigm is that research is not a substitute for action, and recognizes that in many cases immediate relief and service are needed and must be provided before, while, and AFTER research is conducted.

Recommendations

- o The Federal Government establish funding for a consortium to develop a detailed model for community-based research, including practice principles and guidelines for researchers based on the overarching principle expressed above.
 - The community must be informed of the limits to any study, what it can and cannot accomplish or tell us.
 - A steering committee including no less than 50% representation from community groups should be formed.
- o Recommend and demand that NIEHS, CDC (ATSDR) establish a protocol for conducting community-based research based on the community-based research model to be developed as described above.
- o The development of community-based research programs within agencies be a part of overall agency reform, especially of OSHA. In keeping with reform and as a part of implementing the President's EO:
 - It is urged that other members of the Environmental Justice Movement strongly lobby these agencies and the Administration to adopt the 17 Principles of Environmental Justice.
 - A re-orienting of federal health research funding.
 - Accountability on the part of these agencies to commit a certain portion of funds to researchers, institutions, and entities that are truly committed to the principle of environmental justice.
- o To approach non-governmental funding foundations to encourage them to also adopt the 17 Principles of Environmental Justice.
- o Key to this new paradigm is a sense of and commitment to partnership.
 - Where appropriate, must choose cooperation over conflict.
 - Must draw from the strengths of our communities and pull together.
 - Must be guided by these principles and not our own egos and desire for power.

- o To urge the Symposium to adopt the "1993 Recommendations of the National Advisory Council on Migrant Health"² in order to address the needs of migrant and seasonal farm workers in a way not adequately addressed by the Executive Order.
- o Must redefine community and environment. The community is not merely a convenient or malleable representative who government selects for its own purposes.
 - The community itself must decide who its representatives are.
 - The representatives must be broad-based to include activists, PTA members, unions/workers, clergy, homemaker, children, elders, non-political community groups, and others.
 - The environment must include both the indoor and the outdoor, the workplace and the home, the streets (and violence), rural and urban, agricultural setting, not only the U.S. but its protectorates, developing nations, our southern neighbors -- the entire globe.

The work is not done; we must think back on how we have grown and learned from this Symposium. We must renew and maintain our commitment. A huge task is ahead of us. Let it begin.

²Copies of the **1993 Recommendations of the National Advisory Council on Migrant Health** are available from: National Advisory Council on Migrant Health, Bureau of Primary Health Care, Parklawn Bldg., Room 7A-55, 5600 Fishers Lane, Rockville, MD 20857 (301-443-1153).

Recommendations from Community Based Scientists

Leaders - George Friedman-Jimenez, M.D.
Jean Ford, Ph.D.

To achieve environmental justice, high quality applied health science research is needed that specifically addresses environmental and occupational health issues of communities/workers of color, and other impacted or high risk populations. Sustainable structural changes in research priorities, methodology, funding mechanisms and training are needed to ensure that the results of this research are translated into effective public health action whenever possible.

A strong scientific foundation for public health decisionmaking is especially critical in achieving environmental justice. At the same time, delay in enactment or enforcement of regulatory legislation may carry adverse public health impact of great magnitude. If decisionmaking is to be based on sound science, resolution of this apparent dichotomy - further study versus immediate action - will depend on both increasing the amount of environmental/occupational health science research and focusing this research more closely on public health issues of concern to communities / workers of color and other high risk populations.

The scientific foundation for rational decisionmaking in focusing and prioritizing environmental and occupational health science research should necessarily include scientifically acceptable data on incidence, prevalence and distribution of diseases of occupational and environmental etiology. Currently, these data are grossly inadequate in general and nearly nonexistent for communities/workers of color. The inadequacy of the database directly reflects widespread underdiagnosis and underreporting of these diseases. Lack of availability of clinical occupational and environmental medicine services and inadequacy of federal and local surveillance mechanisms are two important reasons for this lack of data. For these reasons, equitable access to clinical occupational and environmental medicine services is included among the research recommendations.

New Paradigm

We call upon the scientific community, communities and workers of color, other high risk populations, and the health care providers that serve them to jointly develop a new paradigm for environmental/occupational health science research. This paradigm should reflect the following points:

- o Environmental/occupational health science research should include a strong focus on human health effects. In addition to toxicology and molecular biology, essential components of this research approach include descriptive, etiologic and molecular epidemiology, exposure measurement, public health surveillance and clinical occupational and environmental medicine.
- o Applied environmental/occupational health science research should be designed and conducted to facilitate translocation of scientific results into appropriate and timely public health action.
- o To this end, mechanisms should be developed to include representatives of impacted communities and/or workers as active participants in all stages of the research process. These stages include development of research agendas, making funding decisions, hypothesis generation, planning and conduct of studies. Interpretation and dissemination of results. Education of communities and scientists in each others' issues will be key in creating successful partnerships.

- o All environmental/occupational health science research centers which receive federal funding should incorporate requisite, verifiable plans for partnerships with their local communities of color and other potentially impacted communities and/or workers.
 - Merit of the proposed partnership and communication plans should be factored into priority scores for funding of research centers as well as individual (e.g., R01) research proposals. The effectiveness of the community partnerships and public health actions should be evaluated through the same peer review and site visitation process as the scientific components of the project. Individuals with specific expertise in community dynamics and in public health and preventive medicine will need to be included as peer reviewers and as members of site visit teams.
 - Research grant proposals should incorporate plans for communication of results to relevant stakeholders including other scientists, clinicians, and representatives of impacted communities. Federal agencies providing research grants should support the infrastructure for such communication. This might include, for example, a staff person responsible for facilitating two way communication between research partners and community partners.
- o A major follow-up to this conference should be a multiagency review of existing models for such partnership plans and the development of guidelines for incorporation of partnership models in the centers. Such community partnerships might include various components, including Community Boards and/or outreach coordinators from the community, and qualified scientists with special interest and expertise in community oriented research. Autonomy of the community voice should be strengthened by requiring each center to allocate a specified proportion of funding to support those activities of partner Community-Based Organizations (CBOs) which are directly relevant to this partnership.
- o As a first step toward development of strategies to achieve environmental justice, all federal agencies listed in the Environmental Justice Executive Order should review the recommendations from the 1992 conference and incorporate them whenever possible.
- o As part of the scientific process, there should be a series of workshops and conferences to explore and develop this new paradigm, with a focus on scientific methodology as well as specific elements of environmental health research (disease etiology, pollutants, biomarkers, different exposure media).
- o In addition to these activities, we recommend that the Institute of Medicine be commissioned and funded by the NIEHS, EPA, NIOSH, ATSDR, CDC and other relevant Federal agencies to produce a report with recommendations on research, clinical, educational and public health action needs to achieve environmental justice.
- o Methodologies need to be improved and developed to address the scientific challenges of low dose and mixed exposures, social and economic factors, interaction of susceptibility and exposure factors, long latency periods, small numbers, vulnerable populations, space-time disease clusters, health effects of bioaerosols, and other difficulties of current approaches.
- o Environmental health science should not be separated from occupational health science, although separate federal agencies currently exist. People are potentially exposed to environmental toxicants in multiple microenvironments in both community and workplace, and scientific research in either setting needs to reflect this. Some of the most clearly documented

human health effects of environmental exposures, and some of the clearest racial/ethnic disparities in risk for these adverse environmental health effects have occurred in the workplace. Therefore, mechanisms should be sought to integrate research on health effects of the occupational and nonoccupational environments to the degree possible.

- o Access to clinical occupational medicine services for all workers who need them is key to diagnosis, treatment, investigation, control and elimination of a broad range of diseases caused by workplace as well as non-workplace environmental exposures. This is a critically important component in advancing our understanding of human health effects of environmental toxicants.
- o We recognize the rising impact of new molecular technologies upon models of risk assessment and disease etiology, as well as the effect that these models will have upon policymaking. Serving the public health needs of the affected communities should be a primary goal of development of these models and tools, and the policies that result.

Funding

In order to achieve these scientific environmental justice goals, major new funding must be appropriated and substantial portions of current ongoing funding should be earmarked for environmental justice initiatives. These initiatives should be targeted to the health research needs for recognition and prevention of environmental and occupational disease in communities and workers of color and other high risk populations. Specifically:

- o A major portion of ongoing and new NIH prevention research funding should be channeled through the NIEHS for environmental health science research designed to lead to public health interventions in these populations.
- o The Department of Health and Human Services should commit a substantially increased portion of ongoing and new funding through CDC to the NIOSH for occupational health and safety research and education.
- o Documentation of incidence, prevalence, distribution and nature of diseases of environmental and occupational etiology should be given a high funding priority. Mechanisms for accomplishing this should include greatly enhanced public health surveillance systems (with particular focus on sentinel health conditions, as in the NIOSH SENSOR program), and provision of clinical occupational and environmental medicine services accessible to communities/workers of color and other high risk populations.
- o Mechanisms should be sought to diminish the largely artificial distinction between the workplace and nonworkplace environments. This might include multiagency funding arrangements between NIOSH and agencies that have focused on the nonworkplace environment.
- o Substantially increased portions of Superfund monies should be earmarked for the ATSDR, EPA, and NIEHS to expand and modify current research for recognition and prevention of environmental/occupational disease in these populations.
- o Other federal agencies such as Department of Agriculture, OSHA, MSHA, DOE, FDA, HUD should commit substantial ongoing funding to improving the scientific basis of their regulations which are relevant to these populations.

- o Scientific Advisory Boards and Councils (such as EPA Science Advisory Board and NIEHS Council) should require that all members disclose potential conflicts of interest, including all sources of funding. This information should be available to the general public.
- o The Department of Health and Human Services and all federal agencies involved in environmental/occupational health science research should strongly advocate that any health care reform package provide sufficient funding and an appropriate administrative structure to assure that clinical occupational/environmental medicine services are universally accessible, and medically objective.

Education

- o Education of people of color and members of impacted communities in disciplines of environmental/occupational health science research should be a high priority. Emphasis should be on recruitment and retention as well as academic advancement of students and faculty from these groups.
- o An important follow-up to this conference should be steps to survey, coordinate and enhance existing efforts in this direction. This must be done with attention to the entire educational establishment, but particularly with respect to Historically Black Colleges and Universities (HBCUs) and Minority Institutions (MIs). A directory of people of color with relevant professional degrees as well as students currently in the pipeline should be compiled and kept up to date.
- o Environmental justice issues should be incorporated into curricula as part of the accreditation process of schools of Public Health, medical schools, and other academic institutions involved in environmental/occupational health science research. In addition, training grants funded by the relevant federal agencies should require specific curricular development related to environmental justice. In particular, curricula for Occupational and Preventive Medicine training programs should include environmental justice issues. The Institute of Medicine should address this curricular issue as they have addressed curricula in Occupational and Environmental Medicine in the past.

Enforcement of Regulations

- o As environmental scientists of color and other concerned environmental scientists, we strongly recommend that where scientifically based regulations exist to limit exposures to specific environmental and occupational hazards, these regulations be equally and effectively enforced in all communities without regard to race, ethnicity, gender or socioeconomic status. Comprehensive and equal enforcement of regulations is essential to the actualization of public health science principles.
- o We applaud the commitment of the EPA, clearly stated at this Symposium, to strongly and equally enforce existing environmental laws. In this spirit, we call on all other regulatory agencies including OSHA, DOE, Department of Agriculture, and HUD to fulfill their mandates and enforce existing recommendations equitably in the interest of environmental justice.
- o Where substantial evidence of health effects of specific environmental toxins exists but is not reflected adequately in regulations, timely action must be taken by federal and state agencies to develop and enforce effective regulations to control these exposures and prevent the adverse health effects. Efforts to make environmental/occupational health regulations reflect

current scientific understanding of health effects should be increased, especially for exposures disproportionately affecting people of color and low income communities.

Indigenous Caucus - An Open Letter

Leaders - Tom Goldtooth
 - Gail Small
 - Karen Medville

The communities of Indigenous America are in a state of grief and deprivation because of toxic contamination of our lands, air, water, and sacred web of life. A comprehensive discourse of community members attending the Symposium expressed our concerns, dilemmas, frustrations. We have come from throughout North America to listen, learn and to provide First Nations voice and perspectives to the Symposium on Health Research Needs to Ensure Environmental Justice. We are here to raise our voices as community members of our respective tribes and as members of Indigenous grassroots environmental organizations. Although we are not in attendance as officers of tribal governments, we expect to be heard in the same way as other participants of color who are here as committed citizens of their respective states. Our issues are varied and many, yet share a common thread.

Our spiritual traditions are inextricably tied to the environmental integrity of our ancestral lands. Hazardous waste contamination of our lands, and exploitation of our natural resources and intellectual and cultural property rights, therefore denies us of freedom of religion as guaranteed to us in the 1978 American Indian Religious Freedom Act. Consequences of hazardous waste contamination include the inability to practice and enforce values, traditions, and beliefs. This results in social instability, disease, violence, demographic decrease, and cultural and physical extinction.

Our concerns are defined not only by what was said but by the frequency with which these concerns were raised. We are concerned with the continuing threat of physical extinction as evidenced by the Shoalwater Peoples of the Northwest whose fecundity has been diminished so as to effectively extinguish this Indigenous group.

We are concerned that the historical and systemic threat of genocide of our peoples is recapitulated in hazardous waste contamination of our traditional lifestyle, and subsistence economic base. The bodies of Indigenous women are the first environment of our future generations. Whole ecosystems, such as the Great Lakes-St. Lawrence River Basin, are contaminated with toxic substances to the degree that our people can no longer be in primary relationship to the fish, a traditional symbol of fertility.

In spite of this burden of grief, we continue to live and work for our families and in the community. We will continue to create culturally cogent definitions, strategies and solutions to the problem of toxic contamination of our environment. We will continue to articulate the need for effective community response to and analysis of development projects which reflect the ideology of progress at the base of western economic enterprise.

A clean environment is a fundamental human right of all peoples. Indigenous peoples for millennia have developed and maintained a sustainable relationship to the land and all creation. We must consider the impact of our decisions regarding this relationship on our children seven generations the future, whose faces are yet coming towards us out of the mother earth, which is not contaminated ground. Therefore, as Indigenous Peoples, we maintain that there are no acceptable levels of contamination of our common earth.

Of particular concern are the limitations of health risk assessment methodologies currently in use by federal agencies. Risk assessment is used by the United States Government, its federal agencies, and industry to continue activities that damage all elements that sustain living things. These assessments fail to consider long-term impacts on conditions necessary to sustain the sacred web of life and the

capacity for what our elders call "continuous birth", or "continuous creation." These assessments consider only the risks involved in damaging the environment as opposed to the benefits of co-existing within the natural environment.

Our unique perspectives on risk analysis must be included in any studies conducted in our territories. All federal agencies and industry must recognize established international agreements, covenants, treaties and trust relationships between the United States and Indigenous People. This includes Indigenous peoples' territories occupied and unrecognized by the United States.

In the struggle to obtain environmental justice, we demand that all environmental and health policy be based on mutual respect for Indigenous Peoples' inherent rights and that all Indigenous governments and community members have a right to participate as equal partners at every level of decisionmaking regarding environmental and human health.

Therefore, the Indigenous Caucus proposes the following:

- o Our vision is to give precedence to Indigenous cultural and spiritual traditional beliefs over economic considerations in determining the future environment we leave for our future generations.
- o Health risk assessments in Indigenous communities must be accountable to the communities affected and must consider all sources of damage and all effects identified by Indigenous Peoples. Principles of cultural relativism must be incorporated into risk analysis, as desecration of lands and resources can lead to sociocultural injury and cultural extinction.
- o Assessments must be made of all alternative proposals, beneficial and detrimental to the environment, not merely proposals to damage the environment. Indigenous proposals must form the foundation of the assessments.
- o There must be permanent ombudsmen positions established within federal agencies interacting with Indigenous Peoples with clear oversight authority on programs involving environmental and health assessments relating to indigenous communities. These offices must be adequately staffed and funded to the satisfaction of the Indigenous communities. The ombudsman's oversight responsibilities include, but are not limited to, identifying underfunded liabilities in federal programs. These liabilities should be included in agencies' reports to Congress such as the Federal Management Financial Integrity Act.
- o We assert the right to reject levels of contamination identified as acceptable by industrialized societies.

To insure environmental justice, adequate funding must be established for implementing the Indigenous Caucus proposal to overcome lack of financial and human resources in the communities.

The United States must sign the International Convention on Children's Rights as mandated in Geneva in 1993. This Document will help to serve our children and all the children of the world, their basic human right to a clean environment.

Southwest Network for Economic and Environmental Justice Recommendations

Leaders - Richard Moore

- Jose Bravo

- Suzanna Almanza/Sylvia Hererra

- o Health impacts: define the site community as the affected population as well as the geographic community.
- o Put members of the affected community on the public health assessment team from the beginning to the end of the process.
- o Include community members in technical meetings between EPA, ATSDR and other related agencies.
- o Environmental regulatory and public health agencies should send information onsite specifics to the affected community in advance of a site visit to provide community members with the background to ask more informed questions.
- o Affected communities should be involved in the cooperative agreement program with state health department. Further, grant cooperative agreements to qualified community groups.
- o Involve communities at the grassroots level by using local health and environmental agencies and affected community groups.
- o Direct more resources toward involving poor and people of color communities.
- o Use public service announcements and community service programs (radio and television) to disseminate information to communities using alternative and community media in appropriate languages of the affected communities.
- o Communities should be provided financial and technical resources to participate in agencies' activities.
- o Provide guidelines to communities on how to follow up with Congress on issues of environmental public health.
- o Conduct workshops for the community on health data gaps, sources of information, and standardization. Information should be understandable to affected youth.
- o Communities should be informed of all environmental and public health agencies' activities, recommendations and actions.
- o Establish a process for affected communities to set priorities on funding for environmental justice issues.
- o Immediately develop health based standards for all pollutants on the hazardous materials index.
- o Set universal standards for emissions of particulate matter at 10 or below.
- o Prioritize funding for research of alternative processes and hazardous material in the workplace.

- o Prioritize funding for prevention or exposure of toxics in children.
- o Take immediate action to remediate, provide health services and notification where identified clusters of cancer, disease, and poisoning already exist without waiting for the burden of proof.
- o Corporate accountability: compensation to affected individuals and communities, criminal penalties and clean-up.
- o Immediately notify affected community of federal, state and local regulatory violations.
- o Track federal, state, and local regulatory violations and clean-up processes.
- o Include a mechanism for community participation in the development of Environmental Impact Statements (EIS) at the beginning of the process.
- o Incorporate socioeconomic considerations in the development of EIS.
- o Technical Assistance Grants (TAG) should be provided to communities, experts or other advisors for permitting discharges for facilities, including military facilities.
- o Enforce environmental racism violations as civil rights violation.
- o Make Department of Justice enforce law civilly and criminally if corporate practices results in sickness and death.
- o Discriminatory not to pursue both civil and criminal remedies against corporations.
- o Abolish the Warner Amendment (Doctrine of Sovereign Immunity).
- o Federal and state government have an obligation to conduct appropriate research on environmental justice issues. Failure to do so is a violation of civil rights protection.
- o Federal and state agencies should do a comprehensive inventory of all pollution sources (air, water, etc.) in high impact communities. This data should be able to be used for new permitting decisions so that cumulative effects are considered. This process should include notification to affected communities.
- o Identify environmental racism as a form of institutional violence that contributes to the degradation of the community.
- o Government contracts (Superfund and others) should be available to affected communities to review.
- o Recognize, protect and respect indigenous sacred sites and territories as vital to spiritual health of land and people.

Southern Caucus Recommendations

Leaders - Connie Tucker
 - Pat Bryant

- o Take action to help the community members before research is finished.
- o Provide health care assistance to victims of pollution, including increased training of local health care providers (but not company-controlled physicians).
- o Maintain registries of health effects -- before morbidity (before people die) -- for biomarkers, etc.
- o Enforcement of existing regulations and fines.
- o Put 1-800 # of CDC physicians for local public health practitioners to call to report trends, to help identify possible clusters of related illnesses, (for instance, in the MMWR-Morbidity and Mortality Weekly Report), like they already do for contagious diseases.
- o Support a Superfund for workers.
- o Adopt a more holistic definition of "environment."
- o Define and promote a new term for "clean-up": not just shifting contamination from one site to another, or from one medium to another; also multiple exposure.
- o Pollution fines should go back into the local communities.
- o Government agencies should completely revise public participation process -- they should be accessible to the public, improve communication methods to assure dialogue, avoid government jargon.
- o Include environmental ethics in decisionmaking, ensure broader consideration during permit review beyond one site to all possible sites.
- o Regulations must keep up with industry actions and developments.
- o Community should be in control of all research designs and methods, including health studies (design, implementation, evaluation).
- o Recognize community groups as local experts; treat them as valid and don't dismiss their input as merely "anecdotal."
- o Let community decide participation through community-based advisory boards and other mechanisms to assure "affected" community involvement. The people self-identify as a community--not the company or the town/city.
- o Documents regarding community's environmental health must be translated into the language of the people -- not scientific jargon.
- o Rather than continuing research on contaminants known to cause health effects, simply ban that substance.

- o New research areas of focus include:
 - impact on chronic exposure to environmental pollutants.
 - disproportionate impact of diseases affecting people of color caused by pollution.

Asian American Pacific Islander Caucus Recommendations

Leaders - Flora Chu
 - Yin Ling Leung

The Asian and Pacific Islander caucus met informally during the Symposium to seek a common understanding of our environmental justice issues and to find out what we each were doing in our respective organizations and agencies. Although we represent only a small cross section of the Asian and Pacific Islander population from both government and community-based groups, a grouping from those informal meetings put together these recommendations because there is a need to identify and act on environmental injustices in our communities. Thus we are calling this a working draft because it is not meant to be the definitive statement on this topic but a starting point for further dialogue and action.

"Asian and Pacific Islanders" is an extremely diverse grouping. Under this Census category of Asian and Pacific Islanders are over 49 distinct cultures (twenty-nine Asian categories and twenty Pacific Islander groups) and all the variations of languages and dialects therein. Given this categorization, it is a challenge to represent all the issues that exist within these communities and it is especially challenging when identifying issues of environmental justice. Our communities' problems are often invisible in scientific statistics and studies, and our population is low in the priority lists of research agendas because our 49 groupings represent only 3 percent of the U.S. Therefore it is important for us to come together and support each other in our efforts to have our issues identified, represented, and acted upon. In this spirit of collaboration and to create a truly representative research agenda, the Asian and Pacific Islander caucus of the Symposium presents the following working draft of our recommendations:

- o **Cultivate Authentic Representation and Participation:** Authentic Asian and Pacific Islander community participation means getting a good cross section of this population as well as getting individuals with demonstrated connections to the affected community. Having an Asian or Pacific Islander face on a panel or committee does not count as Asian and Pacific Islander participation. Getting a good cross section of those voices to the table will involve a true commitment to diversity and pluralism. Understand that newer immigrants, the most vulnerable to environmental injustices, will be at a different stage from the more established Asian and Pacific Islanders in their articulation and nature of their issues. Sometimes indigenous leadership will not be found in easily recognizable forms, or in titled positions. For example, leadership may reside in a church rather than a non-profit, or they may not even have a formal organization. To do good community outreach one must go beyond the most accessible individuals (i.e. articulate English-speaking professionals who are versed in American culture or have titles) and exhaust as many avenues as the project allows and work with the cultural style of the community. Researchers and agencies need to conduct their own ongoing needs assessments, build long-term relationships with the affected local community, develop a working understanding of their issues, and seek their participation and feedback at all appropriate opportunities, especially at the beginning.
- o **Build Language Accessibility into Programs and Projects:** Language access is a key component to doing effective projects with an affected Asian or Pacific Islander community, a large number of whom are non-English speaking. Translation equipment and interpretation staff is essential to full involvement. At the Symposium only English speakers could participate unless they brought their own interpreters. The politics of inclusion and diversity always takes time and it takes money; put these items in the budget and build it into a plan. Other components of language access include variations in formal language versus colloquial and dialect variations. Therefore, word-for-word translations of English brochures may not be the

most effective tools. For example among some Southeast Asian groups, literacy in their own written language cannot be assumed. Sometimes professional translators may use a "formal" language form that many of the less schooled in their community may not fully understand. Also, communication in a community may be orally-based, and perhaps a radio program, a community activity, an English-as-a-Second-Language class, or a person-to-person outreach may be a more appropriate outreach vehicle. Therefore, government agencies, if they seek to truly meet environmental justice needs, must build language access into budgets and do the work to find out the most effective communication avenues for the affected community.

- o **Build in Cultural Competency Requirements into Federally-Funded Projects:** Researchers and government need to understand the culturally specific ways environmental justice manifest themselves in each community. Consumption, demographic, and living/cultural patterns of majority culture Americans may not apply to our communities. Researchers and government communities need to respect specific habits, practices, institutions, and formal and informal organizational and relational norms. For example, in the case of contaminated fish, consumption patterns among Vietnamese are much higher than that of the typical sports fisher person because they are subsistence fishing people. In the case of the Cambodian community, exposure to lead may be exacerbated by their unique style of living which involves a lot of eating, sitting, and playing on the floors of their homes. Still another example is the prevalence of lead in certain Chinese ceramic ware, a source that is unique to those communities who use such dishes. On another level, government agencies need to understand that immigrant communities need to be approached with an understanding that they are not integrated on many levels, even the most basic of levels. Newer communities often do not see social service agencies or even community-based non-profits as part of their community's problem solving mechanism, so their numbers will not show up in the roles of these agencies and render their problems invisible. Cultural competency has profound implications on outreach, education, and research. Therefore a test or requirements to demonstrate cultural competency should be included in project planning and federal funding for all local and state projects.
- o **Value and Pay for our Communities' Expertise:** Many community groups and individuals do not have the resources or the kind of staffing that allows them to participate in research or attend conferences that are not directly related to accomplishing their organizational or community survival work. This has implications for research budgets and for future symposiums which should include compensation for community members' participation. If government can pay professional consultants thousands of dollars for their time and expertise, the same should hold true for those community members who know their environmental injustice situation the best. To be a participant, an environmentally-affected community member is probably taking time off from a tenuous job situation or from taking care of family. Many of the newer community organizations survive on shoestring budgets, and even directors are paid as little as \$18,000 to \$20,000 a year to run essential services for their community. Paying community people and their organizations to participate creates a situation where they are valued as equal partners in these projects.
- o **Affected Communities Should Shape Policy and Research Agendas:** To help break out of our invisibility, Asian and Pacific Islanders need more people from our communities to work on environmental justice. This means that for the long-term there is a need in the education and mentoring system to do environmental justice education, not simply nature/outdoor education, for our youth population. For now, we need community-based and community-accountable individuals to help set research and policy agendas because simply having Asians and Pacific Islander staff within research and technical fields does not mean that our affected communities are also setting these agendas.

- o Workplace Health and Safety Issues Are A Special Focus: For our communities workplaces are significant areas of exposure to toxics. Before these toxics get to a dump site or leak into a water table there are many workers in the Asian and Pacific Islander community exposed to such substances in their workplaces. For example, immigrant electronic assembly workers serve as human guinea pigs to hazardous toxins which cause miscarriages and other serious long-term illnesses and diseases. Another example is that of garment workers, mostly female, who are exposed to chemicals in fabric dyes, inhumane and unsafe work conditions, and sub-minimum wages. In order for workers to begin addressing such issues there is a need to create an environment where people can participate equally in identifying, documenting, and removing toxics and hazards from their workplaces. Such participation is now inhibited by a combination of issues ranging from lack of warnings in languages our communities can understand, economic survival priorities, lack of education and outreach, and neglect from government legislation and enforcement agencies. Recognize that the immigrant workers wield very little or no political power, so government has been slow to respond. For example, "Right to know" legislation around toxic hazards for both workers and their communities needs to be implemented and enforced at the national level, but industry lobbyists have more money and therefore more influence. Therefore, researchers and government agencies must recognize these obstacles for immigrant workers and must coordinate their efforts to break down such barriers.

- o At Every Opportunity Contradict Any Beliefs or Statements About the Model Minority or the Bashing of Immigrants: The invisibility of the many problems and issues facing Asian and Pacific Islanders continues because of the "model minority" myth, which camouflages real existing needs and pits Asian and Pacific Islanders against other groups. On the flip side of this invisibility is the growing tide of "anti-immigrant" sentiment. These sentiments detract from the serious problems facing immigrant Asians and Pacific Islanders. There is a growing tide among politicians, nativists, and even some environmentalists to blame environmental degradation and other social and economic ills on immigrants, instead of recognizing that immigrants are often living and working in areas and occupations that are the most environmentally compromised. This immigrant bashing and scapegoating must stop in order to begin addressing real needs and problems that exist in vulnerable Asian and Pacific Islander communities.

- o Recognize the Unique Situation of the Pacific Island's Indigenous People and Seek Their Expertise: For some of our Pacific Islander communities, their survival as peoples is at risk because of the nature of their environmental degradation. Therefore, sovereignty and self-determination are basic issues for indigenous people of the Pacific. Indigenous Hawaiians, Marshall and Bikini Islanders, are victims of warfare and loss of land base which is an essential part of their being as peoples. For Indigenous Hawaiians, environmental destruction ranges from military testing, geothermal development, pesticides, and the negative impact of tourism. For the people of the Marshall and Bikini Islands, the nuclear testing on their islands has left them without a homeland and concrete information has been hidden by government bureaucracy and secrecy. Given their unique status they must be involved as equal partners from the very beginning in the formulation of research agendas and the development of new protocols for responsive and successful research.

In conclusion, given the unique diverse cultural and demographic characteristics of the Asian Pacific Islander populations, truly inclusive protocols for designing research and action agendas must be developed to ensure environmental justice. In previous sessions around the impact of environmental contamination of communities of color, the discussion of impact of Asians and Pacific Islanders have

been limited to a general description of demographics. We need to move beyond that and act on these problems, and these guiding points are meant to steer us in this direction.

Multiple Chemical Sensitivities Group Recommendations

Leader - Stephen McFadden

Multiple Chemical Sensitivities (MCS) is a chronic condition of extreme sensitivity to low level chemical exposures. It typically occurs following chemical poisoning, such as by pesticides, solvents, reactive compounds (e.g. paints, glues, or epoxies), or "sick" buildings.

A number of groups of individuals with shared environmental exposures have developed MCS. These include workers in industrial accidents and "sick" buildings, those living in contaminated communities, those exposed to certain consumer products (e.g. carpets, pesticides, etc.), and now, many hundreds of Gulf War veterans. While MCS crosses all racial/ethnic boundaries, the nonindustrial/nonveterans incidence is 70-80% female, and there may be a significant bias in the economic ability to obtain accurate diagnosis.

Many individuals with MCS have been denied diagnosis, insurance coverage, accommodation in employment and housing, and/or disability coverage, with severe personal consequences. Much of this discrimination is driven by institutional liability or resource allocation decisions that are literally victimizing. Development of a better scientific understanding of MCS is essential for both justice and prevention.

The MCS community shares with other disability groups and the ethnic/minority community the experience of discrimination on environmental issues, economic oppression, and stigma. In addition, the MCS community and their experts have developed a first-hand understanding of the health effects of toxics and the diagnosis of toxic exposure, an understanding which will be of value to the broader environmental justice community.

This Conference was purportedly set up to determine health research needs to ensure environmental justice, especially for "sensitive populations". Those who through chemical injury have incurred toxic encephalopathy and/or reactive upper airways disease (RUDS), causing multiple chemical sensitivity/reactivity (MCS), were not even mentioned on the conference agenda. This group, crossing all racial/ethnic boundaries, but disproportionately including women and young persons, has been continually refused research attention by the US Government, despite National Academy of Sciences Recommendations for it; while being accorded some fraudulent industry-sponsored research. The very good research that does exist, as reported in Annual Report on Carcinogens, Environmental Health Perspectives, Toxicology and Ind. Review, and other prestigious journals, has not reached the medical community or the media, and hardly the agencies. That this group, which includes (in at least a mild form) 40% of US women and 17% of US men (as reported by NAS panel member William Meggs at an extraneously-organized breakout session at this conference), was totally officially ignored, is appalling.

MCS was not initially included in the NIEHS Environmental Justice (EJ) conference planning; so it did not make the "daylight" program as a breakout session. (We note that other groups were not adequately represented; we saw no wheelchairs at the conference, in striking contrast to the HUD conference 3 weeks previous.) Thus MCS was not included in the core group process of managed consensus. In fact, so little opportunities existed for true grassroots input, that, by the middle of the first morning, the conference organizers appeared to have all but lost control, as the people's cries for justice thundered through the hall in unscheduled open-mike, and one activist concluded that "the process was the problem", given the extent of managed communication. Thus it was not surprising that late in the conference when a MCS community representative seriously requested from the convention floor that no smoking and no perfume be used, some laughed. These issues are, however, matters of education and politics, and will be dealt with appropriately by those methods.

What was notable at the conference, however, was how groups in contaminated communities told of being labeled as "hysterical housewives", and farm worker groups told of the persistent neurological effects of insecticide poisoning. Objectively documenting such toxic effects, which are not reflected in current toxicology safety data, and disarming such oppression, are areas in which the MCS community has developed a substantial expertise. By demonstrating the social stratification of the understanding of MCS, based on the economics of diagnosis, the conference pointed out significant opportunities that exist for coalition action based on shared interest.

The MCS community wishes to thank NIEHS and its director for the opportunity to put together the evening self-directed breakout sessions on MCS at this conference, which included 6 nationally known experts. Members of the MCS community further recommend the following "health research and needs to ensure environmental justice" on behalf of themselves and all at risk of chemical injury:

- o Legitimization of Multiple Chemical Sensitivities (MCS) as a subject of discussion in the Federal research and policymaking arena is needed. Case clusters of MCS resulting from toxicological accidents are becoming larger and more frequent, and the underlying flaws in toxicology must be dealt with. While MCS is "controversial" due to liability issues, basic linguistics shows that a society cannot deal with what is not named. The Federal Government must begin to speak of Multiple Chemical Sensitivities by name as a disability and environmental health issue. An executive mandate sanctioning this discussion is appropriate.
- o Better communication between Congress and NIEHS research managers on new and controversial toxics issues is needed. Examples include the Gulf War veterans and sick-carpets issues. (Note that veterans include a high percentage of minorities and working class.) We wish to see Federal research managers follow these breaking issues not only in Congress but also at National Academy of Sciences (NAS) and the other Federal agencies.
- o Federal research managers must follow prior work identifying specific needs for basic research on MCS that has been done at the NAS and the Agency for Toxic Substances and Disease Registry (ATSDR), and is currently beginning on the Gulf War veterans issue. The process that has been ongoing for the last several years must be continued. NIEHS clearly has a role to play in this subject as part of its mission to do basic environmental health research.
- o Neurotoxicity is a nonthreshold effect particularly relevant to societal risk. The \$5M at EPA Health Effects Research Lab (HERL) and \$2M at NIEHS is insufficient compared to its social significance. The Neurotoxicology research programs at NIEHS and HERL form the basis for Federal neurotoxicity regulation, and need increased support. The safety of current pesticide technology must be questioned based on the lack of pesticide neurotoxicity testing. Attention deficit disorder (ADD) is epidemic in the schools, but schools, like homes and workplaces, still use indoors neurotoxic EPA-registered pesticides which have not been adequately tested for neurotoxicity.
- o Improved basic toxicology research on non-cancer endpoints is needed. Endpoints of neurotoxicity, immunotoxicity, and endocrine toxicity are important. Toxicity screening tests must be developed for these endpoints, and both animal and clinical studies on effects of exposure are needed. Current pesticide, food safety, and toxic substance control policies fail to be protective on noncancer endpoints. Regulatory "risk assessment" approaches based solely on the endpoint of cancer are a threat to public health.
- o The regulatory basis for toxic substances which presumes to guarantee occupational and environmental safety must be fundamentally rebuilt. While 65,000 chemicals are commonly

used in commerce, basic safety data is only available on about 650 of them. Roach and Rappaport have questioned the validity of some of the human test data behind the Threshold Limit Values (TLVs); they found that some studies had as few as 12 subjects for as short as 8 hours exposure with as much as 100% symptomatic complaint. Castleman and Ziem have pointed out the potential for corporate influences in setting the TLVs. A new approach to toxicity regulation must be developed.

- o ATSDR and the National Institute for Occupational Safety and Health (NIOSH) should cease to do community and workplace health assessment studies which are "inconclusive by design", because of a lack of sensitivity of test endpoints, and a lack of study design statistical power. Invalid claims of "no demonstrable adverse effects" mock the credibility of the government. NIEHS and EPA-HERL, together with ATSDR and NIOSH, should develop inexpensive automated screening panels based on new biomarker technologies to improve the sensitivity of tests used in epidemiological studies. Panels should be developed to screen for neurotoxicity, autoimmunity, xenobiotic metabolism phenotype, cancer markers, and hormonal effects, in order to provide a foundation to support further environmental health research.
- o Increased support for epidemiology is needed. Improved physician training in toxicology is needed to improve diagnosis. A mandatory national pesticide incident reporting system is necessary to document pesticide poisoning in the U.S., and to form the basis for epidemiological studies. Current pesticide incident reporting methods (e.g. FIFRA 6(A)2) depend on pesticide manufacturers, and these reports are biased towards acute effects.
- o Support of long range goals for basic non-cancer toxicology research is needed, including: (a) programs relating to genetic polymorphisms and acquired variations in xenobiotic metabolism, requisite to protect sensitive subpopulations, and (b) research on free radical processes, needed to take into account nonclassical mechanisms of the toxicity of reactive compounds.
- o Federal support for a telecommunications network between researchers, clinicians, and community representatives working on MCS issues is appropriate. The Internet could provide backbone telecommunications, although accommodation must be made for MCS community activists who usually live in rural areas and are on limited incomes. The most efficient use of taxpayer money would be an intramural program to support Internet communication for the entire Environmental Justice community, which runs during off-peak periods on an unused Internet-linked computer system at a Federal agency such as NIH.
- o Specific proposals for basic research on MCS include: A) Federal support for an Environmental Control Unit (AC) to support clinical research on MCS, e.g. to study the utility of double-blind placebo-controlled challenge testing, and B) NIEHS support to develop animal models of MCS to support future laboratory research and toxicity testing.
- o The Department of Housing and Urban Development (HUD) should study construction materials in order to minimize the exposure of the public to toxic volatile organic compounds in indoor environments. Research is particularly needed on carpets, plasticizers (e.g. formaldehyde), and finishing products (e.g. paints). CPSC should similarly study household furnishings. EPA should study the breakdown and dispersion rates of pesticides and other household chemicals used indoors.
- o The NIEHS Environmental Justice (EJ) grant program using PHS form 398 is inappropriate to support EJ programs. While the historically disenfranchised EJ community knows the problems

to be addressed best, they may have few of the financial abilities required for grant writing and management.

- o It is recommended that a future environmental justice conference be held at NIEHS/EPA-HERL in Research Triangle Park, NC, so that the environmental health scientists may have direct interaction with the Environmental Justice (EJ) community. Quality problems are usually system design problems, and the communication barriers between environmental health researchers, the Congress, and the constituency community contribute significantly to the quality problems in Federal environmental health research. Let's bring EJ to RTP for direct talks, and avoid managed communication and manufactured consensus.
- o When "reinventing government", justice demands that disproportionate impacts upon the Environmental Justice (EJ) community be avoided. A) The MCS community expects that, in the proposed health care system, some interest groups will try to "redline" those diagnostic tests and medical treatments used to diagnose and treat MCS, in order to "conserve resources", e.g. on the grounds that "no treatment for MCS has been demonstrated as effective". Other groups suffering the effects of toxic exposure should expect the same. B) When building the new "Information Highway", members of the MCS community who may live in rural areas for reasons of health, or have limited incomes for reasons of disability, are concerned that they will become second class citizens in the new "Global Village" due to limitations on network access and bandwidth, permanently affecting visibility and employability. Other disenfranchised groups including those in the EJ community have similar concerns.
- o The Federal Government must improve the development of a consensus on environmental health research needs, to support the marketing of that research to Congress. Adequate Congressional support for environmental health research is a matter of public health.

Lead Caucus Recommendations

Leader - Janet Phoenix

GENERAL

- o More studies are needed which focus on the effects of lead on women of childbearing age who were exposed to lead when they were children.
 - what are the effects of lead stored in the mother on fetuses.
 - what are the effects of lead stored in females through menopause.
 - correlate blood lead levels in pregnant females w/fetal/child effects and cord blood and blood lead.
- o Look at the effect of lead on males.
 - effects on children
 - neurological effects on the males themselves
- o Explore dietary treatments for lead poisoning.
- o Include minority researchers and minority research institutions on research projects.
- o Assess cultural factors/racial factors and differences in lead exposure, uptake, storage, symptomatology, etc.
- o Establish deficit profiles for children exposed to lead at various stages of development.
- o Define standards techniques for compensating for deficits due to lead exposure in children.
- o Develop alternatives to chelation treatment (e.g. natural medicine, herbs).
- o Confirm whether street drugs such as heroin are laced with lead.
- o Look at the correlation between asthma and lead.
- o Ensure that there is a low or no literacy version of educational materials and communications describing agency programs and policies. Assess the readability of materials before designing/distributing them.
- o Distribute information in places where people gather, such as laundromats, beauty parlors, barber shops.
- o Make materials available in languages other than English.
- o Use more than one mechanism for getting information to the public (alternatives to written pamphlets).
- o Studies need to have a mandatory follow-up component. Once a lead source has been positively identified, then some action must be taken towards remediation.
- o We need to proactively integrate lead poisoning prevention into "health reform" initiatives. For example, to prevent lead poisoning doctors, nurse practitioners, and other health care providers should be able to write prescriptions for lead inspections in the homes of those who are most

vulnerable to lead poisoning -- pregnant women and young children in old, poorly maintained housing. When the prescription is filled by a certified lead inspector, and the inspection reveals hazardous lead levels, the health care providers can then write a second prescription for intervention services. The prescription should be the lowest intervention necessary to bring lead exposure to an acceptable level.

- o We need to determine what level of lead exposure is acceptable through scientific inquiry (what is a safe level of lead in household dust based on a clearly established relationship to uptake and blood lead levels in children).
- o We need to determine what interventions are necessary to achieve a safe level of exposure.

HOUSING ISSUES

- o We need to research strategies for reducing lead hazards in occupied dwellings.
- o We need to develop methods for incorporating lead hazards reduction and poisoning prevention work into maintenance activities in residential properties (especially public and assisted housing).
- o We should expand existing programs to address lead by taking a comprehensive approach that includes not only lead but other residential environmental toxins. To do this effectively we need to:
 - recognize that cooperation is required between housing, environmental and health agencies.
 - standardize assessment tools (ASTM, Association for Standards and Testing Materials, is beginning to develop a standardized tool for comprehensive environmental audits for residential properties).
 - develop a housing database to track houses which have been assessed, which have received intervention services, etc.
 - require a comprehensive environmental audit -- not just information sharing -- as part of real estate transactions.
 - develop technology to be used by technicians performing audits.
- o HUD needs to help build the capacity of community-based contractors to participate in solving the lead problem by:
 - significantly subsidizing hazard insurance.
 - providing no-cost training.
 - mandating that all HUD work require that some work be set aside for community-based service providers, including contractors.
 - establishing small-business support programs.
- o There needs to be an ombudsman office or program which can facilitate communication between federal, state and local agencies dealing with housing/health/environment in each HUD-grantee city and/or state.
- o Our "reformed" health system should cover filling prescriptions for housing inspections and interventions. This concept should be piloted in a small, at-risk community now, before health reform is completed.

- o We need to focus on housing-based lead policies to emphasize the targeting of areas where lead hazards are likely to be found.

HEALTH ISSUES

- o Congress should require HHS research on determining:
 - what costs lead abatement expenditures save for government and the public; and
 - how the money to do abatements can come from these sources of savings.
- o Congress should fund HHS demonstration projects to study the cost-effectiveness of Medicaid reimbursement for:
 - "environmental investigations," to determine whether children ages 0-7 or pregnant women under the age of 21 are exposed to lead;
 - lead abatement in their home or another place where they regularly spend time, as necessary EPSDT preventive health measures; and
 - lead abatement in poisoned children's home or another place where they regularly spend time, as necessary EPSDT treatment services.
- o We need to determine what lead levels insure low lead risk to children and the lowest level of intervention necessary to achieve these low levels. Current standards of exposure are not based on human health.
- o Include WIC (Women, Infants and Children program) in outreach for lead. When a woman establishes that she is pregnant, she should be able through the WIC program to receive prescriptions for inspections and interventions. Medical insurance should pay for filling these prescriptions.
- o Medical insurance should cover the cost of chelation therapy whether it's administered on an inpatient or an outpatient basis.
- o In communities at high-risk, we need to identify the health care providers and do very targeted outreach with them. This should be done in concert with housing agencies.
- o OSHA/NIOSH need to define lead-hazardous aspects of operations and maintenance work.
- o NIOSH should investigate the environmental impact of razing buildings in which environmentally unsound substances are present -- including -- of course lead.
- o Establish a tripartite working group of representatives from health, housing and environment agencies.

ENVIRONMENTAL ISSUES

- o NIEHS and EPA need to explore:
 - the impact of demolition work;
 - what lead exposure levels keep children at low risk; and
 - low level interventions that can produce low lead levels.
- o We need to develop comprehensive environmental audits for residential environments.

- o EPA should continue to fund Regional Lead Training Centers for the next five years. This would provide coverage for the time period when demand will be greatest.
- o EPA should provide subsidies to the Regional Lead Training Centers so that they can offer courses at low or reduced cost to low income/minority individuals, small and community-based contracting companies.
- o EPA should improve the satellite formation process for regional lead training centers so that satellites can be established in high risk communities.
- o More resources need to be made available to local health departments so that they can have trained individuals available to work with public on lead issues.

ABATEMENT FINANCING

- o When establishing financing mechanisms for abatement take into account the money that the building owner will save by doing the abatement: e.g. at the end of the abatement process the building owner will have saved the cost of:
 - a new paint job;
 - new walls;
 - new windows;
 - new sills;
 - new doors; and
 - lower ongoing energy and other maintenance costs.
- o Congress should require HUD research on determining which costs often included in "abatement costs" are actually costs to meet other obligations such as:
 - during code violations and structural defects;
 - rehabilitation and modernization (when this occurs abatement is virtually automatic and should not be considered a separate cost);
 - lowering ongoing energy and other maintenance costs;
 - increasing property value; and
 - averting personal injury litigation.
- o HUD should research whether interim controls and other hazard reduction options are inefficient and wasteful because they are only temporary and will have to be redone or repeated again and again.
- o Congress should take a leadership role in implementing acceptable standards of care for housing, including providing incentives for landlords, without lowering these standards.
- o Title X should make clear that its various provisions nowhere limit citizens' rights to enforce compliance by local governments, PHAs, and landlords.

TITLE X

- o "Accessible surface" should include all surfaces that form an edge or protrude from a flat surface.
- o "Risk assessment" and "Inspection," investigate hazards properly, need to include an evaluation and report of all damage and deteriorated painted surfaces and fixtures.

- o "Interim controls" need to be more stringently defined and enforced as landlord and PA (not tenant) responsibilities, the time period needs to be defined as short term and ongoing monitoring by the PHA, HUD, or an independent party needs to be required.
- o "Target housing" should include pre-1978 housing even in jurisdictions that banned lead paint earlier, as lead paint could have easily been acquired in neighboring jurisdictions.
- o Notice requirements for public and private housing: these requirements need to make definitively clear that notice to tenants of any lead paint in their housing does not limit the landlord's responsibility to rent habitable housing free of safety and health hazards.

Concept Paper on Lead Abatement Enterprise Zones

There is a tremendous need to develop new strategies and approaches to financing abatement of low income dwelling units. Although there are financing mechanisms available for public housing, little exists to aid the private owners of low income units in financing lead hazard reduction activities. When a child is identified with an elevated blood lead level, the focus is on the individual unit where the child resides, not on similar units in the neighborhood which are placing other children at risk of poisoning. A good percentage of units which continue to poison children on an ongoing basis fall into this category. They are privately owned and they are clustered in neighborhoods that are low income where traditional financing mechanisms such as home equity loans are largely unavailable. Many units exist that are privately owned where the owner may occupy the dwelling or rent the unit to relatives. Legal remedies which respond to the identification of a poisoned child in these premises severely penalize the low income owners of these properties. They are unlikely to be able to finance abatement with existing resources. Sufficient equity may not exist or equity financing may be unavailable. Redlining of low income neighborhoods still exists. Cities which take aggressive action against owner occupants may be forced to place liens on the property which may result in its eventual loss. Municipalities may deem properties uninhabitable forcing the family to move or the children to be relocated.

Landlords who are unrelated to their tenants have a tremendous incentive to avoid renting lead units to families with children. They fear the potential liability. Yet, the property values or the income generating potential of these units may not be sufficient to cover the cost of investing now to make them lead safe in the future.

An approach is needed which will target housing which has a track record of poisoning children. This approach needs to provide temporary relief from the threat of liability as well as affordable measures for owners and landlords to make these homes lead safe. This approach also needs to create identifiable areas of lead safe housing located in neighborhoods where the risk of lead poisoning is greatest.

Creation of lead enterprise zones

In many cities registries exist of cases of children identified with elevated blood lead levels. In some cities these registries date back to the early 1970's. By cross referencing these address registries with housing data it should be possible to identify the sections of the city which have generated the bulk of the poisonings. In cities where no registries of cases exist, tiger file data on age of properties and numbers of children can be used to identify target areas.

Financing Mechanisms and Incentives

I propose that in a selected group of cities, these sections be designated Lead Poisoning Enterprise Zones. Dwellings within the enterprise zones would be eligible for special financing mechanisms to make them lead-safe using a variety of local, state and federal mechanisms including but not limited to: low interest loan funds, community block grant development monies, weatherization monies, and other federal housing and economic development funding. In addition, owners of property in these zones would receive special exemptions from tort liability if they undertook measures to make their properties lead-safe. Dwellings made lead-safe would be noted as such in public housing records.

Abatement Training for Zone Residents

Training would be made available at reduced or no cost to residents of the zone who desired training in lead abatement. These firms or individuals would receive certification, creating a pool of labor which would be available to property owners in the zone. Incentives would be developed for property owners to hire local firms or individuals for work in the zone (for example, eligibility for loan funds).

Conclusion

The benefits of such an approach are fourfold. First, it creates incentives to property owners to make high risk housing lead-safe. Secondly, it provides lower cost mechanisms to do the work. Third, it creates job opportunities in lead abatement for low income people in the neighborhoods where the work most needs to be done. Lastly, such an approach should bring us closer to our goal of cleaning up the worst properties first, and result in a more dramatic reduction of the numbers of children with elevated blood lead levels.

Northeast Environment Justice Network Recommendations

Leaders

- Janet Phoenix
- Gwynn Smalls
- Vernice Miller

We, environmental justice activists, have come from states, regions and tribal communities throughout this country to attend this Symposium. We, the grassroots people, are those who bare the burden for the country's environmental degradation.

The scientific and analytical methods employed by the Federal, state, and local agencies have been working against the public health of impacted communities and have not been implementing policy to enforce clean-up, improve the health of residents, and prevent more chronic illness and death from toxic substances. Traditional science has consistently failed to demonstrate the adverse health effects of toxins in our neighborhoods.

Environmental health science systemically delegitimizes the realities of sickness and suffering. Community-based research is actively excluded from the scientific discussion of our problems. Furthermore, traditional science has significantly underestimated health risks, and regularly omits, suppresses, or destroys information critical to our environmental health. There is a huge disparity between scientists' and communities' standards for the burden of proof.

All of these concerns about how environmental science is done must be challenged and addressed in a new paradigm that is inclusive and respectful of community-based expertise and research techniques. Furthermore, we must support the scientific capacity of our communities by redressing the systematic exclusion of people of color from the practice of environmental science.

Science has a moral obligation to lead to policy that swiftly protects our public health. This government and this Administration have a social mandate to draft and to reenforce such policy. The time is long past due for action.

- o We call upon all environmental health science conducted in our communities to shift the burden of proof:
 - in epidemiology, assume that nature is polluted and look for evidence to the contrary,
 - in toxicology, to assume a chemical is toxic unless there is evidence to the contrary.
- o We call for an immediate ban on a host of chemicals that are already known to cause disease and death, such as lead, benzene, PCBs, and organ-chlorine compounds. The sale and production of these products should be banned in Mexico and other countries as well.
- o We call for accessible health care to diagnose and treat victims of environmental poisoning. Any comprehensive strategy must include accessible community-based occupational and environmental health clinics.
- o We call for an end to market-based strategies for pollution control, which make an asset out of deadly toxins and prioritized profit over health. These strategies result in an increase in toxic emissions and a disproportionate impact on our communities.
- o We call for better government regulation and especially, strong enforcement of these regulations to bring about reduction of corporate air emissions, including mercury, heavy metals, sulfur dioxides and other toxins from industry and waste stack incinerators.

- o We call for economic incentives for development of alternative methods that do not result in the poisoning of workers and communities.
- o We call for the government to identify, review, and eliminate nuclear contamination of people of color, including tribal communities and their environment.
- o We call for immediate recognition for effective environmental health initiatives to be implemented within Indigenous Tribal Communities. The Federal Government has severely neglected its trust responsibility to adequately develop and maintain programs to address environmental health issues adversely impacting tribal communities.
- o We call for the conversion of the industry to new methods that don't produce toxic waste.
- o We call for the ban of exportation of toxic waste and toxic substances to Mexico supported by NAFTA, or to other countries such as Asia, Africa, Latin America, and other indigenous communities around the world.
- o We respect the government-to-government relationship between the U.S. Government and tribal governments, and we ask that in tribal policy development provisions be developed that would provide an opportunity for the tribal community citizens to have a voice in the development of tribal policy as provided to citizens of states and local governments.

The suffering in our communities is real, and we are building movements and taking action. The government and science must follow the leadership of community-based movements to defeat environmental injustice.

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APPENDIX B

INTRODUCTION

The Symposium on Health Research and Needs to Ensure Environmental Justice was designed as a working conference whose goal included the formulation of recommendations shared by community leaders, representative from diverse government agencies, workers, business and academic representatives and the broader scientific community. People registered for the Symposium worked within one of twenty core groups whose purpose was to provide opportunities to discuss substantive issues raised in breakout groups and plenary sessions.

Approximately 25 people constituted each core group which was supported by the services of two facilitators. Each group met three times throughout the Symposium for at least one and a half hours each time. To maximize effective exposure to the diversity of the Symposium activities, each core group sought to have some members present at the scheduled plenary and breakout groups. Core groups empowered individuals to bring experiences and information from the Symposium session to the discussion.

The core group provided opportunities for individuals to share, integrate, and summarize key Symposium issues in order to help individuals process information. Specifically core groups recommended new health care research paradigms, new intervention and prevention strategies, and new ways for interagency coordination to be carried forth beyond the scope of the Symposium. Each core group was given a list of different questions to address throughout the Symposium in order to make strategies and solutions an integral and ongoing part of the Symposium. Facilitators helped focus the discussion and worked to make sure that the group's information was recorded.

Good, sound recommendations drawn from the cultural and geographic diversity of leaders at the Symposium were deemed important for effective follow-up, and to move us beyond the boundaries of this Symposium. In core groups no one person was designated a content expert, but everyone brought expertise or information from breakout groups and from personal and professional experiences. The core group pedagogy allowed everyone to become teacher and learner, and thereby increased the level of participation. The questions were posed to help structure the responses reported during the Symposium's wrap-up session. For this summary report, the questions posed to each core group prefaces the group's recommendations.

The Core Group Process

The following is a narrative account of the process prepared by JoLani Hironaka of the Asian and Pacific Island Caucus and the Santa Clara Center for Occupational Safety and Health and was adopted by Core Group 8.

Our goal was to focus on a single specific community-based environmental justice problem. Communication barriers included barriers to both listening and speaking; the unconscious collective tendency to marginalize multicultural perspectives and to elevate a mainstream cultural dynamic; historical alienation from and distrust of "science" and "government"; and unfortunate word choices.

The specific ways in which persons representing community-based perspectives achieved communication and collaboration with scientists and government agency representatives provided a constructive model for future work. Similarly, persons bearing research-based agendas and/or representing government agencies discovered ways to understand and collaborate as equals with community people.

This process allowed participants to achieve respectful working relationships with diverse constituents of the environmental justice agenda. Although time was short, the group began to apply a working understanding of how health research and government action can be responsive to community-based problems. Responsiveness to environmental justice needs requires change at the personal, professional, and institutional levels.

Although this group was randomly assembled, the overall process and the transformations which resulted suggest elements of a preliminary framework which may be incorporated into a new environmental justice paradigm.

The First Day

A SET STAGE: After eight hours of plenaries, technical panels, and speechifying, many attendees from communities fighting environmental inequities went to the first core group meeting feeling exhausted, frustrated, and disrespected. While people from subordinated communities described the conference as a subordinating experience, the choice of words such as "your researchers," "science is used against us," and "the government never listens," triggered defensiveness among others in the group. One researcher advised community people to learn the language of science, causing additional heated reactions. Our facilitators did an admirable job of giving each person a chance to speak and summarizing the views expressed, but the content was pedagogical pandemonium. Much time was spent simply reacting to one another.

A PROCESS SUGGESTION: Someone observed that the conference agenda created an imbalance which left community people largely in the position of responding to the agendas of government and science with no reciprocation. She suggested that the core group make community agendas the focus of the next meeting through a fishbowl process. Grace attempted to elicit clarification. We could focus on the environmental agencies and researchers could respond to that community; those understanding the community agenda would be the "experts" at outlining the issues. We left the first core group meeting contemplating this possibility.

The Second Day

The chanting during the morning plenary session on Day Two ("We're fed up! We're fed up! and we're fired up! And we're fed up!") caused streams of people of all colors to leave the Arlington Ballroom with disgusted or uncomfortable looks on their faces, reporting that a "demonstration" had erupted. What was seen by some as a negative event was a catalyst for cooperation in our core group.

CONSENSUS ON A PROCESS: The facilitator summarized the previous core group meeting and asked for process suggestions. Some expressed the desire to try the fishbowl to achieve something constructive. Others needed to vent feelings of alienation in reaction to others. Gradually, most people put their reactions aside and listened quietly, waiting for an agreement to be reached. It seemed that some people became able to distinguish whether a given comment was relevant to a choice of process. Gradually there was a meeting of the minds, that we would ask a community person to share with us the environmental justice objectives of his/her community to be the focus of the group.

CONSENSUS ON A FOCUS AND GOAL: A woman said she had been planning to just sit and listen during core group meetings, because she had felt that the conference was not for her, but that for now, she would agree to share with us the needs of her people.

Hine, of the Maori people of New Zealand, said that her goal is to help the Maori children, especially with their identities.

Members of the circle asked for clarification. Hine explained: The children are separated from the land where their placentas are buried, and they need to know who they are. The women are having jelly babies. We have many dump sites. We think the jelly babies are caused by the dump sites, or maybe the incinerators; we don't know. We want the scientists to help. Fifty years ago, the U.S. Government came to them on the Bikini Atoll and asked to borrow the island for a couple of months."

Another member of the group explained, "They tested nuclear bombs on the island and on the people. The army gave us soap and told us to wash in the ocean to clean it off. Later, they scraped off two feet of soil from the entire island and replaced it, replanted the coconut trees. But when the roots of the trees reached below two feet, the contamination continued."

Hine said, "We want to return to our island. We want to stop the jelly babies. The mothers carry the baby all the way, but when it is born, it is only jelly. No bones."

INITIAL DYNAMICS: Members of the group contemplated the magnitude of this problem. For some, it was a learning experience to internalize genocide. Here and there, a few people forgot the focus; instead they spoke about their own concerns and did not connect them at all to the focus on the Maori people. Others spoke in an analytical and questioning mode, which was inappropriate. Hine said, "I am an expert in knowing the problems of my people, but I only have some of the pieces of the puzzle. Each of you has a piece of the puzzle, and I want you to share them with me. But you must meet me halfway."

The facilitators closed the second meeting asking all to let the problem "sink in."

The Third Day

TIME FOR FEEDBACK REFLECTION: The group agreed to the suggestion that we set aside fifteen minutes at the end during which each person could share a reflection, suggestion, or criticism of any kind.

FURTHER BUY-IN AND CLARIFICATION NEEDED: On the final day, the facilitator was determined to get the group down to business, while others came with fears and reservations.

One woman said, "I'm from an agency, but I've been there less than a year. All through this conference, people keep referring to The Government. Well, I'm Government, but I don't have any power. I'm afraid that when we talk about what government can do, I won't be able to give you what you need." The facilitator asked the woman to save this comment until the reflection period, which caused her to feel alienated. Some could see that this woman needed to express that caveat in order to focus on the Maori people.

Another woman said, "Yeah! I don't buy this split between 'Science' and 'The Community.' I am a scientist and I am from their community." Another agreed: "I live on a contaminated landfill, I am an African American woman, and I am a scientist with a government agency." These sentiments were ones which individuals needed to get on the table in order to buy into the process.

BUY-IN CREATED A BROADER DEFINITION OF COMMUNITY: Someone clarified that the only "line" being drawn there was the one which the group had chosen: between Hine and her people, and the rest of us in order to identify ways to respond to the Maori agenda, which helped bring the group back together. In expressing these sentiments, however, those speakers caused a new realization within the group: by challenging the science/government/community distinctions, these participants awakened for some the realization that each of us has a "community" or possesses the capacity for community, and that communities can assist other communities.

HEGEMONIC RELATIONSHIP AMONG COMMUNITIES: It was instructive for some scientists and agency people to hear from scientists of color speaking passionately about their community identities, because they began to ponder their own capacity for community. People also began to think about how their agencies functioned in relation to other communities, especially whether the relationship marginalizes community views.

WAYS OF KNOWING: CAN THERE BE A MARRIAGE BETWEEN SCIENCE AND COMMUNITY KNOWLEDGE? Another said, "If I am going to go to my agency and ask to work on the Maori agenda, they're going to ask me, "Where's the proof? What proof do you have?"

An African American woman professor responded, "The community has its own science, or way of knowing. "Science" must validate citizen epidemiology. The oral histories of the people should have equal legitimacy."

Another said, "Remember that a basic element of the scientific method is the principles of observation. The people know how many are dying of cancer, and giving birth to jelly babies. The people have observed things which an outsider cannot see. They remember the flock of birds that used to nest on the west side of the island. The demand for proof has got to respect what the people know."

A clinician shared that he was realizing that the way in which he interviews patients based on a "clinical" problem may not ask the right questions to address the bigger environmental justice problem.

Another person burst out, "I'm realizing that in legitimizing what it legitimizes, science actually de-legitimizes the knowledge of communities, or community ways of knowing."

SELF-DETERMINATION IS A GUIDE: A toxicologist said, "I fear that the Maori people have been permanently, genetically damaged. Who am I to tell them that? What are we supposed to do about that? Do they want to figure out who, if anybody, has the best chances to reproduce?"

Another responded, "We have to tell the Maori people then let them decide what it is they want next. It's a process of communicating. That way, environmental justice research needs to flow from the community's desire for survival and self-determination."

ENHANCED POWERS OF LISTENING, CLARIFICATION, SELF-REFLECTION, AND PROCESS-CONSCIOUSNESS: Over the course of this group conversation, our language began to change. People consciously chose to speak in terms of "we" instead of "us and them". We chose to rephrase "talking to the people" to become "listening to the people" and "working with the people". When someone suggested that an ecological risk assessment be conducted on the island, another said, "You need to explain 'ecological risk assessment'. Hine, do you know what an 'ecological risk assessment' is?" to which she shook her head no. After discussion, we decided it would be a good idea.

Our way of interacting began to change as well. Each began to think before speaking, about whether the Maori people were at the center of the thought or comment. As a group, we became able to resist getting off track by a stray but compelling remark. For example, when a person joined the group late in the process and offered a verbose comment, the group listened patiently and then got right back on track.

Similarly, as a group, we became able to gently chide each other on process interruptions. For example, when someone could not help but speak out of turn to offer an excited revelation, the group laughingly indulged the person. When the same person again spoke out of turn, the facilitator made gentle "ah, ah, ah, ah" sounds to remind him he was speaking out of turn. Hine joined in, then

others in unison: "Ah, ah, ah, ah,...." until everybody laughed together in recognition. This event demonstrated that process deviation can ultimately be handled in a team-building or even affectionate manner.

One person observed that time was running out. We were still talking about how to put the Maori people at the center rather than doing it, and grooving on our own revelations. We turned to Hine to ask what she would have us do. She said, "I think I just want to listen. I want to thank you for doing this. After three days, I finally feel that I can trust you, that I can communicate with you from my puku, here, from my spiritual center...".

At that moment, something very large clicked into place. Hine's words, spoken from her spiritual center, touched the spiritual center of everybody else in the circle. We flashed on this symmetry, on the "we" which had succeeded in making Hine feel that she was the center, and feeling "centered" at that.

With twelve minutes left, we needed to wrap up. Each person very briefly shared his or her own unique version of being transformed and reenvisioning environmental justice as the result of this process. There was deep gratitude and emotion expressed, through words, tears and hugs. There was a sense that we had created a community, and that we could continue to work together.

OUR RESOLVE:

We want to continue this process of focus on the Maori people. We want to know whether the Maori people have been genetically damaged, whether there are any therapies. We want experts on childhood cancer, reproductive harm, pain, and other areas to help the people now. We want to access all information held by the U.S. government concerning the testing and effects of testing on Bikini Atoll and seek to declassify information to the fullest possible extent. We want an ecological risk assessment to determine whether the people will ever be able to return to the island and live healthfully. We want to identify data, therapies, and other information developed under similar circumstances throughout the world: Japan, Chernobyl, etc. We want to leverage our professions and our communities to assist the Maori people.

We will meet one month from now by conference call through ATSDR. We hope to share any progress made and support each other's efforts to understand and apply the lessons learned through this process. We will conference call each month for one year, and then convene in New Orleans.

Address of the person who prepared this:

JoLani Hironaka
Santa Clara Center of Occupational
Safety and Health (SCCOSH)
760 North First Street
San Jose, CA 95112

Appendix C

**Evaluation of the 1994 Symposium on
Health Research & Needs to Ensure
Environmental Justice**

EXECUTIVE SUMMARY

On February 10-12, 1994 over 1,000 individuals from all regions of the United States attended a Symposium on Health Research and Needs to Ensure Environmental Justice. The report presents the evaluation of that Symposium. Six Federal Departments or Agencies and many community environmental justice organizations planned and sponsored the Symposium. A major priority was to include in the Symposium individuals with a broad range of areas of concern and backgrounds. In addition, five major goals for the Symposium emerged from the planning process:

- 1) To provide opportunities for community participants to influence priorities and agendas for health research during and after the Symposium;
- 2) To provide opportunities for discussing and/or developing new models of community government interaction and cooperation;
- 3) To transfer information to participants about environmental health and justice topics;
- 4) To gain wider public visibility for environmental justice as a political/policy issue; and
- 5) To encourage individuals from affected communities to pursue careers in the environmental health sciences.

The evaluation findings focus on these five goals. Over 25% (268) of those who attended the Symposium returned evaluation forms. Unfortunately, we have no way now of finding out how representative these respondents are of all those who attended. Because of this, no attempt is made below to generalize the findings to all Symposium participants. The findings do, however, reflect the views of those who returned the evaluation survey questionnaires. Those findings support the following conclusions:

- 1) Most of the respondents thought that the first four of the five goals had been at least partially or well accomplished by the Symposium (scores of 3 or 4 on the scale of 1-4 shown in Table 2). A very sizeable (80%+) majority of the respondents likewise thought that these same four goals were somewhat or very important (scores of 3 or 4 on the 1-4 scale shown in Table 3).
- 2) Of the respondents who thought the four central goals were important, most also thought those goals were somewhat or well accomplished by the Symposium (Tables 4 and 5).
- 3) Most of the respondents felt that the Symposium as a whole met their needs somewhat or well (3 or 4 level responses, on the 1-4 scale shown in Table 6). This pattern holds for the various types of sessions, with some variation in the percentages.
- 4) The comments written on the evaluation surveys generally reflect the patterns shown for goal attainment and needs met, with relatively small percentages of respondents making clearly negative or dissatisfied comments.
- 5) The Symposium as a whole was successful in meeting fairly equally the needs of male and female respondents. Greater differences in average levels of needs met were found for the other background/organizational characteristics. Unfortunately, low numbers of respondents in many categories and the limitations noted above, make it difficult to draw definite, firm conclusions as to the relative value of the Symposium for these different types of respondents (Table 9). Most of the averages for each background category in Table 9 are above the midpoint of the range. This suggests that most of the different types of respondents had generally positive reactions to the Symposium.

The following recommendations are based in part on these five conclusions:

- o The success of a meeting reflects the meeting goals, and how appropriate these goals are to the meeting participants. Organizers/planners of similar meetings in the future would do well to specifically identify in advance the audience(s) (types of participants, identified by interests, perspectives, values, etc.) and goals of the meeting. It would also be wise to gather information before the meeting as to the extent to which the audience(s) shares those goals, in terms of viewing them as important.
- o Planners may want to learn the audience's expectations and yardsticks for success, in order to better meet them and ensure a successful meeting. Important audience goals and measures for success may include any or all of the following: the numbers of different types of sessions; opportunities for audience participation; and ease of obtaining new information on their topics of interest.
- o It is also advisable to identify other needs, besides attaining specific goals, held by the audience. These may include social or emotional needs (e.g., meeting new people, forming closer bonds with others in similar positions, reenforcement of shared values, etc.). They may also include motives or orientations not shared by all other participants.
- o Comments by participants often show their perspectives and assumptions. Such assumptions may inform the planners and facilitators of similar meetings. The comments presented in Appendix B, and the recommendations from the Core Groups of the Symposium, should be seriously considered by planners of future meetings on this topic.
- o Tradeoff decisions are unavoidable in planning and carrying out meetings such as this Symposium. Tradeoffs may be between goals, between broad versus narrow audiences (with their overlapping and/or mutually-exclusive needs), and between meeting formats (e.g., meeting characteristics like size, structure, agenda, etc.). Explicit and conscious tradeoff decisions on such meeting characteristics are important for improving the chances for success.

EVALUATION SURVEY DATA

"Industry representatives and more state and local government sectors should have been here these past 3 days."

"00", "0" The changes in agenda were very beneficial. Loved the public speak out. more public speak outs for agencies."

"Changing the format of the Symposium midstream was exceptionally important. Literature should be in more languages."

"Excellent meeting, impressed with ability of organizers to respond to group need and requests."

"I realize that organizing a conference with diverse groups and emotional issues is difficult, so I commend the organizers."

"Core groups were a great idea. Like "random" assignment. Time to meet each day. Focus questions for each group."

"The Symposium did not really address the lack of minorities in public health. I would like to see more minorities."

"Your willingness to adjust the planned agenda to accommodate the concerns of participants is appreciated."

"I know you tried to integrate community people in the planning process, but there was still a feeling of government control."

"The form is outdated."

"We need scientists and Clinton Administration to come visit the poor rural communities in California, see housing/health problems of farmers."

"A list of community organizations here should be sent to respective EPA regional headquarters. Regional headquarters should then hold open meetings."

"We need money for school and some of us could also teach classes. We know these issues and are committed and passionate."

"A very emotionally charged meeting. A lot of disruptions but very effective for getting the various players."

"Very moving emotional and not-to-be forgotten experience. Core group experience was unorganized and frustrating."

"I came to the conference to be uplifted. I am leaving depressed. I realize that government wants to act like it listens."

"More grassroot people in charge of meetings."

"Please do not have this type of meeting during winter months. I was confined to my hotel during the entire time."

"Arrived Thursday afternoon because of delays in Maine-Boston. (Weather)."

"It may have been helpful to have had something in advance, so that people would have been prepared with recommendations."

"There was too much talking at people, not enough group discussion. It helped to be able to change the agenda."

"More community participation. More community speakers for keynote."

"Registration was very poorly organized. Should have had more time to visit Congress and discuss these issues."

"Additional core groups should be devised for people with similar interest. Was unable to participate in core group due to topic."

"The Symposium seemed to take a better turn after the participants were able to speak."

"The Symposium needed to have someone giving them direction. The core groups and breakout sessions were the best."

"Need more university participation."

"This conference was very anti-science. Great respect was paid to community group needs which is wonderful."

"This is a good conference."

"A magnificent unruly, inspiring example of what re-invented government might mean. Grassroots democracy at work."

"Far too crowded original program. Too little time scheduled for community groups. Friday turned that around."

"I thought the key note addresses were excellent. Keep up the good work."

"Time should be structured. Too much going on 8:30 - 8:30 or 10:30 PM. This is not healthy."

"Need to have similar conferences in each state with funding for affected worker/community participants in each state."

"Big business big corporations are the biggest single polluter. The priority should be to create public opinion to this."

"I enjoyed my core group and was able to give input. I would like to see more people from my community to participate."

"This meeting was way too long each day."

"More open microphones. Community people need a better platform. We are the affected ones. When will you listen to us."

"Would have liked opportunity to make recommendations on other questions."

"Disorganized frustrating and condescending attitude from the registration personnel took away from the enjoyment."

"This is a poor evaluation form. Needs to be more clear. I was disgusted by the way I was treated when registering."

"Groups are split along racial ethnic lines."

"There seemed to be too much confusion about breakout sessions. There were too few researchers from NIH."

"Not enough time to allow public to express opinions."

"Provide the communities an informational session on how to communicate with governmental institutions to address problems."

"Various agencies should have had their name, address, title, listed or an alternate."

"Well organized and educational. Need to have more of these."

"No translators were provided-big concern. Participants were not consulted about core groups. Not enough info to prepare."

"I think there should have been more participation by senators and congressmen who budget these issues."

"Concerned about need for so much more dialogue between."

EVALUATION QUESTIONNAIRE

1. Please indicate on the lines below how important or relevant each goal was to you and your organization. Please indicate the importance of each goal, with a circled 4 indicating very important, and a circled 1 indicating not important.	All numbers in () are in %'s				
	Not Accomplished		Well Accomplished		
	1	2	3	4	X*
GOAL: Provide opportunities for community participants to influence priorities and agendas for health research	(3)	(8)	(21)	(65)	(3)
GOAL: Provide opportunities for discussing/developing new models of community-government interaction and cooperation	(1)	(7)	(24)	(66)	(2)
GOAL: Transfer of information to participants/learn more about environmental health & justice topics	(3)	(6)	(28)	(60)	(2)
GOAL: Gain public visibility for environmental justice as a political/policy issue	(2)	(6)	(23)	(63)	(7)
GOAL: Encourage individuals from affected communities to pursue careers in the environmental health sciences	(8)	(11)	(25)	(42)	(14)

2. We tried to accomplish a number of goals in the Symposium. We'd like your opinion on how well each of these goals was accomplished with a circled 4 indicating very well accomplished, and a 1 indicating not well accomplished.	All numbers in () are %'s				
	Not Accomplished		Well Accomplished		
	1	2	3	4	X*
GOAL: Provide opportunities for community participants to influence priorities and agendas for health research	(9)	(20)	(35)	(21)	(44)
GOAL: Provide opportunities for discussing/developing new models of community-government interaction	(7.5)	(24)	(36)	(28)	(3.7)
GOAL: Transfer of information to participants/learn more about environmental health & justice topics	(8)	(15)	(34)	(38)	(5)
GOAL: Gain public visibility for environmental justice as a political/policy issue	(10)	(20)	(31)	(30)	(8)
GOAL: Encourage individuals from affected communities to pursue careers in the environmental health sciences	(27)	(22)	(14)	(11)	(26)

* No opinion

3. The Symposium consisted of four types of sessions: Keynote sessions, Plenary sessions, Breakout sessions, and Core group meetings. We would like to know how well each type of session, and the Symposium as a whole, worked for meeting your needs. Please circle the appropriate number for each type of session below, with 4 meaning "met needs very well" and 1 meaning "didn't meet needs."

All numbers in () are in %'s					
	1	2	3	4	X*
Keynote Sessions	(8)	(19)	(33)	(26)	(13)
Plenary Sessions	(9)	(25)	(36)	(16)	(15)
Breakout Sessions	(5)	(21)	(33)	(28)	(13)
Poster Sessions	(2)	(15)	(31)	(30)	(22)
Core Group					
Meetings	(8)	(13)	(31)	(35)	(14)
Symposium as a Whole	(2)	(18)	(43)	(24)	(14)

6. Please check all times you attended the Symposium: (70) Thursday Morning; (81) Thursday Afternoon; (77) Friday Morning; (82) Friday Afternoon; (83) Saturday Morning; (76) Saturday Afternoon.

Finally, we also need to know how well the Symposium worked for the many different kinds of people who attended. For this reason we need you to please identify your gender.

GENDER: 49 Female 42 Male

* No opinion

Appendix D



Office of the Director

Telephone: 919-541-3201
Fax: 919-541-2260

National Institutes of Health
National Institute of
Environmental Health Sciences
P.O. Box 12233
Research Triangle Park, N.C. 27709

August 1, 1994

Dear Colleague:

The *National Symposium on Health Research and Needs to Ensure Environmental Justice* marked an unprecedented milestone for reinventing Government. At the symposium, Federal Government workers, community activists, labor and business leaders, and scientists worked together in partnership to set an agenda that would improve the quality of life for all Americans regardless of race, color, creed, or income. As a Government sponsor and participant, I was heartened by this experience and recommend that such partnerships become the rule rather than the exception.

The recommendations in this symposium's report are directed towards completing America's unfinished agenda of equal protection. Now is the time to develop new partnerships and policies that assure a more just and sustainable environment.

Following the philosophy of reinventing Government to be more concerned and responsible, I intend to use these recommendations to help forge an environmental justice strategy for the National Institute of Environmental Health Sciences. I encourage my Government colleagues to do the same. Furthermore, I intend to use these recommendations as guidance for my work with the Interagency Working Group on Environmental Justice which is charged with implementing the President's Executive Order on Environmental Justice (E.O. 12898).

Sincerely yours,

A handwritten signature in black ink, reading "Kenneth Olden". The signature is fluid and cursive, with the first name "Kenneth" being more prominent than the last name "Olden".

Kenneth Olden, Ph.D.
Director



Department of Energy

Washington, DC 20585

July 29, 1994

Dear Colleague:

On February 10-12, 1994, a symposium on the "Health Research and Needs to Ensure Environmental Justice" was held in Crystal City, Virginia. The Department of Energy was a co-sponsor, along with a number of other Federal agencies. Equal partners in the planning and execution of the symposium were Native American, Asian, African-American, and Hispanic community, health, and educational leaders.

About one-half of the 1,000 attendees were government officials and personnel, who actively participated with community-based personnel in the workshops and discussion sessions. The recommendations and report resulting from this symposium reflect the collaborative experiences and thinking of this diverse group of community, academic, and governmental representatives. Many of the recommendations included are consistent with the Executive Order on Environmental Justice.

The Department of Energy not only supports the concept of the symposium, but also supports the vision evident in the recommendations that come from the symposium. Like you, we recognize the critical importance of 'providing effective outreach, education, and communications'--one of the recommendations put forth. The Department of Energy is currently in the process of sponsoring seminars on environmental justice and economic empowerment in communities across the country with DOE sites and facilities. We are committed to funding Historically Black Colleges and Universities as well as other Minority Academic Institutions in the belief that it is an effective means of reaching out to those groups which have been historically disenfranchised. We are formulating an aggressive environmental justice strategy in response to the Executive Order on Environmental Justice which will require effective communications, outreach and public participation.

Overall, we will work to incorporate the thrust of the recommendations into our programs and will continue to work with other agencies, minority and underserved communities, and organizations to further the cause and goals of environmental justice.

Sincerely,

A handwritten signature in dark ink, appearing to read "Thomas P. Grumbly", is written over the word "Sincerely,".

Thomas P. Grumbly
Assistant Secretary for
Environmental Management





Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

JUL 26 1994

Dear Colleague:

On February 10-12, 1994, a symposium on the "Health Research and Needs to Ensure Environmental Justice" was held in Crystal City, Virginia. The Centers for Disease Control and Prevention (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) were co-sponsors, along with a number of other Federal agencies. Equal partners in the planning and execution of the symposium were Native American, Asian, African-American, and Hispanic community, health, and educational leaders.

About one-half of the 1,000 attendees were government officials and personnel, who actively participated with community-based personnel in the workshops and discussion sessions.

The recommendations and report resulting from this symposium reflect the collaborative experiences and thinking of this diverse group of community, academic, and governmental representatives. Many of the recommendations included are consistent with the Executive Order on Environmental Justice. CDC and ATSDR not only support the concept of the symposium, but also support the vision evident in the recommendations that come from the symposium. We will work to incorporate the thrust of the recommendations into our programs and will continue to work with other agencies, minority and underserved communities, and organizations to further the cause and goals of environmental justice.

Sincerely,

David Satcher, M.D., Ph.D.
Director, CDC, and
Administrator, Agency for Toxic
Substances and Disease Registry