

Abstracts of Conference Panel Presentations

For

*“Dialogues for Improving
Research Ethics
In
Environmental
And Public Health”*

*May 30 – June 1, 2003
Brown University
Providence, Rhode Island*

This conference is sponsored by “The Collaborative Initiative for Research Ethics and Environmental Health” at Syracuse University and is funded by a grant from the National Institute of Health, National Institute of Allergies and Infectious Disease Grant Program for Research Ethics – T15 A149650-01

CONFERENCE ABSTRACTS FOR PANEL PRESENTATIONS

Saturday, May 31, 2003

Panel One – Research Protections and Institutional Needs

This panel will review community models with building research protections for community-based research. It will also explore the possibilities of establishing regional community research centers that can aid communities in gaining research protections. Also we will review the importance of community members participating as IRBs to ensure research protections.

“Community Models for Building Research Protections”

Abstract: The Onkwata’karitáhtshera Health and Social Services Research Council (OHSSRC), Kahnawake, Quebec, Canada.

Treena Delormier, Carole Walker, Linda Deer, Marilyn Johnson, Laura Norton (council members)

Kahnawake is a Kanien’kehaka (Mohawk) community of approximately 7200 people located near Montréal, Canada. In response to the volume of research being proposed, the community health agency created a process to address health and social services research in the community. In October 2000 a newly formed, 5 member, partly volunteer research council began its mandate to ensure that any research related to health and social services received approval and was monitored. The council was given the power to make decisions by the community health agency. Strong values of collective benefit underlie the council’s vision. To date the council has reviewed various research proposals, and has facilitated and overseen research in the community. Some projects were highly collaborative and participative, had short-term benefit to the community, some had questionable benefit and one was halted due to inappropriate conduct. In our discussion we will illustrate, using examples of different projects and proposals, the characteristics of approved and disallowed research. Our work has also raised questions about ownership of data, authorship and publication, the role of the council on research projects and addressing research not in the council’s mandate. An important limitation for the council is a lack of resources to efficiently and effectively

run the council with community membership and adequate administrative support. To date it has been difficult to complete an evaluation, integrate existing knowledge on community ethics and health research into our practices and further develop our processes and procedures.

Jodi Sugarman-Brozan, *Alternatives for Community and Environment, Roxbury, MA*

“Gaining Research Protections for Communities by Participating as Community IRB Members”

Abstract: “Community” As in Community IRB Member

Susan Rose, *Human Subjects Program Manager, U.S. Department of Energy, Washington, D.C.*

Community is a multi-meaning word. Its meaning depends on what you expect from it and how you think about community in your life and your work. In the research world, it has many meanings – subjects, victims, participants, geography, activist, recipients, advisors.

My personal attention and concern and I hope contribution, lies in my efforts with “community members” of IRBs and trying to acknowledge and elevate the dedicated folks who fill that most meaningful role on IRBs. I will touch on the role, the need, the value, the problems, and some solutions (identity, education, network). I will also contrast this role with “community” as research subjects and how this dynamic is changing because of genetics and long-needed federal attention.

Susan L. Rose has been involved in human subjects protection since 1981 when she was the member of a drafting committee for the “Common Rule”. DOE has never had another human subjects program manager (Ms. Rose created the own job). Susan has created a system (of sorts) for human subjects protection at DOE and at our sites (national laboratories). Research portfolios at DOE sites span workplace studies, human factors studies, international, genetics, and cancer research.

Human Subjects Web Site: www.sc.doe.gov/ober/humsubj

Community Web Site: www.ora.gov/communityirb

Human Subject Newsletter Subscription: humansubjects@science.doe.gov

“Building Networks to Assist in Community Research Protections”

Abstract: “To Change Something, Build a new Model”

Doug Taylor, *Director of Southeast Community Research Center, Atlanta GA*

For science to work in our interests in the 21st century, it must be democratized. One avenue for accomplishing this is to engage in scientific research and intervention activities that are defined by communities and that are participatory in nature. Participatory approaches to producing new and useful knowledge will create new challenges and new opportunities for those working to build a more just and humane society.

This talk will describe the strategy and approach of the Southeast Community Research Center (SCRC)—a community-based participatory research center located in Atlanta, Georgia—to democratizing scientific research and its application. This strategy includes two tactical elements: (1) conducting discrete participatory research projects initiated through the SCRC; and, (2) activities directed towards building a southern infrastructure to support community defined participatory research projects. Project descriptions will emphasize the politics of the methods employed for identifying and capturing opportunities to conduct participatory research projects, methods for securing funding for projects, and recommendations for applying project findings in a variety of arenas. The discussion of infrastructure building will focus on the motivation for this approach, as well as, insights gained from the preliminary activities we have conducted to create a southern center.

Douglas Taylor is a founder and the executive director of The Southeast Community Research Center (SCRC), a community-based participatory research center located in Atlanta, Georgia. Before becoming director of the SCRC, he led the Community Research Network (CRN), an international network of individuals and institutions conducting participatory research. Taylor was an associate professor in the DePaul School for New Learning, where he mentored student-community partnerships for learning. He was a founder and directed adult literacy programs that operated throughout the southern Blackbelt and employed Freirean models of education and social change. He has worked in the movement for social and political rights for over 30 years. His research focuses on the politics and philosophy of the life-sciences.

Panel Two: Promoting Community (Group) Rights in Research

This panel will consider the problems of community/groups rights in research. Few guidelines and regulations exist to protect group or community rights in research. The complexities of establishing community rights, such as defining community, building community authority, mediating community differences, will be discussed. How these can be promoted with funders and IRBs and effect national research policy changes will be explored.

Section One: Project Team Presentation from the Collaborative Initiative for Research Ethics in Environmental Health On Complexities of Establishing Ethical Guidelines for Group/Community Rights

Abstract: Ethical Innovations in Community Research: Case Examples from Native Communities

Dianne Quigley, *Principal Investigator for Collaborative Initiative for Research Ethics in Environmental Health, Syracuse University*

This paper presents a review of sixteen case studies and articles of research ethics issues in the conduct of environmental/public health research with Native American/other indigenous populations. The purpose of this review is to highlight new innovations in the ethical conduct of research with Native community populations. The findings from this review can promote more dialogue and policy development on the issue of “community rights” in research. Formal guidelines exist in ethical codes for individual rights as human subjects but there is a lack of development on “community rights” in the ethics of research. This review illustrates the common research harms that can occur without such guidelines or policy development. More importantly, it offers tested field methods for improving the ethical conduct of research with Native community populations.

Dianne Quigley, is a research fellow and doctoral candidate, concentrating in ethics in the Religious Studies department at Syracuse University. Ms. Quigley is the principal investigator of a three-year grant from the National Institute on Health titled “Collaborative Initiative for Research Ethics in Environmental Health”. With an interdisciplinary team of academic and community professionals from four community-university research partnerships (UMASS-Lowell, UNC-Chapel Hill, Tufts University- Boston, Brown University – Rhode Island), she is developing innovative approaches for dealing with environmental

health research ethics. Ms. Quigley was the principal investigator of “Nuclear Risk Management for Native Communities (NRMNC)”, a multi-year project funded by the National Institute of Environmental Health Sciences (NIEHS) “Environmental Equity - Partnerships in Communication”, Centers for Disease Control and Agency for Toxic Substances and Disease Registry, a participatory research project dealing with health concerns of nuclear contamination for four Native tribal areas in Nevada, Utah, Oklahoma, and Laguna Pueblo, NM.. Ms. Quigley was also the Executive Director of the Childhood Cancer Research Institute for twelve years, a national public health organization which assisted communities with the health impacts of nuclear contamination.

Abstract: “Ethical Analysis of Group Rights for Collaborative Initiative for Research Ethics in Environmental Health.”

Ernest Wallwork, *Syracuse University*

From the outset, the culture of American research ethics, like American society as a whole, has been individualistic. Individualism narrows the broad concerns of traditional ethics to the immediate problems of isolated individuals, often cutting the individual off from others, as well as from the history of the communities—local, regional, national, international—to which he/she belongs. The language of individualism finds moral expression in utilitarian cost-benefit calculations based on aggregating individual preferences, and in the Kantian-based respect for the autonomous decision-maker that dominates contemporary bioethics, including research ethics. These individualistic ethical orientations are impoverished vehicles for ethical deliberation, because they focus on persons apart from the social traditions, institutions, roles, shared goals and environments, natural and social, without which human beings can neither survive nor flourish. By focusing the moral agent on costs or payoffs to individuals (or aggregates of individuals), apart from their communities and environments, individualistic ethics diverts attention from thinking morally about the traditions that inform agents and about the complex problems of groups seen in light of their stories, experiences, and aspirations.

In the absence of ethical discourse that embodies communal concerns, Principal Investigators (PIs) and Institutional Review Boards (IRBs) confront the daunting task of translating moral principles and rules designed to safeguard the interests of individuals to collectivities, ranging from highly structured Native American tribes and Pacific Island clans, to loosely affiliated urban neighborhoods of poor people united by little more than a few shared interests. Given the scant attention paid to the moral issues involved in conducting research with groups, it is not surprising that moral uncertainty surrounds such questions as: What moral responsibilities accompany group research beyond the familiar duties of investigators to individual research subjects? When does a group become worthy of separate ethical consideration? How do we measure harms

and benefits when the interests of individuals clash with those of a group? How should informed consent guidelines be modified to take account of particular group characteristics, such as third-world communities in which the modern Western concept of the autonomous individual is comparatively undeveloped? What moral qualities constitute a genuine research partnership with a group? Who best represents the group? And how do we think about various kinds of representation, e.g., traditional, charismatic, legal-rational, democratic? How does the researcher deal with competing representatives? Does a community have a right to demand confidentiality? Under what circumstances? When groups become research partners, who owns the data and results? What does the researcher do when his or her commitment to the intrinsic value of truth conflicts with the values of a community, for instance, protection of its reputation? If community representatives have access to research data, how is the confidentiality of individual research subjects protected? Simple enumeration of these questions underscores the poverty of our current ethical thinking about research with groups, and the importance of both deepening ethical analysis of these topics and widening the circle within which dialogue about them takes place. My goal in this paper is to sharpen our thinking about some of the meta-issues that inform moral consideration of questions that arise when groups are involved in research.

Ernest Wallwork, Ph.D. is a Professor of Ethics in the Department of Religion at Syracuse University and Adjunct Professor of Medicine and the Humanities, SUNY Health Science Center, Syracuse. His areas of specialization include ethical theory, biomedical ethics, moral psychology, and sociology. Dr. Wallwork has an M.B.A. from Harvard Business School, a M.Div. from Yale Divinity School, and an interdisciplinary Ph.D. in ethics, psychology and sociology from Harvard University. He has taught at Wellesley College, Harvard University, Union Theological Seminary, Yale University, and the University of Chicago. Currently a Fellow at the Kennedy Institute of Ethics, Georgetown University, he was for 8 years a consulting ethicist in the Bioethics Office of the Clinical Center at the National Institutes of Health. Dr. Wallwork was a Wilson Fellow, at the Woodrow Wilson Center in Washington, D.C. from 1996-97 and he was the D.R. Sharpe Lecturer in Social Ethics at the University of Chicago in 1992. Dr. Wallwork completed his psychoanalytic training at the Washington Psychoanalytic Institute under a waiver of the M.D. from the American Psychoanalytic Association. He is on the faculty of both the Washington Psychoanalytic Institute and New Directions in Psychoanalysis. His four books and numerous articles on ethics include "Durkheim: Morality and Milieu" (Harvard University Press) and "Psychoanalysis and Ethics," Yale University Press

Abstract: "Research Ethics from the Cultural Anthropologist's Point of View"

Ann Gold, *Cultural Anthropologist, Syracuse University*

Although the fields of environmental health and cultural anthropology differ vastly in both aims and methods, ethical issues arising in their respective research practices display striking convergence. First, it is important to acknowledge that any situation

where outsiders who command greater resources wish to study human subjects in communities that have been historically less empowered are situations with enormous potential for ethical downfall and abuse. On a more positive note, anthropologists have a lot to say about how to be ethical in such situations. My comments focus on skewed power and indeterminate responsibility as problems highlighted in anthropology's recent ethics discourse. Then I turn to lessons from participatory studies, and claims about morality and the situated, emergent nature of research ethics to offer some constructive suggestions relevant to health research.

Ann Grodzins Gold (Ph.D. University of Chicago 1984) specializes in teaching and research on Hindu traditions in modern India, as well as religions and gender, narrative, and the natural environment. Gold's extensive fieldwork in the North Indian state of Rajasthan has included studies of pilgrimage, performance, world-renunciation, women's expressive traditions, environmental change, and the transmission of environmental knowledge. Among her publications are articles on spirit possession, semiotics of identity, the practice of ethnography, women's ritual storytelling, children's environmental perceptions, moral interpretations of climate change, memories as history, and three books (published by the University of California Press): *Fruitful Journeys: The Ways of Rajasthani Pilgrims* (1988); *A Carnival of Parting: The Tales of King Bharthari and King Gopi Chand* (1992); and *Listen to the Heron's Words: Reimagining Gender and Kinship in North India* (co-authored with Gloria Raheja, 1994). Gold has received recent fellowship awards from the American Institute of Indian Studies, the National Endowment for the Humanities, and the Spencer Foundation. In collaboration with an Indian colleague, she has just completed a monograph on nature, memory and power in a Rajasthani kingdom and is planning to write about education and children's environmental perceptions.

Section Two: *Field Experiences with Gaining Community and Group Rights*

Abstract: "Promoting Community (Group) Rights in Research"

Omega Wilson, *Director, The West End Revitalization Association, Mebane, NC*

Anyone seriously interested in protecting the "research rights" for historically African-American communities must begin with an appreciation of the need to overcome fear and mistrust. Fear and mistrust prevents community members from sharing private or personal information, advocating for their own rights, contributing to shaping research questions, choosing sampling locations, and asking critical questions about the research and its applications. The African-American communities in Mebane share a history dating back to land acquired by freed slaves. This history affects many aspects of interaction and communication--community knowledge sharing, views of outsiders (regardless of ethnic background), and experiences of environmental injustice.

Grassroots community-based organizations need to be involved in research projects as 'partners' not 'subjects' or guinea pigs. Specific examples will be shared of the basis for

mistrust in research institutions and of how community members were helped to become comfortable enough to be able to participate in an EPA Environmental Justice study.

The prospect of research grants may increase susceptibility of communities to research exploitation because researchers may attempt to appropriate the community story to use it for their own ends. This can impact the integrity of data collection, interpretation, and lead to research that is more designed for 'academic' use rather than 'applied' uses that directly contribute to problem resolutions in communities where data was collected. Specific examples will be shared of two grants that were turned down due to this problem and how attorneys have been engaged to develop guidelines to protect the interests and legal rights of the West End Revitalization Association and communities it represents.

Omega Wilson

Abstract: "Models of Community Empowerment in Research on Breast Cancer and the Environment"

Julia Brody, *Director of Silent Spring Institute*

When Rachel Carson published *Silent Spring* in 1962, she took on the corporate science establishment with a warning that the new wonder chemicals -- DDT and others -- threatened insects, bird, amphibians, and, ultimately, human health. Yet this courageous woman was afraid to tell anyone she had breast cancer. At her death two years later, the breast cancer activist movement was decades away. Since the 1990s, though, breast cancer activists have become one of the most powerful disease-affected constituencies in the nation. Their success has often been dismissed in the media and elsewhere as the frivolous and self-indulgent concern of wealthy women, who are, indeed, at higher risk. But, perhaps because of women's history as a disenfranchised majority and the long struggle with breast cancer as an invisible disease, breast cancer activists have become key innovators in empowerment strategies that parallel and provide new models for environmental justice. For example, the National Breast Cancer Coalition won participation of lay advocates on review panels for proposals to a major federal grants program and established a training program to equip activists to be effective in this role. The Long Island Breast Cancer Study Project and emerging initiatives in San Francisco and Marin County, California, are other examples.

Among existing studies of breast cancer and the environment, the Cape Cod Breast Cancer and Environment Study conducted by Silent Spring Institute most fully implements the principles of community based participatory research. Founded in 1994 by women in the Massachusetts Breast Cancer Coalition, Silent Spring Institute is dedicated to studying the environment and women's health, especially breast cancer, in a context of partnership among scientists, activists, physicians, and policy makers. The Institute is governed by a public interest board of directors, maintains an outreach office staffed by a coordinator and volunteers, and works with a public advisory committee. The first three-year phase the Cape Cod Study was focused on community involvement processes integrated with scientific literature review to define priorities and build the research infrastructure to address them. Innovation in environmental exposure assessment with the dual goals of facilitating etiologic research and providing input to precautionary public policies became a central priority. As new methods are developed and results become available, the Institute maintains ongoing outreach through community information sessions, a web site and on-line atlas of health and environmental data (<http://www.silentspring.org/newweb/atlas/index.html>), and proactive contacts with the news media. These efforts provide avenues for community empowerment, but they also raise new ethical issues, for example with respect to peer review processes, confidentiality protections, and data access and ownership. The financial sustainability of this approach, which requires funding outside of traditional cancer research programs, is challenged by current fiscal realities.

Julia G. Brody, Ph.D., is executive director of Silent Spring Institute (www.SilentSpring.org), a scientific research organization dedicated to studying the links between the environment and women's health, especially breast cancer. She is the principal investigator of the Cape Cod Breast Cancer and Environment Study, now in its eighth year. The Cape Cod Study is investigating exposures to endocrine disruptors and mammary carcinogens from air and water pollutants and common products such as pesticides, detergents, and plastics. Innovative methods include testing for 86 chemicals in women's homes and historical exposure mapping using a geographic information system. Collaborating investigators include researchers at Boston University, Harvard, Tufts, and the US Centers for Disease Control and Prevention. The US Environmental Protection Agency recognized Silent Spring Institute's research with an Environmental Merit Award 2000.

Niem Kret, *Executive Director, SABAI*

Panel Three – *Reshaping Science for Environmental/Public Health Research*

Communities are demanding new changes to science that would overcome the narrow limitations of solely quantitative research outcomes. Some of these limitations and their impacts on environmental health protection will be highlighted in several presentations. This panel will then offer presentations on holistic models of science, including Native science where social, spiritual and other qualitative impacts are assessed as part of the research activity. Community members as knowledge-producers will be highlighted.

Section One: *The Inadequacies of the Western Scientific Method in Environmental Health Research*

Abstract: Inadequacies of Western Health Risk Assessments and Native Definitions of Health and Science from lakoti'satstensserakwis Ne Ohontsia Project

Mary Arquette, Principal Investigator of lakoti'satstensserakwis Ne Ohontsia Project, Akwesasne Task Force on the Environment (ATFE)

Abstract: "Science, Objectivity and Ethics in Environmental Health"

Steve Wing, University of North Carolina, Chapel Hill, Department of Epidemiology

During the past several decades philosophers of science and scientists themselves have become increasingly aware of the complex ways in which scientific knowledge is shaped by its social context. Research in this area has been called science studies. Working scientists need an understanding of their own practice that avoids the naïve assumption that science can become objective by avoiding social influences as well as the reductionist view that its content is simply determined by economic interests. An understanding of science studies is especially relevant to environmental and occupational health research that has implications for profits, regulation, legal responsibility and social justice. A nuanced perspective on the creation of environmental health science can improve research ethics and increase the capacity of science to contribute to equitable public policy.

I discuss research into health effects of the 1979 accident at Three Mile Island as an example of how science is shaped by concepts, assumptions and social norms. I describe how a scientific practice originating in medical and nuclear physics interacted with observations of exposed community members to affect research questions,

interpretation of evidence, inferences about biological mechanisms in disease causation, and the use of evidence in litigation. By considering the history and philosophy of their disciplines, practicing researchers can increase the rigor, objectivity and social responsibility of environmental health science.

Steve Wing, Associate Professor of Epidemiology at the UNC School of Public Health, conducts research on environmental injustice, health effects of ionizing radiation, and community health effects of industrial swine production. He has collaborated on health studies with communities and workers impacted by the nuclear industry, industrial animal production, and other environmental and occupational threats.

Presentation Title: "Prosecuting Toxic Chemicals Without Causality: Implications for Community Research"

Sheldon Krimsky, Tufts University, Medford, MA

Sheldon Krimsky is professor of Urban & Environmental Policy & Planning at Tufts University. He received his bachelors and masters degrees in physics from Brooklyn College, CUNY and Purdue University respectively, and a masters and doctorate in philosophy at Boston University. Professor Krimsky's research has focused on the linkages between science/technology, ethics/values and public policy. He is the author of seven books: *Genetic Alchemy: The Social History of the Recombinant DNA Controversy* (MIT Press), *Biotechnics and Society: The Rise of Industrial Genetics* (Praeger), *Hormonal Chaos: The Scientific and Social Origins of the Environmental Endocrine Hypothesis* (Johns Hopkins Univ. Press, 2000). He is co-author of *Environmental Hazards: Communicating Risks as a Social Process* (Auburn House), and *Agricultural Biotechnology and the Environment: Science, Policy and Social Values* (University of Illinois), and co-editor of a collection of papers titled *Social Theories of Risk* (Praeger). Professor Krimsky has published over 130 essays and reviews that have appeared in many books and journals. His current book is about conflicts of interest in biomedical research and is titled *Science in the Private Interest: Has the lure of profits corrupted biomedical research?* (Rowman & Littlefield Publishers, Inc.) Forthcoming, 2003. At 04:44 PM

Section Two: *Incorporating Indigenous Sciences into Environmental Health Research Activities*

Abstract: "Inclusion Of Traditional Knowledge In The Assessment Of Community Impacts"

Lori Lambert, *Salish Kootenia College, Pablo, Montana*

Chris Walsh, *Yakama Indian Health Clinic, Topenish, Washington*

This presentation is meant to honor Salmon, First Fish, First People, and traditional knowledge. Historically, the perspective of Native people as scientists and Traditional Knowledge Keepers is not included in studies of environmental health. In assessing the social, cultural, and public health impacts associated with the consumption of contaminated fish, we employ a medicine wheel model with four interrelated components: ecology, epidemiology, cultural study, and clinical medicine. In this

situation, comprehensive ecological data are available, characterizing water quality and the amounts of chemical contaminants in fish. Dietary surveys have defined the central importance of fish in the diet, with some Tribal persons eating as much as 300 pounds per year. Epidemiological analysis forecasts high risks for cancer and organ damage for the exposed Native populations. Cultural data include observations of changes in fish runs and health of the salmon over time, and the threat to traditional ways of living and spirituality. Illness and disease among Tribal members is attributed to the poor health of the salmon, and we are investigating concerns about excess cancers.

We argue that risk communication in Native communities, to be successful, must be formulated within the context of Native Science (Gregory Cajate, 1999), and should allow for the free interaction of these components rather than discrete analyses.

Abstract: “Deepening the Ethics of Environmental Health Research Through the Use of Multiple Knowledge Systems”

Dianne Quigley, *Syracuse University, Department of Religion*

This paper is written to explore the use of multiple knowledge systems or indigenous science for assisting with ethical challenges in the field of environmental health research. In a presentation of indigenous or Native science, this paper seeks to demonstrate how the methods and philosophies of this science can offer valuable benefits to all communities seeking new methods for environmental health research problems. The local nature of multiple knowledge systems and the plurality of knowledge production methods inherent in these local sciences are especially important to the local crises of communities and their natural environments affected by pollution and environmental damages. The paper offers several proposals for expanding the research methods and improving the ethical problems of environmental health research with the contributions of indigenous science or multiple knowledge systems. Particularly important are those recommendations that encourage community members to be knowledge-producers and the varied approaches that can be taken to promote local knowledge production.

*(See Panel Two for Bio)

**Panel Four – Perspectives on the Status of Funding Community –
Researcher Partnership**

This panel will address two major challenges to community research ethics. These include (1) how to help communities have more access to research funding and to have grants go directly to their organizations and (2) how do we make more funding available for preparing communities for research – building infrastructure, learning benefits/risks of research, and research ethics. Various presentations will be offered to provide information and encourage dialogue and resolutions to these long-standing problems.

Abstract:

Shobha Srinivasan, *National Institute of Environmental Health Sciences, Raleigh, North Carolina*

>Panel: Perspectives on the Status of Funding Community-Researcher

>Partnerships

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>Presentation Title: Creating opportunities to fund community-based research

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>Shobha Srinivasan, PhD

>National Institute of Environmental Health Sciences

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>One of the basic agendas of the National Institutes of Health's is to

>provide opportunities to advance scientific research on health issues. In

>the last decade there has been a greater emphasis on creating a research

>environment that can lead to impacting public health and policy. This

>presentation will highlight some of the programs within the National

>Institute of Environmental Health Sciences that impact public health and

>policy through community based research and educational efforts. This has

>mainly been addressed through the development of community-university

>partnerships among researchers, health care providers and the community.

>The presentation will also provide an overview of funding opportunities at

>the National Institute of Environmental Health Sciences for communities and

>community based participatory research and address some of the challenges

>faced in these projects and lessons learned.

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>Biosketch:

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>Shobha Srinivasan, Ph.D. is a Health Scientist Administrator at the National

>Institute of Environmental Health Sciences. Prior to this she worked as

>Research Director at a community based health policy organization on

>building community-university partnerships to address various health

>challenges in indigent and immigrant communities. While at UC San Francisco

>and UC Davis she focused specifically on issues relating to inequities in

>access to health care and in promoting cultural competence among university

>and health professionals. She currently directs the Health Disparities,

>Environmental Justice, Community-based Participatory Research and the

>Ethical, Legal and Social Implications of Environmental Health Research

>programs at the National Institute of Environmental Health Sciences.

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Abstract: "Funding Community-Based Partnerships For The Air Toxics Program"

Barbara Driscoll, Policy, Planning and Standards Group, U.S. Environmental Protection Agency, North Carolina

In July 1999, EPA published the Integrated Urban Air Toxics Strategy which discussed in part the need to evaluate the air toxics problem at the community level. EPA recognized that air pollutants coming from many sources, stationary, mobile and indoor create a complex mix of emissions which in urban areas may create higher risk to the public. In particular sensitive populations such as older adults, children and low income groups may be adversely affected. In order to address learn more about the air toxics problem at the local level and obtain risk reductions, EPA has been funding community projects which evaluate local problems and develop plans on how to address these problems.

Funding for these projects has been limited and from a number of different sources within the agency, however with an interested public a lot can be accomplished with only small amounts of seed money. With the help of State/local/tribal groups, communities can receive technical assistance in defining what problems may exist and developing plans for how to best address the concerns. We have also been working on developing matrices of voluntary activities that the public may choose to pursue in addition to the regulatory and enforcement activities of the local air authorities.

Barbara Driscoll has a Master's degree in Geology, and has been with EPA for 16 years working in various regulatory programs. She currently works on community-based projects for the air toxics program.

Abstract: "Ethics Of Research Funding In Community-Researcher Partnerships"

Gary Grant, *Executive Director, Concerned Citizens of Tillery, North Carolina*

Funding for research is typically provided by governments, industry or private foundations that work closely with academic and private researchers. Community driven environmental health research brings challenges to these traditional funding relationships. Communities most impacted by environmental hazards, especially people of color and low income communities, are rightfully distrustful of outside "experts" and yet community based organizations characteristically lack their own

scientific staff. Therefore, funding agencies interested in community-driven research must provide substantial support for organizational development and community education. Partnerships that fail to provide equitable funding for community organizations may fail to identify the best research questions, may experience low rates of participation in surveys, and their research findings may lack credibility with the community that is to be served. However, as community organizations become more involved in research partnerships, invitations or requirements to participate in meetings sponsored by institutions may involve levels of time commitment and travel that conflict with basic responsibilities for community organizing and development. While the main goal of scientists is research, the basic goals of community organizations are improving quality of life, and seeking social and environmental justice, not research. Thus, community research partnerships require funding that gives priority to organizational development, educational and technical needs of communities over the bureaucratic needs of institutions.

Abstract: “The Joys & Frustrations of Participating on Community-Owned Research Projects”

Cynthia Lopez, Epidemiologist, University of Massachusetts, Lowell

Research projects that are owned, funded and spearheaded by affected communities are few and far between. Over the past few decades, more traditionally marginalized and/or economically deprived communities have gained financial independence to conduct their own research. Additionally, some communities without economic power have developed skills and other resources to successfully compete for research funding. Such scenarios have disrupted traditional research relationships, where university researchers with the power of funding resources behind them typically recruit and study communities without such power. Dr. Lopez will speak from the perspective of a university researcher coming to terms with the joys and frustrations of participating in this emerging paradigm of community-owned research.

Panel Five – Institutional Review Boards and Institutional Protections

IRBs all over the country are grappling with the problems of community rights. Presentations and discussion will be offered on the progress made by some research institutions on how to ensure the protections of communities in research; on how IRBs can be more prepared for evaluating community rights in research and the major challenges still to be addressed. Community experiences with IRBs is also discussed.

Abstract: “The Fourth Basic Ethical Principle: Respect for Communities”

Francine Romero, *Northwest Portland Area Indian Health Board*

American Indian and Alaska Native (AI/AN) tribal communities are sovereign nations with community-specific knowledge, norms, and worldviews. The research community, researchers and academic institutions, must evaluate community risks and benefits and equity when partnering with tribal communities. The Indian Health Service (IHS) Institutional Review Board (IRB), at both the National and Area levels, reviews research protocols according to existing human subjects protection federal regulations (i.e., the three basic ethical principles of respect for persons, beneficence, and justice), and according to a fourth basic ethical principle: respect for communities. As of February 2003, over 200 research protocols have been reviewed following the four basic ethical principles. Informal feedback from investigators indicates an increased knowledge and sensitivity to cultural appropriateness of study design, study questions, and study implementation. The IHS IRB balances ethical concerns by incorporated the four basic ethical principles with promoting research.

Francine Romero....

Abstract: IRB Review Processes for Community-based Participatory Research

Nancy Shore, *University of Washington*

What are some of the challenges and benefits of the IRB review process from the perspective of community-based participatory researchers? Are these perspectives unique to community-based participatory researchers or shared by other researchers who use more conventional research approaches? What are the recommendations needed to address these challenges in order to facilitate the IRB review process? These are some of the broad questions that I posed as part of my dissertation study. I will highlight the findings from my preliminary analysis, as well as suggest recommendations to facilitate the IRB review process based upon my experiences serving on a social and behavioral science IRB review committee.

Nancy Shore is a doctoral student at the University of Washington, School of Social Work. Her dissertation work brings together my interests in community-based participatory research, ethics and the Institutional Review Board. Her experiences include working with Community-Campus Partnerships for Health, serving on the University's IRB committee, and assisting the School of Social Work with a wide range of human subjects related tasks. Before returning to the University, Ms. Shore worked for four years at a community-based Head Start program.

Abstract: The Role of Communities in the Ethical Review of Research

Lisa Eckenwiler, *Executive Director of and Senior Research Scientist at the Center for the Study of Medical Ethics and Humanities, Duke University Medical Center*

As the assumptions about rationality, expertise, and moral reasoning that have long-grounded the structure and process of ethical review in research have begun to shift, greater value is being placed on incorporating the perspectives of communities. In this presentation, I will briefly explore these assumptions and how they are now being challenged, and then review what the federal regulations governing research, various health agencies and others say about the role of communities in the ethical review of research. Next, I will note the different and ultimately troubling conceptions that have been put forward by commentators about the proper role of communities and their representatives in ethical review. From there I will discuss some of the challenges IRBs face in trying to incorporate community perspectives. I will conclude by offering proposals that will strengthen the role of communities and promote social justice in ethical review.

Lisa Eckenwiler...

Abstract: WE ACT,

Peggy Shepard, *Executive Director and Co-Founder of West Harlem Environmental Action (WE ACT)*

Abstract

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; from Peggy Shepard (you'll have to edit for space) - her abstract will come today

Peggy M. Shepard
Executive Director, West Harlem Environmental Action, Inc.
ABSTRACT

**CAN IRBs ASSURE INFORMED CONSENT
IN COMMUNITY-BASED OR POPULATION RESEARCH**

By Peggy M. Shepard, Executive Director
West Harlem Environmental Action (WE ACT)

The 13th Principle of Environmental Justice calls for the "strict enforcement of the principles of informed consent and a halt to the experimental reproductive and medical procedures on people of color. Over the last few years, several elite academic research institutions have caused harm allegedly to human subjects through research studies where the issues of informed consent and the credibility of the institution's IRB

were raised. These incidents add fire to the ongoing debate among researchers, ethicists, media, and community residents about the ethics of human subject research. Since human subject protection is balanced precariously by voluntary informed consent, the quality of IRBs, and the responsibility of principal investigators, it seems appropriate to consider: the development of new models for the ethical review of environmental health research, the composition of IRBs, key assumptions underlying informed consent, whether IRBs can assure informed consent in community-based research, and challenges to the current model and status quo

Peggy Shepard is executive director and co-founder of West Harlem Environmental Action, Inc. (WE ACT). Founded in 1988, WE ACT was New York's first environmental justice organization created to improve environmental health and quality of life in communities of color. A former Democratic District Leader, she represented West Harlem from 1985 to April 1993, and served as President of the National Women's Political Caucus-Manhattan from 1993-1997.

From January 2001-2003, Ms Shepard served as the first female chair of the National Environmental Justice Advisory Council (NEJAC) to the U.S. Environmental Protection Agency, and is co-chair of the Northeast Environmental Justice Network. She is a member of the National Advisory Environmental Health Sciences Council of the National Institutes of Health and of the Environmental Justice Advisory Committee to the NYS Department of Environmental Conservation.

WE ACT is a nationally recognized organization in the field of community-based participatory research in partnership with the Mailman School of Public Health at Columbia University. Ms. Shepard is a co-investigator of the Columbia Children's Environmental Health Center's Community Outreach and Translational Research Core and community partner of the NIEHS Center for Environmental Health In Northern Manhattan at Columbia. She is Principal Investigator on an NIEHS grant to foster communications and partnerships between researchers, clinicians and community on environmental health education and outreach.

In 1988, Ms. Shepard co-founded West Harlem Environmental Action, a non-profit organization working to improve environmental policy, public health, and quality of life in communities of color. Based in Northern Manhattan, WE ACT advances its mission through research, public education, advocacy, organizing, government accountability, litigation, legislative affairs and sustainable economic development. WE ACT works for environmental and social justice on issues of land use, waterfront development, brownfields redevelopment; transportation and air pollution, open space and environmental health. WE ACT won a 1.1 million dollar settlement of its lawsuit against the City regarding the North River sewage treatment plant in late December 1993, as well as a monitoring role with the Natural Resources Defense Council in the enforcement of the city-state consent agreement on a five-year plan to fix the North River Plant.

Ms. Shepard is a guest editor of a special supplement of Environmental Health Perspectives, Advancing Environmental Justice Through Community-Based Participatory Research, which was published in April 2002. Ms Shepard is co-author of The Challenge of Preventing Environmentally Related Disease in Young Children: Community-Based Research in New York City; Airborne Concentrations of PM (2.5) and Diesel Particles

on Harlem Sidewalks: A Pilot Study; Diesel Exhaust Exposure Among Adolescents In Harlem: A Community-Driven Study, and a contributor to Urban Air Pollution and Health Inequities: A Workshop Report, all articles which were published in Environmental Health Perspectives between 1999 and 2002. She has also authored Issues of Community Empowerment, and The Federal Advisory Committee's Proposal For Justice, Fordham Environmental Law Journal, 1996 and 1999.

In November 2000, Ms. Shepard received a Union Square Award, administered by the Fund For The City of New York, for her grassroots leadership and advocacy. In 1998, Ms. Shepard received the Earth Day Award For Excellence In Environmental Advocacy from Earth Day NY. In 1997, she received the Susan B. Anthony Award from the National Organization of Women (NOW) NYC Chapter, and the Gay and Lesbian Independent Democrats honored her for political and environmental advocacy. In 1993, Ms. Shepard was honored by the City Club of New York with the Earthling Award for Environmental Justice, received the New York State Environmental Woman of Action by Tambrands, Inc., and was recognized by National Wildlife Magazine as one of the People Who Make a Difference. In 1991, she received the Life of the City Award from New York Woman Magazine, and in 1990 she received the New Yorker For New York Award from the Citizens Committee of New York.

Peggy Shepard, a former journalist, was a reporter for The Indianapolis News, a copy editor for The San Juan Star, and a researcher for Time-Life Books. She has served as an editor at Redbook, Essence, and Black Enterprise magazines. Ms. Shepard began a career in government as a speechwriter for the New York State Division of Housing & Community Renewal and Director of Public Information for Rent Administration. She served as the Women's Outreach Coordinator for the New York City Comptroller's Office.

Ms. Shepard is a board member of the national and NYS Leagues of Conservation Voters, Environmental Defense, NY Earth Day, Citizen Action of NY, the Children's Environmental Health Network, and Healthy Schools Network, Inc. She is an advisory board member of the Bellevue Occupational and Environmental Medicine Clinic; the Harlem Center for Health Promotion and Disease Prevention; and Mt. Sinai's Children's Environmental Health Center.

A frequent lecturer at universities and conferences on issues of environmental justice and community-based health research, she is a graduate of Howard University and Solebury and Newtown Friends Schools. She has one daughter, Nicole and lives in the Hamilton Grange Historic District of West Harlem.

Peggy Shepard

Panel Six – Research Ethics and Community Partnerships

Community partnerships are critical to improving research ethics and dealing with environmental and public health problems. This panel will review progress in the field for making these

partnerships successful. This includes new work on (1) research life cycle approaches to partnerships (2) current successful partnerships in participatory action research and CBR (3) understanding the diverse contexts, values and knowledge traditions of our partners for consensual decision-making (4) working through power differentials of race, class and gender

Abstract: “The Research Cycle Approach to Community-University Research Collaborations”

Linda Silka, *University of Massachusetts Lowell Center for Family, Work and Environment*

Community-university research partnerships hold the promise of resolving some of the long-standing difficulties with academically driven research. Such partnerships can ensure that rigorous research is carried out on topics of paramount concern to communities and that this research is solution focused rather than simply providing more data about problems. Yet despite the promise of such partnerships, they still often go awry. We argue that a research cycle approach can reduce the likelihood that partnerships will be inattentive to the missteps that can derail partnerships, such as those having to do with decisions of who generates the hypotheses, who owns the data, and how the data are to be used. With the research cycle approach, any one study is embedded in a cycle of joint activities that can lead to interventions and future research. Within this approach it matters not merely what is done (e.g., generating a research agenda) but when that activity is done (e.g., community partners are involved before the research agenda is fixed). We will suggest how the research cycle approach can be helpful for identifying all of the opportunities where productive partnerships can strengthen the research enterprise.

Linda Silka, Ph.D. is a University Professor and Professor of Regional Economic and Social Development at the University of Massachusetts Lowell where she also co-directs the Center for Family, Work, and Community (under the Institute for Regional Economic and Social Development). Through the Center she facilitates the work of interdisciplinary teams of faculty, students, and community leaders in carrying out applied research and technical assistance in program evaluation, community problem solving, prevention programs, geographic information systems, and youth-based interventions. In 1999, she was honored with the University of Massachusetts President’s Award for Outstanding Professional Service. The HUD Community-Outreach Partnership Center that she co-directs has received a HUD “Best Practice” Award and been featured in the HUD National COPC Newsletter for outstanding work using technology with communities and engaging in economic development with refugee and immigrant communities.

Abstract:

Swati Prakash, *WE ACT, West Harlem, NY*

Swati Prakash is the Environmental Health Director for West Harlem Environmental Action (WE ACT), in New York City, where she works to incorporate scientific tools into community organizing efforts in low-income urban communities of color. In addition to organizing locally in Northern Manhattan around diesel and asthma, Swati collaborates with the Columbia School of Public Health on community-based research projects on air pollution and children's health. She received her M.S. in Environmental Health from the Harvard School of Public Health, and her B.A. in Environmental Science and Public Policy from Harvard College. Swati is a fellow in the national Environmental Leadership Program, and a graduate of the Center for Third World Organizing's Community Action Training.

Abstract: "The Dance of Race and Privilege in Community Based Participatory Research"

Vivian Chavez, *Department of Health Education, San Francisco State University*

There are very real issues of race/ethnicity, racism and White privilege that every researcher, whether White or a person of color, must consider when doing CBPR with communities of color. The trilogy of race/ethnicity, racism and privilege are underscored not because they are more important than other dimensions, such as social class or gender, but because they are often neglected areas of study. Privilege is one of the most important and difficult arenas for researchers to address, as it in part defines who we understand ourselves to be. To look internally at privilege conferred due to race, income, education, sexual orientation, gender or institutional affiliation forces researchers to consider how privilege permeates how they approach everything we do in our work. This acknowledgement ultimately pierces the veil of scientific objectivity.

By the end of this session participants will 1) learn a useful framework for understanding racism that addresses institutional and personally-mediated racism, as well as internalized oppression; 2) explore the concept of "White privilege" and how this power imbalance can obstruct the trust and respect necessary in CBPR; 3) analyze community dialogue from a power and language framework to address the multiple ways they manifest in both the dominant society and in subordinate communities; 4) identify a set of recommendations CBPR researchers can draw upon in attempting to better address issues of race, racism and privilege that often "hover at the periphery" of community research; and 5) be updated on how this framework has been operationalized in the Department of Health Education at San Francisco State University.

Vivian Chavez, DrPH-MPH is an Assistant Professor in the Department of Health Education at San Francisco State University.

Abstract: “Mediating Values, Contexts and Traditions in Community-Academic Partnerships”

Amy Schulz, *Department of Health Behavior and Health Education, University of Michigan*

Health disparities – including environmental health disparities – arise out of disparities in access to the resources that are necessary to maintain health as well as disparities in exposures to materials that erode health. In other words, systematic differences in health arise out of historic processes that include multiple manifestations of racism (e.g., segregation), classism (e.g., differential access to education), sexism (e.g., differential access to viable employment opportunities) that create and sustain inequitable distributions of the resources that support health. These include the differential distribution of material resources, but also political resources, the opportunity to participate and influence decisions that affect one’s social and physical environment, and opportunities to name one’s lived experience and to participate in the process of generating knowledge.

Partnerships between researchers based in academic institutions, community members, and representatives from other institutions (e.g., public health departments) offer one mechanism for addressing the complex array of factors that contribute to inequalities in health. Within such partnerships, individuals and organizations that reflect the very differences that contribute to disparities in environmental exposures – different histories, sets of resources, opportunities to influence policy decisions, different institutional frameworks, values and traditions -- come together to work toward some mutually identified goal or objective.

As microcosms of our social worlds, partnerships are contexts that offer both challenges and opportunities. The inevitable conflicts that are crystallized within partnerships may contribute to the suppression or the reification of difference and inequality. At the same time, these differences and conflicts contain the possibility for growth – through naming, examining and creating strategies to address the assumptions, values and traditions that reinforce and recreate inequalities. In this presentation, I examine potentials for conflict, growth and change within the context of community-based participatory partnerships, and the implications of those potentials for efforts to promote environmental, as well as social, justice.

Amy J. Schulz, M.P.H., Ph.D. Assistant Research Scientist, Health Behavior and Health Education, Associate Director for Qualitative Methods, Center for Research on Ethnicity, Culture and Health Dr.

Schulz received her Ph.D. in Sociology and M.P.H. from the University of Michigan. Her current research focuses on social factors that contribute to health with a particular focus on racial health disparities and urban communities. Current research efforts focus on understanding social and physical environments in urban communities and their contributions to racial and socioeconomic disparities in health; as well as individual and collective strategies undertaken by urban residents to promote health and well-being. In addition, she has been involved in projects concerned with: the effects of colonization on the health of Native Americans; community-based approaches to research and community change; the evaluation of community partnerships for health promotion; and the role of grassroots environmental groups in addressing issues of environmental degradation and economic development. She co-directs a doctoral program entitled "Promoting Ethnic Diversity in Public Health" designed to increase the pool of doctorally prepared members of racial and ethnic groups historically underrepresented in public health. She has taught courses on race, ethnicity, culture and health; and qualitative research methods and participatory action research. Dr. Schulz's work appears in *Social Problems*, *The Journal of Health and Social Behavior*, *Social Science and Medicine*, *Health Education and Behavior*, *The Annual Review of Public Health*, and *Health Education Research*.

Abstract:

Mildred McClain, Ph.D., *Citizens for Environmental Justice, Savannah, GA*

Mildred McClain...

Abstract: Partnership Successes of the Communities for a Better Environment

Marta A. Segura, MPH, *Communities for a Better Environment, Los Angeles*

Communities for a Better Environment, a grassroots environmental justice organization, from California, has successfully developed its capacity for community based research with various academic partners throughout the last several years, largely as a result of NIEHS funding. The research has led us to work with UC Santa Cruz, University of Southern California, Brown University, Occidental College and UCLA among others, creating a body of sound research about the disparities in health among minority communities as a result of disproportionate siting of polluting facilities and mobile source pollution. In addition to being published in peer-reviewed journals, the findings of the community research partnerships with CBE have catalyzed many EJ policy changes at Statewide, regional and local levels. Examples of agencies that now include Environmental Justice Policies or guidance documents are Cal-EPA, California Air Resources Board, and the South Coast Air Quality Management District. Other tangible benefits to our community include the development of well informed workshops supported by the findings of our research, and in our most recent efforts at analyzing the incidence rate of asthma among children in Southeast LA, the community members

are involved in the design of the survey, implementation of survey and focus groups and in training other community members about the findings through popular media and workshops. The ability to arm community members, organizations and coalitions with sound research on the structural determinants of health and the resulting health disparities is the tool most needed to effect policy and on the ground changes for improved environmental conditions and health in communities of color.

MARTA ALICIA SEGURA, M.P.H.: *Southern California Program Director, Communities for a Better Environment.* The daughter of immigrant agricultural workers, Segura has a personal and professional commitment to eliminating social injustices through community capacity building, grass roots organizing and social movement building through an environmental justice lens. As Southern California Program Director for Communities for a Better Environment, Segura has oversight over regional program planning, alliance building, campaign development and fundraising. In addition, one of Segura's top priorities is to build ties with allies and support coalition based environmental justice efforts that affect regional and statewide policy. Segura was previously a program officer for the Flintridge Foundation for their Community Services Program in 1999 she was a Program Officer with The California Endowment (the 10th largest foundation in the U.S.). Prior to The California Endowment, Segura spent four years as a Program Director for the UCLA Labor Occupational Safety and Health (LOSH) a Program of the UCLA Center for Labor Research and Education. Her major projects included working on Environmental Justice and Border Justice issues with coalitions and networks. Her background in Environmental Sciences, health education, community organizing and comprehensive approach to organizational and community capacity building has brought her to Communities for a Better Environment. Segura has also been very involved in multi-issue progressive social movements of Los Angeles including the areas of immigrant rights, living wage, and Chicano Politics.

Segura holds a B.A. in Environmental Studies and Biological Sciences from U.C. Santa Barbara, and holds an M.P.H. from the U.C.L.A School of Public Health, with a specialization in Environmental & Occupational Health Sciences. She is currently a candidate for the Fundraising and Institutional Development Certificate Program with the UCLA Extension Program. Her fluency in Spanish and social justice background have inspired her to create cross cultural and multi-issue collaborations between various communities.

Abstract: "Qualitative Methods In Environmental Health Research"

Phil Brown, *Sociology Department, Brown University*

Public health researchers increasingly turn to qualitative methods either on their own, or in combination with quantitative methods. Qualitative methods are especially important to community environmental health research, since they provide a way to produce community narratives that give voice to individuals, and that characterize the community in a full and complex fashion. I trace the legacy of qualitative research in environmental health, and then use a case study of my experiences studying the

Woburn childhood leukemia cluster in order to provide personal and scholarly insights on qualitative approaches. That material then informs a discussion of important components of qualitative methods in environmental health research, including flexible study design, access, trust, empathy and personal shifts in the researcher's worldview, bias, and the nature of the researcher's roles. I also address issues in funding policy and research practices.

Phil Brown, Ph.D., is Professor of Sociology and Environmental Studies at Brown University. He is currently examining "contested illnesses" such as asthma, Gulf War-related illnesses and breast cancer, involving public debates over environmental causes. This four-year project is supported by grants from the Robert Wood Johnson Foundation and the National Science Foundation. Among his other research interests are community responses to environmental hazards, and social movements in health. He is the co-author of No Safe Place: Toxic Waste, Leukemia, and Community Action, that deals with the Woburn childhood leukemia cluster. He is editor of Perspectives in Medical Sociology and co-editor of the collection Illness and the Environment: A Reader in Contested Medicine. Prior to studying health and the environment, he studied mental health policy, mental patients' rights, and clinical interaction in psychiatric settings. Among his publications from that work are The Transfer of Care: Psychiatric Deinstitutionalization and Its Aftermath, and Mental Health Care and Social Policy (edited). Phil Brown was previously Chair of the Medical Sociology Section of the American Sociological Association, and is presently Chair-Elect of the Environment and Technology Section of the American Sociological Association.
