

Domestic Policy Subcommittee
Oversight and Government Reform Committee
Effects of the New NIEHS Research Direction
Peggy M. Shepard
Executive Director Co-Founder
WE ACT For Environmental Justice
Tuesday, September 25, 2007
2154 Rayburn HOB -2:00 P.M.

Good afternoon Chairman Kucinich and committee members. I am Peggy Shepard, co-founder and executive director of WE ACT For Environmental Justice, a 19-year old non-profit environmental justice organization based in Harlem, New York City. WE ACT works to build community power to fight environmental racism and to improve environmental health, protection and policy in communities of color. WE ACT has developed a national reputation for its community-based participatory research partnerships to improve environmental health locally, to develop a national environmental health research agenda to address a broad array of community-based environmental exposures, and to translate research findings into reformed public policy. I have also had the opportunity, in the past, to serve as chair of the National Environmental Justice Advisory Committee (NEJAC) to the EPA, and as a member of the NIEHS Advisory Council. Currently, I am a member of the NIEHS Public Interest Liaison Group.

My aim today is to portray an urban community of color and low income that is disproportionately impacted by pollution, and to address the impact of NIEHS programs on community capacity to advance environmental justice and children's environmental health through community-based participatory research (CBPR)..

The Environmental Justice Movement has challenged the current environmental protection model to address environmental inequities, unequal protection, and the disparate and cumulative impacts of pollution. The vision of Environmental Justice places human health at the center of environmental struggles understanding that communities of color and low income are home to more susceptible populations, that multiple environmental exposures must be addressed by studying their cumulative impact and synergistic effects on health, that children, in their early stages of development, are more vulnerable to environmental exposures, and that children of color living in communities of color disproportionately impacted by pollution are the most disadvantaged. The frame is precautionary. It seeks to prevent environmental threats before they occur and shift the burden of proof to the polluter.

I have lived and worked for 22 years in Northern Manhattan which comprises four neighborhoods of mostly African-American and Latino residents with a median household income of \$16,000. There are multiple environmental exposures, high rates of learning disabilities and low birth weight, and excess mortality from asthma, cancer, and heart disease. One of these neighborhoods East Harlem, has the highest asthma rates in the nation. Significant broader impacts are that Manhattan is a non-attainment area for clean air standards and is ranked #1 in cancer risk from air toxics by the EPA.

Peggy Shepard Testimony to Domestic Policy Subcommittee

In 1988, WE ACT was born out of community struggles around the use of Northern Manhattan as the dumping ground for the downtown elite neighborhoods. With my neighbors, we began organizing around the operations of the North River sewage treatment plant whose odors and emissions were exacerbating respiratory disease. And in 2000, WE ACT filed a Title VI Civil Administrative Complaint with federal DOT against the Metropolitan Transit Authority because Northern Manhattan neighborhoods bear the disproportionate burden of hosting one third of the largest diesel bus fleet in the nation. There are six diesel bus depots in Manhattan and Northern Manhattan communities host five of those.

When I first began organizing around these issues, I recognized that the lack of scientific literacy, information, data, and context was and is a serious void that contributes to the systemic exclusion of communities of color and low income from decision making that affects their families and their communities. Around the nation, environmental justice advocates have realized that evidence-based campaigns move policymakers and empower residents. Though we understand that science cannot always correlate exposures with suspected point sources, or confirm community suspicions about exposures and outcomes, we recognize that science and technology are important tools that can impact our ability to develop safe, sustainable communities.

To achieve that goal, we must ensure translation of research findings, scientific data, health information and government regulations into policy reform and educational materials for a broad range of stakeholders including research participants, residents, health care providers, elected officials, policy makers and civic and advocacy organizations. For that information exchange to be effective, we need to build and expand the capacity of low-income communities of color to improve public health and children's environmental health pre-natally and post-natally by training area residents and organizations to apply this information in ways that will help to inform individual choices and to modify current policies to improve community environmental conditions.

To achieve those aims, WE ACT began a process of inquiry that led to collaborative research projects over the last 12 years, with research centers at the Columbia Mailman School of Public Health. In 1995, WE ACT and Columbia's Harlem Health Promotion Center were awarded an EPA Community-University Partnership grant that allowed us to begin relationship building and community identification of concerns with our academic partners. In 1997, WE ACT was awarded a three-year grant from the National Institute of Environmental Health Sciences (NIEHS) new grant program, Environmental Justice: Partnerships for Communication, and received a competitive renewal in 1999. We began work with the understanding that there was room for us to shape the research agenda to include community concerns. Through trainings that have developed 200 environmental health leaders, involved scores of community-based organizations and housing groups, and through briefings to elected officials, WE ACT and our academic partners have translated the scientific and regulatory foundation of environmental health issues that affect community residents.

The NIEHS EJ grant program supported our efforts and those of other partnerships to raise the profile of environmental health research and particular disease burdens not only for the communities of Northern Manhattan but throughout New York City, and the nation. I thank the

NIEHS for their support of the EJ and CBPR grant programs. Nationally, researchers point to the NIEHS as providing the vanguard support for health disparities research that really does address issues that matter in low income and communities of color.

Our engagement in community-based participatory research (CBPR) -- a method where scientists work closely with community partners involved in all phases of research, from inception of research questions, to study design, to collection of data, monitoring of ethics, and participation in the interpretation and communication of study results -- has allowed us to answer community residents questions regarding their exposures from a variety of sources of pollution.

We have had a total of 10 years of these partnership grants that have allowed us to develop capacity. We have been able to hire staff with advanced degrees in environmental health and science and provide technical assistance within our local, regional and national environmental justice community. WE ACT has leveraged additional funding for our research partnerships, and one Columbia Center alone has leveraged over \$6 million in grants, due, according to them, to the effective community component. We have sustained the partnership for a decade and continue to develop collaborative projects. We have developed new tools such as GIS, curricula, and air monitoring procedures. There is policy and system change with all levels of government, academic institutions and community groups who want to consult or work with us. And importantly, we are having impact on the field through our trainings, findings, publications, policy changes, new models of action, and the new perception -- that it can be beneficial to work with affected communities.

Three years ago, the Kellogg Foundation identified the WE ACT/Columbia partnership as one of 10 CBPR projects that document the impact of CBPR on health policy. In a peer-reviewed article published last January 2007 in the Journal of Urban Health, a bulletin of the NY Academy of Medicine, the authors found that *“carefully designed CBPR that is committed to strong science, high level community involvement, engagement in policy steps and activities, and the strategic use of study findings to help impact policy, can be an important part of the broader struggle for urban health and environmental justice... “Conversion of NYC’s bus fleet to clean diesel and installation by the EPA of permanent air monitors in Harlem and other hot spots were among outcomes for which the partnership’s research and policy work was given substantial credit.”--.* (Promoting Environmental Health Policy Through Community Based Participatory Research: A Case Study from Harlem, New York by Vasquez V., Minkler M., Shepard P., Jan.2007,Journal of Urban Health, NY Academy of Medicine.)

Today, we are here to review the effects of the NIEHS director’s new research direction. Well recently, I spoke to a Boston toxicologist who works in the field of environmental health who expressed her concern and that of her colleagues regarding the co-opting of many federal agencies that we rely on for information and basic protections. She observed that the “hijacking of NIEHS’s research agenda to divert it away from environmental health hazards is anti-public health and works against any sense of justice. I think it is possible and necessary to restore an independent technical team at NIEHS that we can rely on to provide accurate information on some of our most challenging public health problems.

The NIEHS has been the source of key information regarding the health impacts of pollution. The information it generates in its research in chemicals is used daily in setting protective federal, state, and local policies, in arguing for the protection of children, the elderly, and our communities. It provides much of the evidence necessary to adequately regulate polluters, require disclosure and cleanup, obtain enforcement actions, and obtain just settlements for those who have been harmed. While something as seemingly obscure as research results may have little interest for most people, accurate evidence regarding chemicals can make the difference between safe children and sick children, between an intact family or the loss of a parent, or between being able to work or being chronically ill.

Community-Based Participatory Research (CBPR), with its emphasis on translation i.e. approaching research with the goal of converting it into information, resources or tools that can be used by public health and medical professionals and by the public to improve overall health and well being especially in vulnerable populations, has demonstrated the ability to improve the accuracy, precision, reliability and relevance of environmental health data. CBPR and translational research play a key role in achieving NIEHS's mission of reducing the burden of human illness and dysfunction from environmental causes. That role must continue.

Regarding environmental justice, the NIEHS strategic plan states that the NIEHS is committed to research on populations that are exposed to high levels of environmental agents; however, it has been said, that the director has cut funding for CBPR and the Environmental Justice: Partnerships for Communications grants programs. Prevention and environmental interventions represent the most effective and efficient ways to improve human health, and this core principle should not be lost in favor of technical, individually-oriented medical solutions. To answer the question of, why some communities are more affected by some diseases, NIEHS must continue to assess the degree to which environmental exposures disproportionately impact specific communities, whether the interaction of multiple exposures plays a role in those health disparities, and, ultimately, what types of interventions will effectively reduce those disparities in health burdens.

At one point, the NIEHS had begun to look at the built environment as a key environmental exposure that merited further investment of resources. We would hope that the NIEHS will further consider the relationship between urban, suburban, and rural built environments and their relationship to obesity, respiratory health, and cardiovascular health as mediated by exercise. Access to healthy and nutritious foods is also an important environmental health issue given the key role that food supply infrastructure plays in defining the living environment (where we live, play, pray and go to school) of most Americans. The research agenda will be strongest if it includes the prioritization of developing better ways to understand the effects of multiple and cumulative exposures. In addition, NIEHS should continue training and research programs that educate researchers and communities on ethical issues associated with environmental health research (as distinct from the biomedical research model of ethics training that most academic institutions provide.)

The NIEHS Children's Environmental Health Centers Program (which WE ACT has been a part of through our partnership at the Columbia Children's Environmental Health Center and as an advisory board member of the Mt. Sinai Children's Center) has catalyzed development of the

new subspecialty of environmental pediatrics, and has provided an evidence base for a solid children's environmental health and place-based advocacy movement here and abroad. The children centers program has been highly productive, contributed greatly to our enhanced understanding of the environmental causes of childhood disease, and successfully translated state-of-the-art information on developmental toxicology and environmental genomics to exploration of the causes and mechanisms of disease in children living across this country. This multi-disciplinary program was intentionally designed to over-sample populations of color and low income who live in toxic environments disproportionately impacted by pollution.

Yet, NIEHS has recommended a cut in funding and a radical change in the funding mechanism for the children's centers which have provided robust scientific data on both exposure and health outcomes for thousands of individuals followed from birth through childhood. They propose to change these centers from operating centers that directly support multidisciplinary research such as the birth cohort studies into centers that support only research infrastructure. This funding mechanism is problematic because it favors laboratory research at the expense of clinical translation and primary prevention. Rather than seek innovative opportunities to translate the latest developments in laboratory science into the community and to field-test them in these well-characterized cohorts for the betterment of children's environmental health, the NIEHS proposes a retreat to the laboratory.

Review panels and study sections of the EJ, CBPR, and children's centers research programs need to embody a broader range of perspectives that include senior scientists from the fields of pediatrics, public health, preventive medicine, as well as public interest advocates of environmental justice, CBPR, and public health.

And finally, translation begins at home. The NIEHS peer-reviewed journal EHP which has a solid scientific constituency, needs to continue its move to create accessible and user-friendly environmental health references and resources for the media and other lay consumers. NIEHS must continue to make EHP accessible (in terms of cost and its lay language reports and news articles) to the public which, in turn, will bolster public support for the work of NIEHS.

Thank you for the opportunity to share with you the significant public health impact that NIEHS has had, and I hope will continue to have on our communities. I would like to urge this committee to ensure NIEHS's commitment to these remarkable and unparalleled programs, to fund the Environmental Justice and CBPR research programs at \$6 million per year, to designate staff to participate and lead federal inter-agency EJ and CBPR efforts, and to invite community representatives to engage in the NIEHS strategic planning process. The NIEHS has had a legacy of responding effectively to identified research needs of the most vulnerable among us. I hope that it will return to that legacy, and to improving the environmental health of all this nation's residents.