

Using Community-Based Participatory Research to Ask and Answer Questions Regarding the Environment and Health

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From left to right: Vincent E. Hutchinson, Rachel Swaner, Katherine Shoemaker, Roger D. Vaughan, Mary E. Northridge, and Betina Jean-Louis. Not present for the photograph were Benjamin Ortiz, Linda F. Cushman, and Stephen W. Nicholas.

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The Olden Years

In 1991 Dr. Kenneth Olden became the first African-American director of an institute in the National Institutes of Health (NIH) when he assumed the leadership of the National Institute of Environmental Health Sciences (NIEHS) (Brown 2004). That same year, the NIEHS—with Dr. Olden in prominent attendance—hosted the Interagency Symposium on Health Research Needs to Ensure Environmental Justice, which was held 11 February 1994 in Arlington, Virginia (Shepard et al. 2002). Throughout his tenure at the helm of NIEHS, Dr. Olden has listened to the needs, both small and large, of communities that have experienced severe disparities in both environmental exposures and health outcomes. This

Dr. Olden made a bold leap of faith in devoting substantial resources and the institutional leadership of the NIEHS to give communities a role in asking and answering the research questions that matter to the environment and health.

has been vital to the development and implementation of grant programs designed specifically in response to the concerns voiced by underserved constituencies, notably, people of color, immigrants, and poor and working class populations in both urban and rural areas.

As one manifestation of its commitment to community involvement in the research enterprise, the NIEHS has been at the forefront of U.S. funding agencies in using community-based participatory research (CBPR) as a tool to advance environmental health sciences (O'Fallon and Dearth 2002), thereby addressing social disparities in health (Northridge et al. 2000a). The NIEHS defines CBPR as a methodology that promotes active community involvement in the processes that shape research and intervention strategies, as well as in the conduct of research studies (O'Fallon et al. 2000). Recently, Minkler and Wallerstein (2003) have argued that CBPR is not a method or set of methods but rather an orientation to research that changes the role of the researcher and the "researched." For well-conceived and time-tested recommendations for using CBPR in health initiatives, we continue to point students and colleagues to two landmark reviews by Green et al. (1995) and Israel et al. (1998).

Regardless of how CBPR is defined, there is little doubt that this approach to the research enterprise has gained wider recognition and acceptance under Dr. Olden's leadership at the NIEHS. Indeed, the "adolescent years" (Northridge et al. 2000b) have matured into adulthood. Two of the prominent initiatives within the NIEHS Translational Research Program—namely, Environmental Justice: Partnerships for Communication (initiated in 1993) and Community-Based Participatory Research (initiated in 1995)—have helped institutionalize CBPR within the NIEHS per se (NIEHS 2001).

Finally, the NIEHS has partnered with other agencies and divisions within the NIH on collaborative initiatives that foster and/or mandate the inclusion of studies using CBPR approaches. These include but are not limited to the 12 Centers for Children's Environmental Health and Disease Prevention Research [a collaborative program of the NIEHS, the U.S. Environmental Protection Agency, and the Centers for Disease Control and Prevention (CDC), which was initiated in 1998 (NIEHS 2003a)] and the eight Centers for Population Health and Health Disparities [a joint program of four institutes/offices within the NIH consisting of the NIEHS, the National Cancer Institute, the National Institute on Aging, and the Office of Behavioral and Social Sciences Research (OBSSR), which was initiated as recently as 2003 (NIEHS 2003b)]. As the next director of the NIEHS is handed the leadership baton, it is important that CBPR approaches continue to be valued as a means of providing scientific answers to research questions that communities care about regarding the environment and health.

Asking the Research Questions That Matter to Communities

In a conference convened at the NIH in May 2004 by the OBSSR, William R. Shadish from the University of California, Merced, summarized 2 days of discussion on alternatives to randomized experiments by emphasizing that the research question should drive the method. Translational research, in particular, involves more than just causal questions, and so it requires many different kinds of study designs. Further, even when the health effects of given environmental exposures are sought, randomized experiments may not be feasible or ethical.

One of the hallmarks of Dr. Olden's career at the NIEHS is that he traveled often and listened first-hand to

the concerns of community members (Brown 2004). Only then was he able to discern what needed to be done to better provide the scientific answers to the research questions from the members regarding the environment and health. To us, this is what distinguishes CBPR approaches from other public health sciences, including epidemiology, the social sciences, and the basic sciences. This does not mean that the questions asked by other scientists are any less central to increasing our understanding of the environmental etiology of diseases or their disparate distributions across populations, principally along color and poverty lines. Indeed, CBPR in its fullest expression encourages the use of theories, methods, and tools from multiple sciences and brings them to bear on the research question of interest. Accordingly, Dr. Shadish concluded his summary remarks at the May 2004 NIH meeting by heartily endorsing triangulating using different designs as a “good thing.”

The authors of this article are currently entering their third year of collaboration on the Harlem Children’s Zone Asthma Initiative (HCZAI), a population-based intervention in Central Harlem in New York City, with multiple partners led by the Harlem Children’s Zone (HCZ) and the Department of Pediatrics at Harlem Hospital Center (HHC) (Nicholas et al. 2005; Northridge et al. 2002). In the remainder of this article we, as representatives from three of these partnering organizations, offer our collective hopes for the future of CBPR as it contributes to research on the environment and health, with contributors from Columbia University, HCZ, and HHC presenting their perspectives in turn.

The Perspective of the Academy at Columbia University

A guiding principle that serves us well in our ongoing CBPR initiatives is that we consider our institution (Columbia University) to be part of the communities in which we work. We acknowledge the historical record of inequalities and ongoing power differentials that exist between this wealthy institution of higher learning and other neighborhood institutions and organizations, and yet we regard our included schools, personnel, and students as being part of Harlem and Washington Heights, not separate from them.

In considering potential research initiatives, we talk about “us” not “them.” If we decide to pose a particular research question, then all partners around the table are involved in framing it. Depending upon the research

question, we may or may not be able to bring together the resources we need for the answer. Increasingly, we are finding that we need to invite additional partners to the table to be effective in addressing research topics of concern to our communities, including local agencies such as the New York City Department of Education and the New York City Department of Health and Mental Hygiene. A unifying theme of our recommendations for the future of CBPR is the movement of the locus of control out of the academy and into the community organizations, institutions, and agencies that can best address a given research question and/or best ensure the sustainability of the devised intervention.

Employ systems thinking. Communities are part of dynamic systems. Many of the environmental concerns at the “meso,” or community level (e.g., investment in public transportation systems, housing quality and affordability, progressive and regressive environmental policies, enforcement of environmental regulations) are influenced by “macro,” or fundamental factors (e.g., political orders, social and cultural institutions, and ideologies such as racism, social justice, and democracy) (Schulz and Northridge 2004). In turn, community-level factors influence “micro,” or interpersonal-level factors, which are composed of stressors such as environmental toxins, health behaviors such as physical activity, and social integration and social support. In complicated and poorly documented ways, factors at all of these levels—macro, meso, and micro—contribute to population health and well-being.

Conceptual frameworks, analytical methods, and spatial tools are being developed for a better understanding of cause and effect within dynamic systems (CDC 2004). Ecological systems have been invoked as models, but many have inherent limitations, especially those that do not include human agency and accountability regarding the distribution of environmental exposures across geographical regions and population groups. The academy can make further contributions to CBPR by working with partners who understand the dynamics of systems at the institutional, community, and societal levels and how they interact with one another to influence the environment and health of populations. In order to interrupt the status quo and eliminate health inequalities, future environment and health interventions may usefully target systems and policies not commonly considered within the purview of the health sector (Schulz and Northridge 2004).

Develop more effective methodologies for conducting health impact assessment. According to Krieger et al. (2003), “Health impact assessment [HIA] seeks to expand evaluation of policy and programs in all sectors, both private and public, to include their impact on population health.” The HIA framework is a notable advance over the discredited term “natural experiments,” which is at best a misnomer (they are neither “natural” nor “experiments”) and more often a failure of researchers and society to hold those in power accountable for the environmental and population health impacts of their policies and actions.

Procedurally, HIA must involve—from the outset—environment and health researchers, policymakers and analysts, and members of affected populations in joint discussions. These groups will help determine *a*) the research questions to be asked and from what perspectives and *b*) the data necessary for answering the research questions of interest. Rather than hiring consultants and repeating the same pitfalls as those that beset the development process of environmental impact statements, trained health scientists familiar with the substantive work of public agencies and community-based organizations (CBOs)—for example, urban and regional planning, childhood and adult education, civil and environmental engineering, occupational and environmental protection—should be hired to conduct HIAs “in-house.” The role of the academy in such arrangements is to better educate and train students to work in interdisciplinary ways with multiple partners, as is inherent in CBPR approaches.

Enhance the research capacities of community-based organizations and agencies. Through our collaboration in the HCZAI, we have learned the not-so-subtle lesson that the institutions and organizations with which we partner have ongoing research needs that do not fit easily into the disjointed funding mechanisms on which we rely in “soft money” research enterprises, especially as it sustains funding for the long-term in order to effectively evaluate ongoing environmental, social, and health care services programs. Hence, it is essential to train dedicated students—including students of color from poor and working class backgrounds who are woefully underrepresented in the health care professions (Sullivan Commission 2004)—to work in government agencies and CBOs to enhance their capacities to conduct CBPR and work toward the elimination of social and environmental disparities in health. This does not render the academy

irrelevant. Rather, it provides the vital role of mentoring successive generations of environmental and health scientists and instilling in them the knowledge and wisdom gained through decades of working in CBPR projects.

It is our deeply held conviction that regardless of where our graduates choose to work, they can contribute their talents and skills to building a better world and working toward the elimination of health disparities (Northridge 2003). CBPR experiences at every level of training—undergraduate, master’s, doctoral, and post-doctoral—can help to foster this mission in our students.

The Perspective of the Community at Harlem Children’s Zone, Inc.

Over the past decade, HCZ—a CBO serving more than 7,000 children in central Harlem—has become increasingly involved in research partnerships with the academy, a term we employ loosely to include universities, “think tanks,” and private research groups. By having worked through the processes of preliminary discussions, grant writing, project implementation, and evaluation of jointly designed initiatives many times over, we better comprehend the power dynamics inherent in community-academic research partnerships. As a financially sound, mission focused, and “research-savvy” CBO, we have successfully challenged the power imbalances in our CBPR relationships to achieve positive outcomes for the children and families we serve. It is from this vantage point that we offer both a summary of the key drivers of these imbalances and three recommendations designed to help right them.

Although the academy and a CBO may begin partnering by uniting around a common interest—such as improved child development—their goals and methods often diverge at some point thereafter. For example, researchers may want to study the effects of a fitness regimen on obesity in children, whereas CBO staff may want to create an effective and sustainable fitness program for obese children in their neighborhood. Both goals can be achieved through CBPR that involves careful negotiation on everything from funding to design to implementation. However, an entrenched power imbalance prevents many CBOs from maximizing the value of CBPR on behalf of their communities. This imbalance stems from a research enterprise that favors ceding decision-making authority to the academy over CBOs, and that ultimately affects every aspect of CBPR—from initial resource allocation through dissemination of

findings. These grave power disparities undermine stated CBPR principles (Israel et al. 2003) and must be righted if CBPR is to live up to its promise. Below we offer three ways forward.

Level the field for principal investigators from community-based organizations. Providing opportunities for staff members at CBOs to assume the role of principal investigator (PI) is vitally important in equalizing the distribution of power, and the NIH has made genuine strides forward in this aspect of CBPR. A review of the bulletin for the June 2004 NIEHS joint environmental justice and CBPR grantees meeting revealed that PIs from CBOs led 17 of 38 CBPR projects—nearly half! (NIEHS 2004). Having created these opportunities, we must help ensure that these partnerships continue to thrive and mature.

Although CBOs bring a multitude of strengths to CBPR partnerships, a robust research infrastructure is seldom one. Indeed, one enduring feature of CBPR partnerships is the following division of labor: CBOs devote most of their energies toward providing direct services, and the academy provides access to riches that their partners can tap into, notably useful contacts, library access, and systems and staff that support research. At the same time, the current system reduces the agency of CBOs, forcing them to rely upon the “kindnesses” of their academic partners for a host of vital needs. A review of the U.S. Department of Health and Human Services (DHHS) Office of Human Protections web site revealed that none of the 17 CBOs who led CBPR grants funded by the NIEHS had established their own institutional research boards (IRBs). Rather, CBOs obtained their ethical assurances via university partners or through the Indian Health Service (DHHS 2004).

We can easily imagine how such a system could develop, as IRBs at academic institutions were established to allow their faculty to conduct research, not to further the investigative aims of other organizations in the community. We conceived three approaches to improve the current situation vis-à-vis CBOs and IRBs: a) CBOs intending to engage in research sufficient to make it worth their while could be given seed money to create their own IRBs; b) research institutes could create independent IRBs that would convene to review the grants of organizations that do not maintain their own IRBs; and c) we could build upon existing structures by providing incentives for university partners to adapt their procedures to facilitate having PIs from CBOs conduct research in ways that honor their agency.

Ensure reasonable university overheads for research in poor communities. Academics with high university overhead rates that approach HCZ to propose research partnerships are often rejected outright unless they are willing to pursue means to reduce the overhead dollars earmarked for the university. Spending large amounts of grant monies on overhead impedes our mission to improve outcomes for poor children and their families, as it drains desperately needed resources away from program implementation and evaluation.

Because the academy has no financial self-interest in changing this system, CBOs need to construct incentives by refusing to collaborate with institutions unless overhead percentages are reasonable and ethically set. Overhead should be based upon a grant-by-grant analysis of the resources that the research actually consumes, as per current CBO practice. Accordingly, projects that use little overhead would not be forced to supplement projects that consume great amounts of overhead. CBOs must recognize their own assets as liaisons to particular communities and search for opportunities to leverage these assets through negotiation before a grant is submitted for funding. Certain federal grants require community partners, which is a prime opportunity for CBOs to assert their bargaining power. Universities should begin implementing a sliding scale for overhead on the basis of established principles such as those discussed here, with the most resource-rich institutions leading the way.

Devise ethical and equitable guidelines for data use, data ownership, and publishing. Successful partnerships begin with a memorandum of understanding (MOU) in which partners establish their guidelines for data use, data ownership, and publishing. Collaborations that develop MOUs early in the process improve their chances of creating and maintaining successful partnerships. Making decisions at the beginning about important issues ensures that all participants are “on the same page” regarding expectations, approaches, and commitments. To develop a useful MOU, partnerships must create opportunities to resolve contentious issues from the outset of their CBPR projects. All partners must approach these discussions with open minds.

As CBOs become more sophisticated and develop their own research capacities, the academy will cease to be the physical and metaphorical repository of CBPR knowledge. When information that is collected with the assistance of community partners is turned over to the academy as a matter of course, the false

dichotomy of “university brain” and “community brawn” is perpetuated. When the academy controls data use, its researchers are considered the “experts” and CBO staff are denied legitimacy in speaking about work and experiences with which they are intimately familiar. When members of the academy publish peer-reviewed articles based upon CBPR findings without their community partners, they tarnish their own reputations and harm their CBO partners.

Thus, it is necessary for CBPR collaborators to develop approaches to data use, data ownership, and publishing that serve the essential needs of all partners. All collaborators should share proprietary rights to the data they have helped to collect. At a minimum, all partners should: *a*) maintain up-to-date copies of stored data, *b*) exercise their rights to request analyses and interpret results, and *c*) affirm consent before the public release of any data. When the findings are to be published in peer-reviewed journals, at least one member from each partnering group should earn authorship on every publication, and writing should begin only when all partners agree to authorship.

The Perspective of Health Services at Harlem Hospital Center

We are convinced that disease prevention and health promotion are the most effective forms of health care because keeping people healthy saves money, minimizes suffering, and improves quality of life (O’Fallon and Deary 2002). To prevent disease effectively at the population level, health care providers and local communities must better understand the causes of illness and work together to change the social and environmental conditions that foster disease, disability, and premature death. A future challenge for those of us working within health care systems—both large and small—is to identify and counsel individuals and families on preventive health strategies that can promote longer and healthier lives. Hence, our reason for calling for renewed emphasis on health services research using CBPR approaches is that we believe that—through collaboration with university and community partners—we can better understand how to prevent disease and improve health outcomes in communities. Next we present three major challenges to this goal and how to surmount them.

Renew emphasis on health services research. Providing state-of-the-art medical services and meeting requisite standards of care without the resources

necessary to achieve every desired outcome continues to pose severe barriers to population health and well-being in poor communities such as Harlem. Although a limited number of public hospitals still exist—including HHC, which is owned and operated by the New York City Health and Hospitals Corporation—relatively little public money is directed into CBPR programs. Further, anticipated cuts in medical reimbursements will adversely affect the creation and sustainability of CBPR efforts. The emphasis has shifted away from public health models and toward individual health models (O’Fallon and Deary 2002).

Our experiences at HHC through our partnership in the HCZAI have demonstrated that intensive interventions can indeed improve the health and well-being of children with asthma, even as disparities in health outcomes remain unacceptably high in Harlem compared with those in other New York City neighborhoods (Geronimus et al. 1996). Most of the social, environmental, educational, and health service deliveries of the HCZAI are funded through private, philanthropic monies. Although adequate funding is provided on a year-to-year basis to address the needs of a specified number of enrolled children and their families, there is no link to public funding that can help ameliorate identified program deficiencies. For example, certain clinical indicators (e.g., medication prescriptions and third-party reimbursement of durable medical equipment) cannot be fully assessed and tracked because our collaborative program has no direct connection to the community and academic health centers providing medical care to our program enrollees.

Nonetheless, we are able to integrate public health strategies into the HCZAI to encourage and support our families in using the health care system appropriately. By listening to the comments and frustrations that families have voiced about the local health care system, we are able to meet the challenges of limited resources by addressing families’ concerns directly, and thereby amplify the effectiveness of the health services delivered by our program.

Integrate community needs with health service delivery plans. Local communities often have histories of strained relationships with large university medical centers. Harlem is no exception. Although there may be reluctance on the part of community residents to give information to local health agencies, there is also a genuine willingness to work toward the “greater

good” (O’Fallon et al. 2000). From our perspective at HHC, our collaboration with HCZ has both helped us identify the chief health care concerns for children and their families, and design more effective programs and interventions to meet these needs. The addition of evaluation members from Columbia University has better ensured that we can effectively document our progress and setbacks and continually improve our initiative. Through our collaboration, each partner in the HCZAI has gained a better understanding of how our organizations and systems affect one another.

For instance, we are still struggling to identify all children with asthma though the public schools in Harlem, but different partners hold different information that cannot be easily shared. Indeed, ensuring patient confidentiality has posed a significant challenge to CBPR collaborations between health systems and local communities. Under the strict federal guidelines and procedures of the Health Care Portability and Accountability Act of 1996 (1996) (HIPAA), health systems are prohibited from disseminating protected health information about anyone being cared for within that system. This confidentiality has been incorporated into the operations of many health care delivery systems but causes confusion and tension when that information cannot reliably be shared within the boundaries of specialized academic–community partnerships. In the HCZAI, we have been able to comply with HIPAA rules by explaining the process to all our formal partners and encouraging them to integrate IRB guidelines into their daily programmatic operations. As HIPAA guidelines are revisited and improved to meet the needs of clients in community-based as well as hospital settings, we recommend expanding the confidentiality inclusion criteria so that health service delivery programs with multiple partners can gain permission for all involved institutions to share patient data, which is essential to improve health outcomes.

Build sustainability for health care services research initiatives. A strong investment in research by the public and private sectors over the past 30 years has led to healthier and longer life spans for most of the U.S. population. Nonetheless, certain communities—including central Harlem—continue to suffer high rates of premature death (Citizens’ Committee for Children of New York, Inc. 2003; Geronimus et al. 1996). Translation of medical research to patient care does not occur instantaneously, even as information technology has increased public awareness of research findings that may eventually lead

to improved treatments. Continued funding for health services research is imperative if we are to help patients, families, and clinicians answer questions about cutting-edge, evolving medical therapies. Additionally, health services research is needed for us to effectively address national health care policy challenges, including confronting unequal treatment in health care along color lines (Institute of Medicine 2002). Increased access to and use of medical therapy options will increase patient and clinician confidence in the health care system. Health services research can lead to the answers that our communities and policymakers are seeking, including “best principles” for providing adequate and respectful health care, regardless of the individual’s ability to pay for services.

Using CBPR to Promote Civil Society

A hopeful promise of CBPR lies in its capacity to promote civil society and help eliminate egregious disparities in health and health care for those without sufficient resources to pay high costs for safe and affordable housing, education across the life course, and adequate and respectful medical care. Dr. Olden made a bold leap of faith in devoting substantial resources and the institutional leadership of the NIEHS to give communities a role in asking and answering the research questions that matter to them regarding the environment and health. His legacy will live on through the increased capacity to conduct research within communities and demonstrable improvements in the environments and health that will follow from needed policies and funding of programs that CBPR approaches have helped motivate. The true test of CBPR will be its continued evolution once Dr. Olden has passed on the leadership torch at the NIEHS. We will all miss his steadfast commitment to CBPR and his listening ear, which was tuned into the environment and health needs of vulnerable constituencies.

SUMMARY

We are honored to contribute to this special issue of *Environmental Health Perspectives*. Our task for this article is both constrained and expanded by the collection of invited articles. That is, various other authors have covered related topics to which we are devoted to and that comprise the bulk of our past and present research. On the other hand, their collective contributions allow us to focus particularly on the topic of community-based participatory research (CBPR) and offer our views

on what the future holds for this approach to the research enterprise. We begin by reflecting upon Kenneth Olden's legacy, and how the National Institute of Environmental Health Sciences has embraced, institutionalized, and promoted CBPR both internally and externally. Second, we articulate what we believe is at the crux of the CBPR process, namely, the opportunity to ask—and sometimes answer—questions that matter to communities regarding the environment and health. Finally, we imagine what the future might hold for CBPR from our various perspectives: inside the academy at the Mailman School of Public Health of Columbia University, from the point of view of a community-based organization devoted to improving the lives of children at Harlem Children's Zone, Inc., and through the lens of physicians who provide health care to poor families at Harlem Hospital Center and its network of school- and community-based clinics. Dr. Olden has inspired us all to contribute to positive change in the environments and health of the communities we serve. doi:10.1289/ehp.7642 available via <http://dx.doi.org/>

NOTES

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