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Case History of the Center for Urban Epidemiologic Studies in New York City

Nicholas Freudenberg

ABSTRACT This case history describes the history of the Center for Urban Epidemiological Studies (CUES), an urban research center based in New York City. Between 1996 and 1999, CUES was transformed from an institution that worked with the medical schools of the region to a center seeking to define a new practice of community-based participatory research (CBPR). The report summarizes how and why CUES has changed, identifies its main accomplishments and challenges, and discusses some of the lessons learned to date. It illustrates how the principles of CBPR have influenced the development of CUES. The case history suggests that it is possible for an organization to transform itself from a researcher-driven orientation toward a more participatory model. The early history also demonstrates that it is possible to engage community organizations and activists in an ongoing effort to study and address complex urban health problems such as asthma, substance abuse, and infectious diseases. Finally, the report illustrates that CBPR is a process that evolves in response to specific situational factors.

KEYWORDS Asthma, Community-based participatory research, Urban health, Substance abuse.

INTRODUCTION

East and Central Harlem, two adjoining communities on the upper half of Manhattan, a major center of the global economy and home to almost half the world's billionaires, are among the poorest, least healthy communities in the US. Harlem is also home to hundreds of community organizations and health and social service agencies dedicated to improving Harlem's well-being and to some of the nation's most prestigious medical research centers. This case history describes the creation and early history of the Center for Urban Epidemiological Studies (CUES), an urban research center sponsored by the Centers for Disease Control and Prevention (CDC) and based in New York City. The report describes its transformation from an institution that focused on working with the region's medical schools to a center seeking to define a new practice of community-based participatory research (CBPR).

As discussed in the introduction to this section of the *Journal*, CBPR is defined as research in which community members and representatives are actively involved in decision making throughout all stages of the research process.¹ This includes (1) identifying health issues of concern to communities; (2) developing assessment tools; (3) collecting, analyzing, and interpreting data; (4) determining how data can be used to inform actions to improve community health; (5) creating the research

Dr. Freudenberg is Professor and Director, Urban Public Health, Hunter College, City University of New York, 425 East 25th Street, New York, NY 10010. (E-mail: nfreuden@hunter.cuny.edu)

designs; (6) designing, implementing, and evaluating interventions; and (7) disseminating findings.

The New York Academy of Medicine, a 150-year-old organization dedicated to improving health and health care in New York City, and the New York City Department of Health created CUES in 1996. Its original goals were to bolster the research capacity of several New York City medical institutions to carry out epidemiological studies of urban health problems. Its founding board was a consortium of seven academic medical centers, as well as the sole school of public health and the Blood Center in the New York metropolitan region. The proposed center, which included support from both public and private organizations, sought a partnership to bring together the talent and expertise of these academic institutions to develop new approaches to assess and improve the health of urban populations.

This case history describes the first 4 years of CUES, from 1996 to 1999. It summarizes how and why CUES has changed, identifies its main accomplishments and limitations, and discusses some of the lessons learned to date. A key goal of this report is to ascertain in what ways the principles of CBPR have influenced the development of CUES.

METHODS

The case history is based on interviews with 14 key participants in the process (CUES staff, community representatives, and staff from partner organizations); a review of documents such as minutes of meetings, proposals submitted, and annual reports; and field notes of observations of several CUES meetings and events. Respondents were selected based on their knowledge of CUES history and the larger community and their active involvement in CUES activities. Interviews were conducted by graduate public health students trained for this purpose. The study was based on a set of research questions developed by the Urban Research Center (URC) Evaluation Group, a research collaborative that includes CDC staff and local evaluators from each of the CDC-supported urban research centers.¹ Instruments and the study design were reviewed and approved by the Hunter College Institutional Review Board. Transcripts of interviews and all other documents were reviewed for themes identified by the URC Evaluation Group and the local New York City evaluation team, then coded so that descriptions of certain topics (e.g., staff interactions with community organizations) could be analyzed for additional themes or patterns using methods developed for case study research.^{2,3}

EARLY HISTORY

In the early 1990s, officials of the New York Academy of Medicine convened local medical researchers and city health department officials to propose the creation of CUES as a response to the human immunodeficiency virus (HIV) epidemic and other health problems sweeping through the city's low-income populations. Its mission, in the words of a founder, was to assemble and apply "municipal intellectual assets" to the city's most pressing health problems. Several corporate and philan-thropic organizations contributed money to establish the center.

In its initial proposal, the center identified a wide range of health problems it hoped to address, including breast cancer, hypertension and other cardiovascular diseases, acquired immunodeficiency syndrome (AIDS), substance abuse, adverse reproductive outcomes, and teen pregnancy. It also proposed to conduct research to explain the widening gap in death rates between whites and blacks, to help expand the access of minorities to clinical trials, and to contribute to the development of sound health policies for disadvantaged urban populations, with a special focus on minority women, infants, and school-aged children.

The initial proposal did not include any discussion that reflected emphasis on community involvement in research, and it appears that no community organizations participated in these initial discussions. None of the early participants had much experience in participatory research, a method that seeks to engage the "subjects" of research in planning, implementing, and analyzing the proposed studies,⁴ and engagement with communities for the purpose of collaborative research was not mentioned as a priority. The New York Academy of Medicine, the host organization for CUES, has had relationships with a variety of medical and nonprofit institutions throughout the region, but at the time of the founding of CUES, it had no specific relationship to the East Harlem community in which it is located. In 1996, CUES was notified that, although it did not receive core funding for a URC, CDC would assign two staff epidemiologists to work with CUES on its projects. Thus, unlike the URCs in Detroit and Seattle, until late 1999, the New York center relied primarily on funds raised from other sources, and it continues to have an independent base of operations.

THE SETTING

East Harlem, the home of CUES, and Central Harlem, where it also works, are among the poorest and least healthy communities in New York City. Rates of illness and death are often several times higher than for New York City as a whole (Table 1). East Harlem has New York City's highest rates of hospitalizations for childhood asthma and substance abuse.^{5,6} A study a few years ago found that men in Central Harlem were less likely to reach the age of 65 than men in Bangladesh.⁷

At the same time, however, both the East and Central Harlem communities have considerable assets: a dense network of community organizations and social service agencies (e.g., there are 60 drug abuse treatment centers in Harlem), a history of mobilization to improve living conditions, and thousands of individuals who work hard to support their families, educate their children, and make their neighborhoods better places to live.⁸⁻¹⁰

While the two communities share many characteristics, they also differ in important ways. In 1990, East Harlem had twice the proportion of Latinos (primarily Puerto Ricans) as Central Harlem, and Central Harlem had 1.5 times the proportion of African Americans.⁵ These ethnic differences dictate that the two communities play different roles in the long-standing political, economic, and social issues that sometimes divide and other times unite African Americans and Latinos in New York City.^{11,12}

In the past, according to respondents interviewed for this study, community residents and activists have sometimes criticized the various scientific and medical organizations involved in this effort (e.g., Mt. Sinai Medical Center, the New York Academy of Medicine, and the New York City Department of Health). These institutions and their staff have been accused, among other things, of being divorced from the community, concerned only about their self-interest, and collecting data for the purpose of publishing papers rather than improving the community. These perceptions influence the extent to which community residents, service providers, and activists are willing to trust researchers.

Characteristic (source)	East Harlem	Central Harlem	New York City
 Demographic⁴			
Total population (1990)	117,716	185,666	7,319,759
Race/ethnicity, %*			
Black	52	73	29
Hispanic	50	25	25
White	21	14	52
Other	27	13	19
Households in poverty, %	37	35	18
Not high school graduates, %	49	42	32
Not working, %	52	48	35
Under age 15 years, %	23	21	19
Over age 75 years, %	5	5	6
Health ¹³			
Infant mortality 1996, per 1,000	11.3	15.2	7.8
Tuberculosis 1996, per 100,000	44	105.6	28
Gonorrhea 1996, per 100,000	649.9		127
Homicides 1996, per 100,000	19.6	39.0	13.9
Cancer deaths 1996, per 100,000	174.4	179.2	67.5
Heart disease deaths 1996,			
per 100,000	286.0	423.4	376.5
Childhood hospitalizations for			
asthma ⁵ 1996 (0–14 years),			
per 1,000	29.9	17	10.7
Hospitalizations for substance			
abuse ⁴ 1992, per 1,000	22.6	18.2	6.3

TABLE 1. Demographic and health profile of East and Central Harlem and New York City

*Totals may be greater than 100% because Hispanics can be identified as whites or blacks.

CUES was created at a time when the role of government in health and social services was changing rapidly. Changes in welfare policy, Medicaid, criminal justice, and drug policies had a significant influence on the ability of individuals to find the services they needed and of community organizations to identify stable funding streams that would enable them to deliver the services their clients needed.^{14,15}

PROJECTS

Project Efforts

In its first two years, CUES developed a number of projects in areas in which its staff had expertise and funding was available. By early 1998, CUES had initiated 10 projects in three broad areas. These included projects on behavioral strategies such as a study of risk behaviors and HIV in injecting drug users (IDUs); a study of the determinants and antecedents of weapons acquisition in children; and research on innovative reproductive health prevention strategies. Environmental health projects included school-based surveys of asthma prevalence in East Harlem and South Bronx public schools; an asthma conference, Working Together to Control Urban Asthma, sponsored in partnership with CDC, the New York City De-

partment of Health, the US Environmental Protection Agency, and Pfizer Pediatric Health; a study of asthma outcomes following discharge from emergency departments conducted in partnership with Long Island Jewish Medical Center; and an exploratory study on occupational asthma. Some of these studies were carried out in partnership with the Asthma Working Group, 50 asthma experts from the city's main medical and health institutions. Finally, studies of early life antecedents of adult health status included birth cohort studies of in utero exposures and health disorders in later life; a study of prenatal polychlorinated biphenyl (PCB) exposure and neurodevelopmental outcomes in adolescence and childhood; and an exploratory study on the determinants of low birth weight.

During this time, CUES also developed relationships with several local networks: the East Harlem Community Health Committee and its offshoot the East Harlem Asthma Working Group, the East Harlem Substance Abuse Group, and the East and Central Harlem HIV Care Networks. It also began to interact with several community service providers, including local health centers, substance abuse treatment programs, and harm reduction centers. From these affiliations, CUES identified the individuals and organizations that became part of its Community Advisory Board. These early relationships were developed primarily by CDC research scientists assigned to CUES, one of whom had family who had lived in East Harlem. This connection facilitated positive interactions with community organizations and helped to build the trust needed to pursue ongoing projects.

In 1999, CUES developed six new projects. The Urban Research Center Social Determinants of Health Project was created to study and develop an intervention to address the social determinants of substance use in Harlem, using a CBPR approach and emphasizing the determinants of social support and social cohesion. HOPE: Prevention of HIV Among New IDUs and Non-IDUs in Harlem is a cohort study designed to determine the prevalence and incidence of HIV and hepatitis positivity among young non-IDUs (e.g., those who smoke crack or sniff heroin) and to identify correlates and risk factors for infection and transition to injection drug use. The Drug User Intervention Trial (DU-IT): Drug and Sexual Risk Behavior Reduction for New Young IDUs is a randomized trial that evaluates the effectiveness of an empowerment intervention in reducing sexual and injection risks associated with HIV and hepatitis C virus (HCV) infection among young or recently initiated drug users. Hepatitis C in New IDUs: Implications for HIV Prevention is a cohort study to determine the incidence and risk factors of HCV among recently initiated IDUs and to define host and viral factors that are associated with HCV clearance. Inspire: Intervention Research Addressing the Primary and Secondary Prevention Needs of HIV-Seropositive IDUs is a randomized trial to evaluate the effectiveness of a hybrid cognitive-behavioral and empowerment intervention in promoting utilization of HIV care, adherence to HIV medications, and sustained reductions in sexual and drug use behaviors among HIV-positive drug users in methadone programs. Finally, the Asthma in Head Start Centers project is implementing and evaluating a program of early asthma detection and intervention in 10 Head Start centers in East and Central Harlem.

Shift in Content

A comparison of the CUES projects developed in its early years and those developed and funded in 1999 revealed several differences. First, the activities have become more focused in East and Central Harlem. In 1998, only 2 of 10 projects listed by CUES were in Central or East Harlem; of the new 1999 projects, all 6 were based in Central or East Harlem. The new projects in 1999 were more likely to include community partners in the design and execution of research; in 1998, only 1 project had a community advisory board. By 1999, this board advised all projects, and 3 of the 6 projects had community partners involved in their design and implementation. In 1998, several projects had active involvement from CUES Management Advisory Committee (MAC), the board of medical school deans that advised the center. By the end of 1999, the MAC or its constituent organizations did not have an active role in any project. Finally, the more recent studies were more likely to address the two core topics that CUES selected in 1998: infectious diseases related to drug use and asthma. Of the 10 early projects, 5 addressed one of these issues, while all 6 of the new projects did.

These differences in the content of its work reflect the success of CUES in shifting its focus and direction. By late 1998, CUES had decided to change its scope of work in several directions. It had identified participatory research⁴ as an important characteristic of its mission. In June 1999, the Community Advisory Board approved a Statement of Principles that defines its commitment to this process (see Table 2). It opted to pursue ongoing partnerships with a few community-based organizations and local coalitions, as well as with other research institutions. It decided to focus its work on the geographic community in which it was located, East Harlem, and the neighboring community of Central Harlem. It chose two

TABLE 2. CUES operating principles

The community within which we will conduct public health research is currently defined as all of Harlem.

The purpose of any research conducted is to benefit the community either through increased knowledge or by promoting change.

The purpose of participatory research is to develop a partnership of community-based organizations, public health agencies, and educational institutions.

Members of the community advisory board, local community-based organizations, public health agencies, and educational institutions are involved in all major phases of the research (e.g., defining the problem, gathering data, analyzing data, using results, sharing and disseminating results).

Whenever possible, training of community persons on how to collect, analyze, and report data will be conducted.

Any publications resulting from the research will acknowledge the contribution of, consult with, and invite to collaborate as coauthor (when appropriate) partners that participated in the research.

Dissemination of findings will go beyond peer-reviewed publications and will include community forums, community newsletters, and other community venues.

All research projects must adhere to the human subjects review process.

The community partners will be educated about the institutional review board process and informed consent whenever research ideas are conceptualized.

Participating research partners are not limited to members of the community advisory board, and, in fact, involvement of local residents, other CBOs, other public agencies, and educational institutions are encouraged as long as the above principles are followed.

These principles were approved by the CAB on June 9, 1999.

health issues on which to concentrate its research: the nexus between substance abuse and infectious diseases and asthma.

A key role was played by CDC in the shift from traditional, institutionally based research to a more participatory, community-based model of research. CDC exerted continuing influence on the research model in several ways. CDC Atlantabased staff encouraged the CDC assignees in New York, who they supervised, to develop closer collaborative relationships with community organizations. In the Request for Proposals (RFP) for the second round of URC funding issued in 1999, CDC clearly indicated that future funding depended on collaborative relationships with community groups and participatory research models. The RFP reinforced a message that CDC had already given: If the New York site wanted future funding, it would have to develop methods of working more closely with community organizations. Many CUES staff welcomed this new direction and embraced the task of developing community partnerships.

Another factor contributing to the transformation of CUES was changes in its leadership. In its first 3 years, CUES had three different directors, each with somewhat different research interests and institutional affiliations. These changes made it more difficult to establish a stable and consistent research agenda or to form stable partnerships with other organizations. By early 1999, however, a new permanent director was hired, an epidemiologist with a record of working with community organizations.

ACCOMPLISHMENTS

CUES has succeeded on many of the dimensions by which academic research centers are traditionally judged. Between 1996 and 1999, CUES submitted more than 40 research or educational proposals. Since its founding, CUES has been awarded a total of \$25 million from 20 different funding sources and has established active research programs on substance abuse, infectious disease, asthma, and several other topics. While it will require a longer time to assess the contributions of this work, CUES has clearly succeeded in launching several research studies that address important urban health problems. CUES researchers have published more than 44 papers based in whole or in part on their work at CUES and in 1999 made 15 presentations at professional conferences. These accomplishments also demonstrate the early success of CUES in disseminating the findings from its work to other professional and scientific audiences.

CUES has also succeeded in some less-traditional ways. It has opened a dialogue with several community organizations. Through its engagement in coalitions, its involvement in community events such as the Asthma Conference, and health fairs, its research partnerships with local agencies and, most importantly, its establishment of a Community Advisory Board, CUES has created a forum in which open discussion of important community health issues can take place. Participants in the board include community service providers, local residents, and former drug users. While the long-term value of this dialogue cannot yet be assessed, it seems clear that CUES has introduced the possibility of a different kind of relationship with the community.

CUES has also made several direct contributions to the networks and coalitions to which it belongs. It has provided staff support, a Web site with data on East Harlem, meeting space and refreshments, and assistance in fund-raising, and it has carried out research studies designed to answer questions raised by these groups. Given that these coalitions often lack direct funding or staff, these institutional contributions can significantly increase the capacity of the coalitions to achieve their aims.

BARRIERS AND CHALLENGES

At the same time, however, CUES also faces limitations. Trust continues to be an issue, and the institutions of East Harlem have so often disappointed many participants in the process that they will need to see concrete benefits over a longer period of time before they are willing to accept that CUES in fact is different from other research institutions. In addition, despite the genuine interest of CUES in community participation, many funding opportunities still expect researchers to be in control, making it difficult to find the resources needed for a genuine participatory research process. As one respondent at CUES said: "The cold, hard fact of the matter is we choose research based on what we can get funded. So far it's been a funding-driven process. If we don't think we can get funding for it, we're not going to write that grant." (Note: this and subsequent quotations are taken from interviews conducted for this evaluation.)

Finally, several CUES projects are part of multisite studies that are centered at federal agencies, perhaps limiting the opportunity for community organizations in Harlem to tailor interventions to local conditions.

Another problem is conflicts among institutional partners. CUES began as the creation of the largest academic medical institutions of New York City and now has more than 25 very different types of community partners. Finding common ground both within these types of organizations and between the two types (i.e., medical institutions and community groups) remains a difficult challenge, especially in communities that lack a history of strong cross-institutional partnerships. For example, smaller grassroots organizations feared that joining with the larger institutions on proposals for new projects could threaten their autonomy. A related problem is the difficulty of establishing a unique niche. Harlem may have a shortage of primary care practitioners, but there is no shortage of researchers who want to work in these neighborhoods. For CUES to define its unique role, to establish a distinctive relationship with community organizations, and to convince funders to support that role is a complex task given the other research institutions with a foothold in the area.

CUES defines both a specific research agenda and a broader social mission. As an organization that hopes to contribute knowledge both to reduce specific health problems and improve living conditions and advance social justice, CUES may have difficulty finding the appropriate balance among these different goals.

Finally, the difficulty of working out ways to share power will continue to challenge CUES and its partners. Who sets the agenda for Community Advisory Board meetings? How does CUES decide which grants to apply for or which organizations to partner with? Answering these questions will require that the stakeholders involved will need to take risks, often in uncharted territory. For example, CUES staff and board members agree that research should benefit the community, but often differ in how they value different types of benefits, such as new knowledge versus jobs for community residents or expansion of needed services. Creating a framework for resolving these differences is a key priority.

LESSONS LEARNED

At the end of 1999, CUES is a work in progress. In part because of changes in its leadership and in part as a result of its increasing interactions with community organizations in East and Central Harlem, it has become a different organization from the one founded in 1996. The main lessons learned to date are thus about this process of transformation from a more traditional medical research institution into one that is more community oriented. While it is premature to judge final outcomes, the following preliminary generalizations are offered.

First, the experience of CUES suggests that it is possible for an organization to transform itself from a researcher-driven orientation toward a more participatory model in which community organizations have a voice in shaping the research. That this process could occur within as established an organization as the New York Academy of Medicine implies that a wide range of organizations may be capable of this process.

The history of CUES also illustrates that CBPR is a process with a continuum of stages, rather than a dichotomous outcome. CUES makes more participatory decisions now than at its inception, but as several community and staff respondents indicated, much more can still be done to give all parties an equal voice in shaping the direction of CUES.

Second, it appears that the incentives and penalties (e.g., the threat of not winning new funding for the URC) that CDC provided to encourage this transformation played a central role. While individual researchers at CUES supported the change and community organizations were able to exert continuing influence to maintain the change, the CDC exerted a critical influence by providing a consistent message that the expectation was to develop a center committed to the practice of CBPR. The regular interaction with the two other sites that were also working to implement this model provided further reinforcement for change. In addition, the CDC-assigned researchers had the freedom to pursue an agenda that was more community driven without worrying about writing another grant to support their salaries. The broader lesson is that funders can change the research behavior of organizations in at least some cases.

Third, the experience of CUES suggests that creating space for dialogue on significant community health issues may be a first step toward overcoming distrust. At CUES-sponsored community meetings on asthma and substance abuse, for example, participants debated about the relative importance of social, behavioral, and medical causes of these conditions and the implications for intervention. While researchers and community representatives sometimes disagreed, the act of coming together for respectful discussion opened the door for finding common-ground solutions. Similarly, CUES willingness to step outside its own doors, to attend community meetings and events, and to participate in local coalitions helped it begin to build the trust needed for more formal partnerships. As one respondent noted:

CUES is at a point now where they realize that they cannot survive without the community, and they are making overt efforts to be involved and to gain credibility, not professional legitimacy, but qualitative credibility in the East Harlem community. That's a process.

Fourth, CUES demonstrated that participation in community coalitions can help an organization become acquainted with a wide variety of grassroots agencies and larger, more formal institutions. It may be a more efficient way of "meeting" a community than sending staff to meet with each agency, a process that is both time consuming and can force an agency to pick partners, perhaps prematurely, at the risk of offending those not selected.

Finally, the experience of CUES has shown it is possible to engage community organizations and activists in an ongoing effort to study and address the complex health problems that face urban, low-income communities, such as asthma, substance abuse, and infectious diseases. One CUES staff member explained:

The community advisory board has shifted focus from advising investigators on a particular study, to thinking about the social determinants of health in East and Central Harlem and taking on a broader agenda. That's a big transformation [that has] happened very fast.

The willingness of community organizations to approach these problems from a research perspective and of CUES researchers to acknowledge the importance of community partnerships to the improvement of community health provide grounds for optimism that CUES can continue to realize its aims.

EPILOGUE

In 2000, many of the trends identified in this report continued. CUES received additional funding for its work on infectious disease and asthma. A leadership cadre from the community emerged within the Community Advisory Board and became more assertive in defining an active role in shaping the future direction of CUES, sometimes leading to more sustained differences with CUES staff on power, money, and the nature of benefits to the community.

CUES implemented several projects that gave it a more active presence in the community, including a community forum on substance abuse that attracted more than 250 community residents, service providers, and policy makers to discuss and debate strategies for responding more effectively to Harlem's substance abuse problems. CUES staff also worked to produce a survival guide for Harlem residents (based on the California Wellness Guide¹⁶) and a resource directory on substance abuse and other services for staff of community agencies; both are in development with an interactive process with academia, the health department, and the community. Another project surveyed service providers to identify policy obstacles that made it difficult for their drug-using clients to get the services they needed. In each of these projects, Community Advisory Board members played a key role in designing and implementing activities.

As noted above, CBPR is a process, not an outcome. In its first 5 years, CUES has taken several steps down this path. In the years to come, it will be necessary to document how the center continues this journey and to examine the relationship between this process and the health outcomes CUES seeks to achieve.

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