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## SPECIAL FEATURE: URBAN RESEARCH CENTERS

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# Implementing Community-Based Participatory Research Centers in Diverse Urban Settings

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### INTRODUCTION

This issue of the *Journal of Urban Health* contains descriptions of the implementation of community-based participatory research (CBPR) activities at three Urban Research Centers (URCs) funded through an initiative of the Centers for Disease Control and Prevention (CDC). Now in their sixth year, the URCs have each formed research partnerships among community-based organizations (CBOs), universities, private organizations, and public health agencies. The articles presented here, describing the first 4 years of the development of the URCs, focus on the process of conducting participatory research and include an overview of the urban health issues that are being addressed. Health outcomes will be reported in the future as the URCs analyze findings from their multiple research activities. Here, we document the processes that have become the cornerstones of the activities of the URCs so we can link these processes to health outcomes down the road.

The URC-specific reports presented here describe the implementation of CBPR partnerships in the context of urban settings, demonstrating that this approach can be used both to establish new participatory research centers and to guide the transition of traditional research centers to more participatory entities. Our goal is to provide community representatives, public health researchers, and funding agencies with information about how research can be done with equitable opportunities for all partners to contribute. Drawing on the expertise of all partners increases understanding of the factors and processes leading to poor health outcomes and informs the development of interventions to improve community health.<sup>1</sup> We begin by exploring the background of the URCs.<sup>2</sup>

### BACKGROUND\*

Residents of US urban communities are more likely to experience excess rates of heart disease, cancer, asthma, interpersonal violence, and other conditions when compared to persons from nonurban areas.<sup>3</sup> Low-income residents, predominantly people of color, who are increasingly concentrated in cities and their surrounding

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\*This background section draws heavily from Ref. 2.

metropolitan areas, bear a disproportionate burden of these diseases.<sup>4</sup> Many factors contribute to these health outcomes, including social, economic, political, structural, and environmental factors that interact to create conditions and behaviors conducive to poor health.

Multiple public health activities, including the nation's blueprint for improving public health as outlined in *Healthy People 2010*, are focused on the problem of a disproportionate burden of disease among disadvantaged groups of people. Complicating the ability to address long-standing public health issues effectively among people of color is a well-documented mistrust of health researchers by community members, many of whom have come to view research as, at best, "collecting data for the purpose of publishing papers rather than improving the community."<sup>5(p510)</sup> In worst-case scenarios, mistrust of researchers has resulted from actual harm to community members, with the Tuskegee Study of Untreated Syphilis as the most frequently mentioned example in the US.<sup>6,7</sup>

In 1995, CDC funded the URCs to develop innovative strategies to improve health and health-related characteristics of communities of low-income, inner-city populations.<sup>8</sup> The funding announcement encouraged the development of collaborative relationships across research institutions, health care providers, and CBOs. Core operating funds and a CDC scientist were provided to the University of Michigan School of Public Health, for the Detroit Community-Academic Urban Research Center, and to Public Health: Seattle and King County for Seattle Partners for Healthy Communities. Fiscal constraints limited the initial awards to two sites; however, the New York Academy of Medicine was provided with two CDC scientists to assist with the development of the Center for Urban Epidemiologic Studies in Harlem, New York. The findings in the New York URC report reflect their financial limitations. The URCs were also encouraged to seek additional funding from other sources to add to their core awards.

The initial project period was 4 years, from 1995 to 1999. The project period of the second phase of the URCs is from 1999 to 2003. With the CDC funding, the URCs support their partnership infrastructures and conduct demonstration projects that develop and test conceptual models and interventions for addressing social determinants of health using CBPR methods. The original URCs, including the New York sites based in Central and East Harlem, successfully competed for Phase II funding through a peer review process.

The URCs focus on specific low-income communities of color within their respective cities. Communities are defined by either geographic area (e.g., East Detroit and Southwest Detroit, MI; Central and South Seattle, WA; and Central and East Harlem in New York City) and, in some cases, by common characteristics such as ethnicity, gender, or age. The Detroit and Seattle URCs formed partnerships at their respective sites that included community members and representatives of CBOs, academic institutions, public health agencies (CDC and state and local health departments), and private organizations. In New York City, funding constraints and other factors somewhat delayed the emphasis on CBPR.

#### **URBAN RESEARCH CENTER MISSION AND GOALS**

The original funding announcement stated that: "Combined resources of the recipient, other local organizations, the local community, and CDC"<sup>8(p6)</sup> should be brought to the task of conducting research activities for the purpose of improving health in urban communities. The three URCs clarified the nature of new partner-

ships when they collectively agreed that, to achieve the mission of improving health in low-income urban communities, they would (1) establish effective partnerships among community members and CBOs, public health agencies, health care systems, and academic institutions to identify problems jointly that affect the health of urban communities and (2) implement and/or evaluate solutions for these health problems that recognize, build, and enhance the resources and strengths in the communities involved. Specific URC goals were and continue to be to (1) foster and develop CBPR; (2) establish an infrastructure to facilitate collaboration among community, public health, health care, and academic partners to develop, implement, and evaluate research projects and programs to promote the health of urban communities; and, (3) develop, evaluate, and disseminate promising approaches that address urban health issues. The mission and goals were developed through a collaborative process involving partners from CBOs, local public health departments, integrated managed-care systems, academia, CDC, and community representatives not affiliated with institutions or agencies.

### **COMMUNITY-BASED PARTICIPATORY RESEARCH**

The URCs use CBPR methods in which community members and representatives are actively involved in decision making throughout all stages of the research process. Increased attention on the need for community-researcher partnerships to address public health goals has led to the development of multiple models of collaboration. The insights and perspectives of community participants enhance the knowledge and understanding of researchers about community dynamics and conditions that affect health. As well, CBPR builds on the strengths and resources in the community.

Multiple terms and ideas are used to describe CBPR. In general, a CBPR approach involves community members or the recipients of interventions in all phases of the research process, including (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 designs; (6) designing, implementing, and evaluating interventions; and (7) disseminating findings.<sup>1,9,10</sup>

In addition, all URCs adopted principles of participation to guide both the partnership development and the implementation of research activities. As with the definition of CBPR, there are no specific components to principles of participation. Essentially, they are developed collaboratively by members of the partnership and spell out agreements on such issues as decision-making processes, confidentiality, or dissemination of findings.<sup>11</sup>

Using CBPR methods to guide the partnerships is consistent with a democratic and colearning approach to research by which members participate as equals, sharing control throughout the research process. Partners work together to design projects that promote community change and benefit community members, in contrast to researcher-driven research, by which community representatives are included primarily as consultants or advisors.

### **ROLE OF CENTERS FOR DISEASE CONTROL AND PREVENTION ASSIGNEE**

The initiative supporting the development of the URCs included providing the opportunity for CDC to learn about the process of implementing CBPR in public

health research. Original plans called for a CDC scientist to be assigned to each URC to learn from and contribute to the research activities. As midcareer professionals, “assignees” have scientific and technical skills to contribute to research activities, as well as knowledge about CDC policies and procedures, program activities, and how to access institutional resources. In addition to what the assignees bring to the URC partnerships, each is also there as “learner”—to learn about the process and methods of developing collaborative partnerships for the purpose of conducting public health research, improving community health, and building community capacity. The CDC URC assignees acquire new skills and are frequently called on to share “lessons learned” with other CDC scientists, program managers, and administrators.

In practice, the CDC assignees played different roles and spent varying amounts of time with their respective URC. In fact, the Seattle URC had no assignee for most of the time period covered in this evaluation.

### **PROGRAM EVALUATIONS**

By 1998, the third year of the URC projects, the URCs were actively addressing urban health issues. However, it was clear that, although they shared the common goal of conducting CBPR to improve health in urban communities, they each realized this aim in different ways. The projects are located in different types of institutions (academic, public health, and medical research) and different cities, and each has had different experiences working with communities in addressing health issues. To understand better the methods used by the URCs to ensure community participation, the context in which URC activities occurred, and the range of research projects being conducted across the sites, CDC provided program evaluation funds to look at these program issues at each URC, building on extensive program evaluation activities already under way in Detroit and Seattle. The objectives of these individual case studies were to examine the following at each site: (1) how CBPR has been fostered and developed; (2) how infrastructures have been established to facilitate collaboration across diverse community partners to address urban health issues; and (3) whether and how promising approaches to addressing urban health issues have been developed, evaluated, and disseminated. By documenting these processes, the evaluators hoped to be able to produce a “chain of evidence” that can link URC activities to health outcomes that will emerge in later phases of these projects.

To establish these initial links in the chain, a case study approach<sup>12</sup> was adopted by the three URCs and was adapted to fit the needs of each URC (e.g., as noted above, the New York URC had no funding to develop an infrastructure for community involvement in the first phase of the URC project, and they accommodated for this circumstance in their evaluation). Community members at each URC provided assistance and guidance in the cross-site evaluation. Generally, sources of information dating from 1995–1999 were identified, including data from ongoing process evaluations, board surveys, and archival documents such as field notes and minutes from board meetings, grant proposals, and annual reports. A series of open-ended discussions with staff and board members was used to obtain information not contained in the existing sources of information and, in the cases of Detroit and Seattle, to supplement their ongoing process evaluations. Details of the methods used by each URC are provided in the individual articles that follow.

The following topics are discussed in each of the papers: contextual informa-

tion on the URC (the institution in which the URC is housed and the communities where it operates); a description of how each URC began, including the development, structure, and operation of the boards; their goals and objectives; principle accomplishments; facilitators and barriers to success; and lessons learned. The papers reveal that each of the URCs differs in form and function, illustrating how the CBPR approach is adapted in actual urban settings. Given that the URCs operate in different settings, work with community members in different ways, have different cultures represented on their boards, address health issues specific to the communities in which they work, and as in the case of the New York City URC, are in different developmental stages, it is not surprising that the projects function differently.

Common among the URCs, however, is a commitment to CBPR principles, “a yardstick against which current and potential projects are measured.”<sup>13(p523)</sup> Although there is some variation among the principles developed at each of the URCs, an explicit goal of all three is to involve community partners equitably in all aspects of the research process. In each case, principles of participation are credited with guiding the partnership and research activities and the transformation of traditional research organizations into more participatory ones. Principles of participation are repeatedly referred to as one of the most important factors accounting for the strength and success of the partnerships, particularly the building of trust among community members and researchers.

Other facilitators credited with the successful development of the partnerships include the use of asset-based approaches to defining community resources; well-defined organizational structures with ground rules stating how meetings are conducted, agendas are set, and decisions are made; the importance of leadership; and the opportunity to commit the necessary time to develop the partnerships before implementing full research agendas. CDC is credited with contributing to the development of the partnerships through the provision of core operating funds to develop infrastructure and scientists to contribute to research activities, by being flexible regarding the length of time required to establish the partnerships, and by providing leadership on the importance of using a CBPR approach when needed.

The URCs also face many challenges in the development of the CBPR partnerships, including tension between a commitment to process versus research products; sharing resources, responsibilities, and opportunities; balancing the interests of communities, researchers, and public health partners; and sustaining the partnerships and the projects.

### **COMMUNITY-BASED PARTICIPATORY RESEARCH: MISSION POSSIBLE**

From these reports, it is evident that a CBPR approach is an effective way to identify urban health issues and the social and environmental factors that contribute to these health conditions. Using CBPR methods, diverse groups can build productive, trusting partnerships to address health issues in urban communities. CBPR is also an approach that has been successful in securing funding to address these issues. In addition to core funding from CDC, the URCs collectively acquired \$4.3 million in 1999 and \$11 million in 2000 (from such sources as the National Institutes of Health, the Department of Health and Human Services, and private foundations) to address a variety of community-identified health issues. The range of research projects being conducted by the URCs (including human immunodeficiency virus/

acquired immunodeficiency syndrome (HIV/AIDS) and hepatitis C prevention, identifying and addressing the social determinants of drug use, domestic violence, and asthma) demonstrates the utility and versatility of a coordinated participatory research center approach.

The theoretical benefits of and the ideological bases for using participatory research approaches are well described in the literature.<sup>1,9,10</sup> However, more information is needed on the efficacy and application of CBPR methods in actual projects. The partnerships of the URCs offer many lessons for community organizations, academic researchers, and public health partners. Readers of the articles in this issue will emerge with an understanding of how CBPR is conducted, including how infrastructures can be established to facilitate collaboration among diverse community partners to address multiple urban health issues. Each URC has met the challenge of bringing diverse groups of people together to “articulate a common vision and a clear process for conducting research that proceeds in partnership with communities.”<sup>14(p504)</sup>

As indicated by the number of proposals, projects, papers, presentations, and funding, the URCs are highly successful endeavors. Their efforts to build trusting partnerships, where sound relationships are viewed as indispensable to the conduct of sound science, provides a new approach to addressing the health challenges of disadvantaged urban communities systematically. Although it is too soon to assess the impact of URC activities on community health, the strength of the foundations on which the partnerships are built is clearly identifiable.

Following President Clinton’s apology to African Americans for the abuses that occurred during the Tuskegee Syphilis study,<sup>15</sup> a task force representing multiple federal agencies was asked to develop recommendations for rebuilding trust with communities for the purpose of conducting research to improve health. Chief among the recommendations of the group was the development of community-based partnerships that include community members through all phases of the research process.<sup>16</sup> The experience of the URCs demonstrates the feasibility and power of this approach for creating a climate in which trust between researchers and communities can be restored.

The URCs are clearly evolving and changing. What we describe here is the intent of the CBPR model chosen by the three URCs: a continuum of activities and ideas that represents a shift from the traditional researcher-driven model to a way of conducting research in which all partners participate more equally. The task now is to demonstrate that this approach does in fact lead to improvements in health. We need to determine when CBPR is effective and when it is not, what it really means to build community capacity, and what is an appropriate role for public health agencies in supporting this approach.

When asked about the role of CDC in the development of the URCs, one URC partner commented, “I feel like CDC has learned from us.”<sup>13(p530)</sup> We are indeed learning a great deal from the URC partnerships. We hope you will, too.

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