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Improving Health Services for Residents Through Community-Based Participatory Research: A Public Housing Leadership Perspective

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Abstract

Background: In response to feedback from a health forum, resident leaders of public housing in Washington, DC, were inspired to create a health survey for and by the residents.

Objective: The survey was designed to document residents' concerns about health, health care, and environmental threats. It also explored tobacco use and support for smoke-free housing.

Methods: A newly created Health Planning Committee of the Citywide Advisory Board, including residents, academics, and representatives of health and housing organizations, facilitated the creation of a health needs assessment. Questionnaires were initially mailed, then hand-delivered to every public housing household. More than 1,000 completed questionnaires have now been returned.

Lessons Learned: This project highlights a model that places resident leaders in charge of health issues, including leading advocacy efforts for policies to reduce health disparities in public housing. It identifies research challenges and ways to overcome them and empowers the community for continued research.

Keywords

Community-based participatory research, community health partnerships, power sharing, health disparities, health planning, needs assessment,

It has been well-documented that residents of public housing suffer from much poorer health compared to the community at large. This substantial health disparity can be attributed to several factors, including that "residents of public housing are more likely than the community at large to be members of a racial or ethnic minority."[1] Other factors that impact the quality of life and health of public housing residents include relatively low levels of education and high rates of unemployment, illicit drug use, and crime.[2] Resident councils are charged with improving the quality of life for fellow residents and facilitating their participation in self-help initiatives, but psychosocial and institutional barriers have historically impeded the process and limited the results.

In response to some of the health challenges among residents of public housing, congress established the HOPE VI Program in 1992. The program sought to improve the health of public housing residents by relocating them to mixed-income communities.[3,4] Although this approach achieved some success in improving the built environments surrounding these residents, the relocations were associated with a corresponding decrease in community-based resources and social support systems that are related to better health.[3,5]

Residents of public housing in the District of Columbia are at great risk for poor health, not only because they live in public housing, but also because they live in the District. In many respects, health indices for the District parallel those

of developing countries. In 2010, the infant mortality rate in DC was 8 per 1,000 live births overall, and 10.7 for African Americans. Low-birth weight that same year was 10.2% (13.3% for African Americans), and the premature birth rate was 10.3% (12.5% for African Americans).[6] The prevalence of type 2 diabetes, HIV/AIDS, and cancer in the District of Columbia are also excessively high.[7]

The District of Columbia is subdivided into eight wards that differ from each other socioeconomically and demographically. The unemployment rate in Ward 8, which has the second highest number of public housing units in DC, stands at 21.9%.[8] The unemployment rate in Ward 7, which has the highest concentration of public housing units, is 14.5%. In contrast, the unemployment rate for Ward 3, which has the highest concentration of White residents and the smallest number of public housing units (fewer than 10% of the number of units in Ward 7), is 2.2%.[8]

The impact on public housing residents in DC of high rates of chronic illness and unemployment led public housing resident leaders to conclude that something drastic had to be done immediately. The time was long past for mere storytelling and anecdotes; hard facts and figures needed to be collected to document and understand the health status of this population and the conditions that contribute to their disparities. For the first time, resident leaders initiated a project to improve access to health care and prevention services for themselves and their fellow public housing residents.

COMMUNITY MOBILIZATION AND EMPOWERMENT STRATEGIES

In 2010, staff from the DC Housing Authority worked with well-respected resident leaders to host a health forum designed to educate, empower, and activate public housing residents. At the forum, residents viewed two segments of the seven-part PBS documentary *Unnatural Causes.* This viewing highlighted and explained some of the social determinants of health inequities and emphasized the necessity for advocacy for reform. The presentation was followed by a discussion that focused on why place of residence is a remarkably accurate predictor of life expectancy in general and of specific chronic diseases in particular. The audience also included a U.S. Department of Housing and Urban Development official who specializes in health policy, representatives from the DC Department of Health, local universities, and other community representatives including senior officials and Commissioners from the DC Housing Authority.

After this inaugural health forum, a focus group was conducted. The group was composed of thirteen residents from four public housing units where senior citizens and persons living with disabilities reside. Preliminary findings from the focus group revealed that residents wanted a more active role in selecting health and nutrition topics for future forums and workshops. More important, the group made it clear that residents wanted to be included in the decision-making process for designing and implementing health-improving interventions. The residents also voiced concerns about the stereotyping of public housing residents, especially in the southeast sector of DC. Other concerns that emerged from the focus group included limited access to fresh fruits and vegetables, environmental problems including roaches and polluted air inside and around public housing units, and limited access to good health care for disabled and senior residents.

Resident leaders and DC Housing Authority staff began to meet regularly with community health professionals and organizations. By the end of 2010, the group, led by residents, decided that a resident-led community needs assessment would be the best foundation for efforts to improve the health status of public housing residents in a sustainable way. Unlike previous initiatives, the discussions around this effort maintained a focus on how local organizations, including the Department of Health, health clinics, acute care hospitals, universities, and nonprofits could support and empower residents. Ensuring that residents guided, and "owned" the needs assessment process emphasized their responsibility for leading the effort to determine the needs of the residents, to implement the health care and prevention services that residents wanted, and to advocate for policy changes to address the pervasive health inequities in public housing. A Citywide Advisory Board Health Planning Committee was formally created, and began to meet monthly. The Citywide Advisory Board is a jurisdiction-wide tenant association composed of elected leaders in each public housing development in the District.

NEEDS ASSESSMENT SURVEY IMPLEMENTATION AND PRELIMINARY FINDINGS

Unlike traditional research targeting public housing communities, this project was designed and conducted *for* resi-

dents and *by* residents as a way to empower and equip them to take charge of planning and advocacy for their own health needs. By late 2010, residents and health professionals on the Health Planning Committee decided to develop a research tool to assess the health needs of residents. Community health partners quickly responded. In early 2011, several representatives from health organizations on the committee helped residents to develop a questionnaire. The questionnaire asked respondents to prioritize their concerns about health and health care and environmental threats including violence, crime, illegal drugs, and pollution. It included questions about specific health conditions, whether the respondent had a medical home ("my own doctor or health center"), tobacco use, and interest in smoke-free housing. Respondents also had the opportunity to express their preferences for hours and locations for the delivery of health services, and for the types of recreation and physical activities that should be made available. The questionnaire asked about age, race/ethnicity, and health insurance status, but explicitly instructed respondents not to put their names anywhere on the instrument.

Resident leaders worked together with the local housing authority, which organized the printing and mailing of the questionnaires. A local university agreed to assist with data analysis of the questionnaire. The questionnaire was mailed to all public housing households in May 2011. By August 2011, fewer than 500 completed surveys had been returned. In response to this low return rate, a resident leader arranged for reprinting of the questionnaire and the printing of posters that encouraged residents to respond. Resident council presidents and property managers redistributed these questionnaires with care to avoid duplicate submissions by households. The competed questionnaires were collected in specially designated boxes located in every property management office. More than 1,000 completed questionnaires have been collected to date. Because the questionnaire was designed to reach all public housing households, random sampling was not a critical consideration in this preliminary research.

Preliminary findings from this needs assessment confirm the large body of research on health disparities.[9,10] Residents show concern about their public safety and environment. Asthma and mental health rank high as specific resident health concerns.

A university-based member of the Citywide Advisory Board Health Planning Committee obtained exemption for this stage of the project from the Institutional Review Board of the University of the District of Columbia. Reporting of comprehensive results from this survey is contemplated for future publication when additional qualitative research and more careful data analysis have been completed.

This resident-led survey has sparked great interest. The organizational membership of the Citywide Advisory Board Health Planning Committee has grown to more than twenty professional groups and associations. There is clear agreement that public housing residents will maintain the lead on this project, including controlling the use and release of the data gleaned from this effort. Representatives from academic and health organizations on the committee provide technical assistance and support.

LESSONS LEARNED AND NEXT STEPS

The year 2010 marked an important beginning of public housing residents and their resident leaders taking more responsibility for improving their own health. From the onset, residents and community health professionals understood the challenges they faced. Research professionals often refer to public housing residents as a "hard-to-reach" population. Many residents still feel that they do not really have a voice, that completing the questionnaire would be pointless, and that no benefits could come from the information they provide. More work must be done to overcome these barriers and to continue to empower a population that has been deemed relatively powerless for so long.

One of the strengths of this project was that the questionnaire was completely anonymous; respondents were specifically instructed not to put their names anywhere on it. Placement of collection boxes in property management offices facilitated return of the completed questionnaires. The personal involvement of a key resident leader has lent authority and legitimacy to the effort. Data access is limited to those who receive approval from the Citywide Advisory Board Health Planning Committee. Another strength of this project is that the questionnaire contained a cover letter to explain its purpose and the fact that public housing residents were leading the effort. The then-president of the Health Planning Committee who also was vice president of the Citywide Advisory Board signed the letter and served as

the telephonic point of contact for all questions. This led to conversations with the contact person to say that residents were pleased to see this effort was resident driven and to share feelings of empowerment. Some thanked the contact for doing the assessment; others wrote comments and suggestions on the questionnaire. Some residents from the Section 8 program learned of the assessment and requested their inclusion in future assessment efforts.

Residents are becoming more aware of the value of the health needs assessment, and the Health Planning Committee is optimistic about follow-up activities. Additional steps currently being considered include continued engagement of property managers and the presidents of each resident council to encourage more residents to complete the questionnaire. Another contemplated activity is to redesign the instrument to get more in-depth information from the residents. Plans are also being made to train public housing resident leaders and health career students at local universities to conduct face-to-face interviews with randomly selected households for a second stage of assessment. This approach would address the limitations of low literacy among many residents, as well as apathy and other barriers to questionnaire returns.

Currently, resident leaders see this project as an empowerment tool that can serve a number of important functions. The information gleaned from this effort will provide the public housing community with evidence (not just anecdotal information) about its needs and priorities for health improvement interventions. With this information, residents can better advocate for their health equity through the implementation of wise public policies. Health organizations will be able to respond to the residents' needs more productively and efficiently. The collaborative process will increase patient activism and empowerment, which research shows leads to better health.[11] The committee model gives residents encouragement and support from the health and education communities. Residents will be able to see that their participation helped drive the interventions that will follow this needs assessment.

The public housing community is encouraged that professionals are helping them as they tell their own stories supported with real data. The Health Planning Committee is committed to this important collaborative empowerment process. This project builds the foundation for more sophisticated future research. It also provides invaluable support for community empowerment where both community members and health professionals work together toward the elimination of health disparities.

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