

Sowing the seeds for sustainable change: a community-based participatory research partnership for health promotion in Indiana, USA and its aftermath

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SUMMARY

Community-based participatory research (CBPR) increasingly is being used in both developed and developing countries to study and address community-identified issues through a collaborative and empowering action-oriented process. In 2003–2005, a study was undertaken to document the impacts of CBPR on healthy public policy in the US. From an initial review of 80 partnership efforts, 10 were selected as best capturing the range and diversity of projects meeting the study criteria, and were the subject of in-depth case study analysis. This article presents and analyzes one of these cases, a collaboration between researchers at the Indiana University School of Nursing and the Healthy Cities Committee of New Castle, IN, USA. With its action component still underway a decade after the formal study's completion, the partnership was selected to enable an examination of sustainable change through CBPR. Beginning with a participatory door-to-door health survey

of 1000 households using a non-probability quota sampling strategy, the project involved community members in many stages of the research process. A smoking rate of twice the national average was among the study findings that helped to galvanize the community into action. A variety of health promoting environmental and 'small p policy' changes were undertaken ranging from a bill restricting indoor smoking in public places to an initiative to develop a system of trails throughout the county to promote physical fitness and decreased reliance on automobiles. This article examines the evolution of the original CBPR partnership, its research methods and findings, and the environmental changes it sought to promote healthier lifestyles. Success factors, barriers and sustainability benchmarks are discussed. The case study offers an example of the potential of CBPR for helping to lay the groundwork for long-term sustainable change in support of healthier communities.

Key words: community-based participatory research; healthy communities; sustainability

INTRODUCTION

With its strong roots in the work of Paulo Freire and others in Latin America, Asia and Africa, participatory research has a long and proud tradition in Brazil, Tanzania, India and other

developing nations (Freire, 1982). More recently, and grounded as well in the action research tradition of Kurt Lewin (Lewin, 1946), community-based participatory research (CBPR) has

attracted growing attention in the US, the UK, Australia and other developed nations, with the Institute of Medicine even naming it one of eight new content areas in which all schools of public health should offer training (Gebbie *et al.*, 2002). With its commitment to strengths-based approaches and action as part of the research process, CBPR has shown particular goodness of fit with fields such as health promotion and nursing (Minkler and Wallerstein, 2003).

In the public health field, CBPR has been defined as:

a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. (CHSP, 2002)

This article presents the findings from a study of a CBPR partnership involving the Indiana University's School of Nursing and the Healthy Cities Committee (HCC) of the town of New Castle, IN, USA. With the overarching goal of 'making the healthy choice the easy choice,' the partnership—and later the community partner, (renamed Healthy Communities of Henry County (HCHC))—worked to promote a variety of changes in 'small p policies' that would help to achieve this goal. Following a brief look at the background and conceptual framework for this case study, we critically examine the evolution of the partnership, its research and policy goals and activities, and evidence of sustainable change long after the formal partnership had ended. Lessons learned are presented with particular attention to the role CBPR projects can play in helping to lay the groundwork for sustainable community level change. In keeping with principles of CBPR, the lead academic (Warner) and community partner (Steussey) each participated as co-authors on this paper.

BACKGROUND

Best known for many years as a center of automobile parts manufacturing, New Castle is a rural town whose population has declined to under 18 000 in recent decades, largely as a result of declines in the automobile industry. As Rains and Ray have noted, New Castle 'has a history

of helping itself and using the resources available,' an attitude reflected in its formation of a HCC in 1988 (Rains and Ray, 1995). Part of a larger statewide Healthy Cities initiative, the HCC was designed to promote the health of the town through multisectoral collaboration. Representatives of health and social services, government, business, the arts, environmental concerns, the media and transportation were among those comprising the HCC. The Committee in turn attempted to build on local assets and address shared health problems in ways that were tailored to the local community.

Funded through an initial grant from the WK Kellogg Foundation, the collaboration between HCC and the IU School of Nursing was conducted in the tradition of CBPR (Gaventa, 1993; Minkler and Wallerstein, 2003) and adhered to the principles inherent in this approach. As Israel *et al.* note, such research is participatory and cooperative; emphasizes co-learning, systems development and community capacity building; is empowering; and balances research and action (Israel *et al.*, 1998). Facilitating intersectoral collaboration and health-promoting public policies may be an important component of the action dimension of CBPR efforts.

CONCEPTUAL FRAMEWORK

Although community processes are always unique, Gray has argued that three non-linear phases—deciding on the problem, deciding on the strategy and taking action—comprise the threads tying diverse community-based change efforts together (Gray, 1989). Frequently missing from such an analysis, however, is attention to the temporal dimension, and particularly the sustainability of community change over the long haul. In the latter regard, the sustainability benchmarks developed by the Center for Collaborative Planning (CCP, 2000) provide a useful frame of reference. These benchmarks suggest that the successful collaboration:

- Has mobilized residents who are committed to sustaining efforts to improve the community,
- Is sustaining its efforts at community improvement through policy and systems change at the local, regional and state level,
- Is spinning off or institutionalizing its effective strategies, activities or programs,
- Is successfully raising funds and/or incorporating to sustain core functioning and

- Is implementing its key strategies but also functioning as a learning community, using evaluation findings to make needed revisions.

STUDY CONTEXT AND METHODS

In 2003–2005, a Kellogg Foundation funded study was undertaken to document the impacts of CBPR on healthy public policy in the US. Building in part on Viswanathan *et al.*'s extensive review of CBPR projects in English speaking North America, two of the present authors examined the more recent literature, and conducted an internet search using 24 relevant list serves to locate collaborations that met CBPR criteria and had a substantial policy focus (Viswanathan *et al.*, 2004). Of the 80 total partnerships identified, 10, including the HCC partnership, appeared to capture the range and diversity experienced and were selected for in-depth study. With an action component that had lasted for a decade, the HCC partnership was chosen in particular because of the opportunity it afforded to study sustainable change through CBPR.

A site visit to New Castle in May 2004 included key informant interviews with four academic and community partners, a focus group with community members, participant observation, phone interviews with two policy-makers, and archival review. Audiotapes of the interviews and focus group were transcribed and coded by two research team members to identify key domains (e.g. partnership development and sustainability indicators). The qualitative software package, ATLAS.ti was used to group all key domains by site and generate reports for key domains. Members of the team then independently identified key themes and codes by site using these reports, and compared and reconciled findings. Case reports based on the findings were shared with partners at each site for member checking as an added means of ensuring the accuracy of data interpretation.

PARTNERSHIP AND PROJECT FORMATION AND EVOLUTION

The original CBPR partnership was between four faculty members at IU School of Nursing and the HCC, which provided local direction to the project. Their goal was to craft a study and follow-up action agenda that would help 'make

the healthy choice the easy choice,' in part by getting City decision-makers and the general public to think about the potential health impacts of any policies or programs being considered. Beyond that very general policy-related goal, however, the lead academic partner reported that 'we had no preconceived direction. We wanted the community to speak and to own the data' that would be collected, using it to set their own agenda for change.

RESEARCH METHODS AND PARTNER ROLES

The original study included the collection and use of secondary data from the Census and a door-to-door survey distributed to 1000 households using a non-probability quota sampling strategy. HCC members helped to create the questionnaire, collect the data and interpret findings. The academic partner provided training in the basics of research methods, after which the City was broken into voting precincts and questionnaires administered to randomly selected households throughout the precincts. Commenting on the role of the academic partner, a community partner remarked:

Whenever we had our meetings a representative from IU would come and watch us and be a resource for us...Whenever we floundered [we had] that outside person come in and get us re-energized, restarted. We would find that what we were doing was the right thing to do but we didn't always have enough confidence in ourselves in what we were doing to keep moving forward.

Academic partners also stressed the importance of the HCC's role in the research process, and attributed the almost 50% response rate achieved ($n = 496$) in part to its work in gaining advance publicity for the study from local media.

STUDY FINDINGS AND THEIR INTERPRETATION AND USE

The survey findings revealed a troubling portrait of individual health indicators and health behaviors in New Castle, including high rates of smoking (32.2%; $n = 158$) and problematic dietary choices, e.g. added salt at meals (75.2%; $n = 372$). While study participants scored well in a few areas, e.g. the proportion of the hypertensive population having its condition controlled (79%; $n = 392$) and the percent of respondents

reporting regular and vigorous exercise (36.6%; $n = 184$), considerable room for improvement was apparent. Almost 27% of study participants ($n = 144$), for example, reported getting no regular exercise. Close to 40% ($n = 184$) failed to seek medical care when needed because of the cost, with 24% ($n = 119$) reporting being deterred by the long wait at doctors' offices. Nearly half of respondents ($n = 238$) were dependent on publicly funded health insurance. Finally, 17% of study participants ($n = 84$) reported being 'downhearted or blue' much of the time, with fully a quarter ($n = 124$) reporting that they were 'anxious or worried' much of the time.

To give the study findings meaning and context, they were presented to community members against the backdrop of corresponding goals set forth in 'Healthy People 2000: National Health Promotion and Disease Prevention Objectives' (USPHS, 1992). Community members thus could see that their City's smoking rate was twice that of the HP 2000 objective (32.2 versus <15%) and the proportion of those who exercised less than once a week was well above the HP 2000 objective (27 versus <15%). They saw that while higher income residents scored higher on most of the indicators examined, no income group reached the Healthy People 2000 goals for diet, exercise, tobacco or alcohol consumption (Rains, 1994).

National data also were used to enable residents to compare New Castle's rates of cancer, heart disease and other conditions with corresponding national rates. For example, New Castle's overall mortality rates over several years ranged from 11.5 to 14.4/1000 compared to national and state rates of about or of $\sim 8.75/1000$. Disease-specific mortality rates for cancer ranged from 222 to 292/100 000 population while the national and state rates ranged from 180 to 200/100 000. Based on their discussion of these data, and their insider knowledge of other health issues of particular importance to the community, the HCC then developed a list of five health problems (smoking, exercise, alcohol use and abuse, mental health, and dietary choices) which it believed merited special attention (Rains and Ray, 1995). A community meeting then was held to encourage broader participation. As an academic partner noted:

We wanted the community to speak and to own the data. The community discussed the implications of the data. For example, the fact that the proportion

of smokers in New Castle was double the Healthy People 2000 goal jumped out. Deaths by cardiac disease also jumped out—it was well above the national and state rates. The community had never looked at what they looked like compared to state and national data.

The primary data collected in the HCC surveys grounded the actions in science, empowered the community to examine itself against state and national norms, and allowed citizens without preparation as health professionals to have an informed idea of the health of their community. Some of these data are lost to retrieval in the more than 10 years since the completion of the initial survey, but the role played by data was substantial.

Focus groups, and a statewide workshop including sessions on data interpretation, priority setting and policy change, also were included as part of the CBPR process, and helped the HCC and the broader community move into the action phase of the project. Of particular importance was the involvement of members of the City Council, the newspaper editor, the fire chief and other key stakeholders.

POLICY GOALS, STEPS AND ACTIVITIES

The partnership between the IU and HCC was unusual among partnerships focused on healthy public policy in that it had no *specific* policy goal but rather a broader health promotion goal. As the lead academic partner commented:

We didn't use the words 'impacting on policy' or even [participatory research]. We used, 'make the healthy choice the easy choice.' Frame it through an environment that provides an array of healthy choices. We wanted to get health on the agenda of City Council meetings, school board meetings etc. so in meetings they always ask, 'What's the health impact?'

Under this broad goal, a number of different policy and related efforts were undertaken both in the immediate aftermath of the original survey and in the decade that followed. Key among these were a successful effort to help get a measure passed creating non-smoking areas in all City buildings, several intermediate goals (e.g. building an elaborate playground on City owned land) and longer term efforts (e.g. an ambitious trails project and a comprehensive land use

policy that would promote physical fitness and environmental protection).

A variety of policy steps and activities were employed to help achieve policy-related objectives. In their early efforts to get a smoking measure passed, for example, the partners worked to create community awareness; studied what other communities had done; and mobilized a strong turnout at the City Council meeting where they presented the survey data, and summarized the problem and the proposed bill. As an academic partner commented: 'We put things in the context of what would work in our idiosyncratic community. Put it right back up against the health data. "Will this affect our mortality rate from cancer?" We always try to keep it grounded.'

On this and other issues, the partners were ever mindful of the local context in which they were working to promote change. As one partner remarked, 'In Indiana you can't tell people what to do. That's why we have no motorcycle helmet law.' The partnership therefore worked for incremental change and built support by connecting diverse allies and stakeholders. Their efforts appear to have paid off: The partnership was widely credited for a strong favorable vote on the smoking measure by the City Council.

Although this measure was described in retrospect as a fairly easy win, other policy goals were harder to achieve. A long-term goal of the HCHC, for example, has involved getting approval for and implementation of a 'spider web of trails' that would encourage physical activity by tying together many diverse destinations in this sprawling community. In the words of New Castle's mayor, 'They bring about awareness and bring it out in front of the population and hold it there. They don't go away. The people have to, at some point, recognize that "this is an issue and it affects my health."'

In addition to identifying and increasing awareness of the problem (e.g. high rates of heart disease and obesity, and sprawl discouraging walking) the HCHC refined its policy objective and 'did its homework,' identifying and studying an Ohio town's successful efforts to implement a system of trails similar to the one they were proposing. Members of HCHC also considered the potential costs and benefits of the initiative. They talked with the mayor and City Council about the economic and health benefits of the trails, noting, for example, that

they could help support local businesses by encouraging residents to shop locally. The HCHC further made clear its willingness to help raise needed funds and involve community members in much of the physical work of trail construction. And they helped create support among and strengthen intersectoral alliances with key stakeholders (e.g. the Department of Transportation).

Although members of HCHC spoke of actions they had taken in terms of formal meetings with government officials, testifying and writing press releases, they also noted that much of the work 'happens informally' in a town the size of New Castle, e.g. in conversations with neighbors and acquaintances who also hold relevant professional or elected positions.

OUTCOMES

The passage and implementation of an indoor smoking measure was the first concrete outcome to which many study participants pointed. More recently, getting permission to build, raising funds for and then creating a large new playground on public land was described by an HCHC member as 'our keynote effort,' contributing to both physical activity and social connection. More than 1200 community volunteers took part in the playground's construction in a single week, and the process itself was considered an important outcome. As an HCHC member commented: 'you had businessmen out there and you also had guys who were factory workers,' a 90-year-old, a very pregnant woman and 'county commissioners working alongside prisoners in their stripes.' Indeed, an oft-cited story was of a prisoner who worked on the park for several days, completed his prison term and then came in on his first day of freedom to help complete the work. As an HCHC leader reflected: 'At the end of building the playground we had more than a playground. We had built a community.'

The web of trails initiative, while still in progress, was cited by many as a significant outcome of HCHC's work. Community residents' planting of over 5000 trees along the trails and elsewhere, and recent efforts to acquire a 100-year-old iron bridge which would be used as a pedestrian cross-over for a six lane highway (Steussey, 2004), are among the aspects of the initiative in which HCHC takes particular pride.

Development and implementation of a comprehensive land use policy was named by an HCHC leader as probably the biggest policy issue and one for which outcomes remain to be realized. In her words, 'I think in so many ways, the biggest health deficit, the biggest detriment to "making the healthy choice the easy choice" in Indiana is our sprawling development.' Although this work is still in progress, an HCHC member sitting on the land use committee noted a change in the mind set of planners, with increased recognition of the need for natural space and not simply categorization of land as agriculture, residential, business or industry.

Finally, even some initial defeats have had positive outcomes embedded within them from a process perspective. The City Council thus opposed the Committee's proposed placement of a new skate park designed to help encourage exercise and discourage drug use among teenagers. Reflecting on the meeting where victory proved elusive, an HCHC leader commented:

The City Council chambers were packed. Sixty percent of the people there were teenage boys. Getting teenage boys to a City Council meeting; to care what mayor got elected this year; to care about what was happening at City Council. . . that is just engaging citizens. I think it is so much a part of healthy communities.

PARTNERSHIP AND PROJECT SUSTAINABILITY IN CONTEXT: BARRIERS AND SUCCESS FACTORS

When evaluated against the CCP's sustainability benchmarks, the partnership both achieved some substantial successes and showed room for improvement (CCP, 2002). Consistent with the first benchmark, for example, the collaborative has indeed 'mobilized community residents who are committed to sustaining efforts to improve the community.' The lead academic partner played a key role in mobilizing the community early on in the context of a major, city-wide participatory research study. As she noted, the troubling nature of early health findings was used as an opportunity to promote change. 'When the data were alarmingly bad we used it as a window. Because no community wants to be the worst.'

By putting research skills in the hands of local community members who could then later conduct their own surveys, and by returning the study's findings to the community, the research

component of the project successfully built upon a sustainability strategy that 'understands that the gifts, talents, skills, and capacities of individuals are essential building blocks for healthy communities' (CCP, 2000). In the decade after the original CBPR collaboration, the community partner broadened and deepened its reach in terms of community mobilization. The HCHC thus counts among its core members individuals representing business and labor, elected officials, and many key community stakeholders. Yet two groups with among the poorest health habits—factory worker and farmers—are greatly underrepresented, as is the County's small but growing Hispanic population.

The sustained efforts of the partnership, and later the HCHC, to 'improve the community through policy and systems change' at the local and regional levels (CCP, 2002) were clearly in evidence in this case study. The expansion of New Castle's original Healthy Communities Committee to a county-wide entity (HCHC), moreover, spoke to its realization that effective and sustainable change increasingly requires a broad regional focus. In contrast to the early and 'easy win' on the indoor smoking measure, however, progress in achieving systems change goals often has been slow. The conservative and antiregulatory mind set of much of the population frequently was described as leading to an almost knee-jerk opposition to any new efforts to impose measures seen as extending government control. Relatedly, and particularly with reference to proposals like the comprehensive land use plan, the strong emphasis on private property and a corresponding lack of valuing of shared public space were described by a community member as having resulted in frequent apathy and occasional outright opposition. Finally, the economically depressed status of the community has hampered some efforts which require even relatively modest amounts of new capital.

Two important sustainability indicators include the extent to which a collaboration is 'spinning off or institutionalizing its effective strategies, activities or programs' and incorporation and fundraising to promote sustainability (CCP, 2002). Interviews with key informants and a review of HCHC annual reports and other documents (Steussey, 2004) provided evidence of such institutionalization, e.g. in HCHC's regular monthly meetings, incorporation as a non-profit organization and publication of a quarterly

newsletter. However, the HCHC's small core operating budget (\$30 000 annually), lack of a full-time director and the time constraints of volunteers have prevented regular, detailed monitoring of progress and outcomes needed for systematic assessment of sustainable change. For example, there was no written evidence of an HCHC leader's technical assistance to a nearby town interested in replicating the park building effort, or of the HCHC's fundraising to send interested members to a 15 week leadership training course. Such potential indicators of capacity building risk being lost without written documentation, ideally including publications that can stimulate critical analysis and disseminate information about project processes and outcomes.

ANALYZING THE PARTNERSHIP'S CONTRIBUTIONS TO SUSTAINABLE CHANGE

Fawcett *et al.* suggest changing our evaluative mind set from *the attribution of contribution* to one of *analyzing the contribution* that a particular collaborative or change effort may have made toward reaching a desired goal (Fawcett *et al.*, 2004). As noted above, a major outcome of the IU/HCC partnership and its aftermath was the widespread acceptance of the concept of healthy communities and 'the community's increased concern about health.' As an academic partner noted, following the original community health survey and public discussion of its findings, 'the community had different ownership of health. They no longer saw it as the domain of doctors and nurses. They had the feeling they could do more about health.' At the same time, however, the initial partnership took place at a time of growing national attention to diet, exercise and smoking, and 'heightened national awareness' of such issues was seen by some as in part responsible for the fact that 'little by little it has gotten better in this community.'

Analyzing the partnership's contribution to specific changes, e.g. the passage of the indoor smoking measure, was easier than attempting to assess contribution to broad changes in community norms and behaviors. In the case of the smoking measure, for example, policy-makers and a variety of community stakeholders independently identified what they saw as the

partnership's leading role in this effort. Similarly, HCHC was widely credited by community members, policy-makers and the local newspaper editor with developing both the plan and the strategy for the 'web of trails' initiative. The HCHC thus got a purchase agreement to buy an abandoned rail corridor, developed awareness of a business incentive that could help sell the plan and did major fundraising for the initiative. The mayor, for example, credited HCHC with having won several large government grants and contracts including a \$950 000 grant from the Department of Transportation, and \$450 000 from the Department of Natural Resources to buy land for a new trail. Another \$250 000 in new food and beverage tax money recently was received, with additional monies raised through HCHC fundraisers (Steussey, 2004). This level of commitment on the part of HCHC, and its success in reaching out to government and other partners to access the resources needed to help realize its 'web of trails' vision, are further indicators of its contributions to promoting sustainable change.

Community members, policy-makers and other stakeholders also discussed the seminal role of the HCHC in envisioning, getting needed government support for, funding and bringing to fruition a new playground. An early HCHC member discussed the genesis of the park noting that: 'It grew out of our early data showing the community was proud of the parks and wanted them clean and safe.' HCHC also took the lead in disarming the opposition to park construction (e.g. neighbors worried about increased traffic congestion), built strong intersectoral collaborations to support the work, and oversaw a massive community turnout for both initial park construction and follow-up maintenance.

CONCLUSION

Studies of the impacts of community-based health initiatives, including CBPR projects, often have been disappointing in their ability to demonstrate with confidence likely impacts of these collaborative efforts on the individual, institutional, community or policy levels (Kreuter *et al.*, 2000). Yet as this article suggests, when the outcomes of a CBPR collaboration are followed over the long haul, changes along a variety of dimensions may be observed. This longer time frame further

may enable a more careful teasing apart of the extent to which outcomes may be related to the project itself and/or be at least in part a function of other contextual changes (e.g. increased national attention to health).

Although a number of factors in the broader environment did appear to impact on the changes that took place in Henry County over the past decade in the name of 'making the healthy choice the easy choice,' the prominent role of the IU/HCC partnership in setting the stage for much of this change, and of HCHC in continuing implementation efforts over the next decade, was apparent. Without minimizing the obstacles faced, the partnership and its aftermath illustrate the role that CBPR can play in catalyzing sustainable change when a strong and dynamic community partner is willing to continue to work for change long after the formal partnership has ended.

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