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Promoting Healthy Public Policy through Community-Based Participatory Research:

Ten Case Studies

Design by: Leslie Yang

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Promoting Healthy Public Policy through Community-Based Participatory Research: Ten Case Studies

UC Berkeley School of Public Health Team

Meredith Minkler
Victoria Breckwich Vásquez
Charlotte Chang
Jenesse Miller

PolicyLink Team

Victor Rubin
Angela Glover Blackwell
Mildred Thompson
Rebecca Flournoy
Judith Bell

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Preface

This report is the product of a collaboration between the School of Public Health at the University of California, Berkeley, and PolicyLink, a national research and action institute advancing economic and social equity by Lifting Up What Works.®

With its commitment to evidence-based research, diversity, community partnerships, and moving from "publication to public action," the School shares with PolicyLink a deep interest in ensuring that the findings of scholarly research are translated and used in ways that can promote the public's health and well-being. Increasingly, however, we in academia are realizing that for some of the most complex and challenging public health problems we face, simply translating findings after the fact is not enough. Rather, research is needed that is *community based* rather than simply *community placed* and in which community members and other stakeholders are actively involved with formally trained researchers in studying and addressing health and social problems and promoting equity.

In the pages that follow, we share 10 case studies of diverse community-based participatory research (CBPR) partnerships around the United States that have in common a commitment to foster healthy public policy. The 10 partnerships examined—in areas as diverse as South Los Angeles, California; New Castle, Indiana; Harlem, New York; and Tillery, North Carolina—were selected from among more than 75 CBPR projects originally considered by our staff and advisory committee members. The projects deal with topics that range from environmental justice and food insecurity to disability rights and the desire for "small p" policies that "make the healthy choice the easy choice."

Together, these case studies offer a window into the world of community, health department, and academic partnerships throughout the nation that are working to change policy to improve community health, reduce disparities, and foster equity. This report draws on data from dozens of in-depth interviews with partnership members, community focus groups, and policymakers, as well as document review and participant observation. We hope these stories and the lessons they provide will contribute to the evidence base and further understanding of CBPR's promise as a tool for promoting healthy public policy.

Meredith Minkler **Angela Glover Blackwell**

Case Study Projects and Partnerships

Addressing diesel bus pollution and its health consequences in Northern Manhattan, New York: *West Harlem Environmental Action, Inc., and the Columbia Center for Children's Environmental Health*

Tackling environmental injustice in industrialized hog production in rural North Carolina: *Concerned Citizens of Tillery and its partnership with the School of Public Health, University of North Carolina, Chapel Hill*

Moving out of the nursing home and into the community: *Promoting systems change through a partnership among the Progress Center for Independent Living, Access Living, and the Departments of Disability Studies and Rehabilitation at the University of Illinois, Chicago*

Using "data judo," community organizing, and policy advocacy on the regional level through the Southern California Environmental Justice Collaborative: *A partnership among Communities for a Better Environment; the University of California-Santa Cruz; Occidental College; Brown University; and the Liberty Hill Foundation*

Addressing food insecurity in San Francisco's Bayview Hunters Point: *Literacy for Environmental Justice and its partnership with the San Francisco Department of Public Health*

Preventing lead exposure among children in Tar Creek, Oklahoma through Tribal Efforts against Lead (TEAL): *A partnership among eight tribes, the University of Oklahoma, Emory University, and the University of New Mexico*

Improving school conditions by changing public policy in South Los Angeles: *The Community Coalition, Imoyase Research Group, and the Department of Psychology at Loyola Marymount University*

Making the healthy choice the easy choice: *A partnership between Healthy Communities of Henry County and the School of Nursing, Indiana University*

Empowering New Mexico's young people in public policymaking: *Youth Link and the University of New Mexico Masters in Public Health Program*

Reintegrating drug users leaving jail and prison: *The Center for Urban Epidemiological Studies/Harlem Community and Academic Partnership and the Community Reintegration Network*

Executive Summary

Community-based participatory research, or CBPR, is increasingly recognized as a potent approach to conducting research with—rather than on—communities. CBPR builds capacity at the same time that it collaboratively studies locally relevant issues and concerns. As defined by the Kellogg Foundation's Community Health Scholars Program, CBPR is "a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research 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."

A hallmark of CBPR—one that sets it apart from more traditional research paradigms—is its commitment to action as part of the research process, not leaving follow-up to others after studies have been completed. Yet to date, little research has been conducted on the policy efforts and impacts of CBPR in the United States. This monograph is the result of the first known systematic effort to explore the effects and outcomes of CBPR on health-promoting public policy. The study was funded by the W. K. Kellogg Foundation and took place from 2003 to 2005, with subsequent follow-up as needed.

Faculty and graduate students at the UC Berkeley School of Public Health and their partners at PolicyLink, assisted by a national advisory committee (see Appendix A), critically reviewed the published CBPR case studies in the United States that appeared to have had an impact on health-promoting public policy or that showed promise for doing so in the near future. Just 27 of the nearly 80 cases reviewed met criteria for CBPR (e.g., being participatory and empowering; fostering co-learning, capacity-building, and systems change; and balancing research and action) while also having a strong and demonstrated policy focus. The 10 case studies described and analyzed in these pages both provide impressive evidence of the potential of CBPR to help promote change on the policy or systems level, and capture the range and diversity of the cases examined. A multimethod case study approach was used to examine each of these partnership projects in depth and to conduct a cross-site analysis that would identify key themes, challenges, success factors, and lessons learned across the sites.

Diversity in Partnership Structure and Research Methods

The 10 CBPR partnerships we explored involved strong community-based organizations that typically were collaborating with university partners. However, in a few instances (e.g., the Literacy for Environmental Justice partnership in San Francisco), the outside research partners were based in non-academic settings, such as health departments or in a nonprofit research and evaluation group. The research methods used varied considerably, ranging from spatial analysis to secondary data analysis utilizing large government data sets to the collection of primary data through surveys, interviews, or focus groups. The creative use of newer technologies and approaches, such as Photovoice and store-shelf diagramming, also was demonstrated. Most of the research projects used multiple methods of data collection to capture the range of data needed to understand multiple aspects of a complex problem at hand and potential policy solutions.

Getting to Action

The partnerships displayed substantial differences in their approaches to the policy process and indeed, sometimes preferred not to use the term "policy" in reference to their work. Yet we also observed important similarities. As noted below, for example, most partnerships appeared adept at identifying or refining a problem of shared concern, determining how their research findings could be used to address the problem on a broader level, identifying potential targets and policy change approaches, and working with allies (including policymakers) to move forward. We also observed frequent and effective use of media advocacy; participation in public hearings and meetings with key decision makers; and a commitment to continued engagement, sometimes well beyond a funded project period.

"Public office, in my opinion, doesn't work, won't work, unless there are really strong grassroots organizations to pressure elected officials. That holds for me too because my plate is so full. I'm only one person. The community [has to] help keep me focused." —Policymaker

Policy- and Systems-Level Impact and the Difficulty of Analyzing Contributions

Each of the 10 case studies appears to have contributed to policy- or systems-level change, and not infrequently, several policy-related changes appear to have resulted at least in part from the work of the CBPR partnerships. These achievements ranged from achieving a 75 percent reduction in allowable cancer risk from toxic emissions in South Los Angeles to reinstating Medicaid for prisoners in New York immediately after their release—and helping to ensure their release during daylight rather than at 3:00 a.m. Some victories were subtler, such as effecting "small p" policy changes designed to promote a healthy community in New Castle, Indiana, and the surrounding Henry County. Healthy Communities of Henry County leveraged its CBPR study results with years of follow-up work to secure substantial funding and widespread support for creating a web of walking and biking trails that would connect key points of interest in this sprawling rural community and promote physical fitness and environmental improvements.

Changes in the policy environment, including a change in the economy; the opening of a window of opportunity in the wake of a natural disaster or media exposé; or the election or appointment of a new policymaker or other key decision maker who shares the partnership's goals may greatly affect the likelihood of a policy victory. Additionally, the very nature of CBPR work, with its emphasis on building alliances and frequently working in coalition with numerous actors and stakeholders, makes singling out the role of the community, academic, or health department partnerships in helping to achieve a policy victory all but impossible. Although we have attempted in this monograph to highlight the ways in which CBPR partnerships appeared to contribute to one or more policy or systems changes, we do so cautiously, underscoring in each case that we are *analyzing connections and contributions,* and not *attributing contributions* to the partnership's efforts alone.

Our task in this regard was sometimes made more difficult by challenges faced in studying the partnership's potential contributions to policy change efforts. Among these challenges was the reluctance of some of those involved in partnerships to talk about their potential policy-level work, since federal or other funding was seen as precluding this type of work due to funding restrictions on lobbying. The media's tendency to single out one contributor (often a politician), together with the potential for over- (or under-) stating the partnership's role or give credit to a policymaker ally, further compounded the difficulty of analyzing contribution. Despite these difficulties, our multi-method investigation allowed us to conclude with some confidence that efforts highlighted by the 10 CBPR case studies did indeed play a substantial role in helping to promote healthy public policy or other systems-level change.

Success Factors across Sites

Many factors contributing to the success of these case studies were context-specific and unique to a particular project and partnership. At the same time, several factors emerged in our cross-site analysis as facilitators of effective functioning and outcomes. These include:

- The presence of a strong, autonomous community partner organization prior to the development of the partnership
- A high level of mutual respect and trust among the partners and an appreciation of the complementary skills and resources that each partner brought
- Appreciation by all partners of the need for solid scientific data as a prerequisite for making the case for policy action
- Commitment to "doing your homework"—finding out what other communities have done, who holds decision-making authority, key leverage points, etc.
- Facility for and commitment to building strong collaborations and alliances with diverse stakeholders beyond the formal partnership

"There is an unholy matrimony between science and activism." —Academic Partner

- Knowledge of and facility for attending to a variety of "steps" in the policy process, *whether or not the language of policy was spoken*

The last point, in particular, is worthy of note. Although many partnerships acknowledged that they needed to learn much more about the policymaking process, each also appeared to have an innate or a learned sense of many necessary policy steps, from reframing issues and policy goals to identifying policy targets, finding and using windows of opportunity, and effectively using the media to carry their message and pressure for change.

Challenges Faced across Sites

Each partnership faced challenges grounded in the historical, political, economic, and interpersonal realities surrounding their research, organizing, and policy work. These challenges ranged from the strong opposition of powerful corporate interests (e.g., the hog industry in North Carolina and the nursing home lobby in Chicago) to problems posed by high staff turnover and severe funding cutbacks in mid-project (Harlem Community and Academic Partnership and Youth Link). The partnerships also encountered several common challenges:

- Differences in the research timetable of the community and academic partners, with the former often eager for quicker data analysis and release of findings in the interests of using them to promote change
- Different perspectives on policy work held by academic/health department and community partners, with the latter often more clear from the outset about the policy goals and objectives they wished to achieve
- Funding constraints and/or termination of funding or changes in sources of project support, which in turn delayed or changed the emphasis of research and action
- Perceptions among partnership members that they lacked sufficient understanding of policymaking processes and avenues for systems change
- Difficulty talking in terms of policy goals and activities because of real or perceived prohibitions and constraints due to tax-exempt status or funder concerns
- Difficulty measuring the longer-term impacts of project or policy change: who follows up when the money runs out?

Recommendations

Each of the partnerships included in this study was selected in part because of its perceived role in contributing to health-promoting public policy and health equity. Based on their experiences and shared concerns, the following recommendations are offered to other CBPR partnerships interested in adding a policy component to their work or increasing their effectiveness in policy-focused research and advocacy:

- **Build leadership and base of support for research and action by being genuinely community driven:** Start where the people are by having the community partner and its base determine the "hot-button issue" to be studied—an issue the community partner is committed to help research and mobilize around.
- **Use a mix of research methods:** People's stories (captured in qualitative data) as well as the facts and statistics that emerge from quantitative approaches are needed to move policymakers and reach the media. Different forms of data also may be needed to reach different audiences.
- **Produce high-quality research that can stand up to careful scrutiny, but make results easily accessible and highlight their policy relevance:** Policy briefs, short reports and "talking points," and liberal use of pie charts and other graphics to help translate the findings will help policymakers and the media, as will "quotable quotes" from your interviews and other data sources.
- **Use approaches and processes that reflect the local community culture**

CBPR is "… a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research 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." —Community Health Scholars Program, 2001

and ways of doing things (even if it slows down the process).

- **Remember that research includes not only the partnership's original investigation but also subsequent study of the policy considerations involved:** Community partners should be helped to research whether the policy level is the best route for achieving the change they seek; who has the power to make the change(s) being sought; what sorts of policy-relevant data need to be collected, from whom and how (this is all part of "data collection").
- **Make sure all partners, including academics, understand that advocacy is different from "lobbying":** Gain an understanding of the different types of advocacy activities allowed of nonprofit organizations, including universities and community organizations; the activities are often more plentiful than partners believe.
- **Decide on a policy goal and identify the relevant policy targets and change strategies, but always have at least one "Plan B" and be open to compromise.**
- **Build strong linkages with organizational allies and other stakeholders, but be strategic in your choice of partners:** In policy work, as in community organizing, there are "no permanent enemies, no permanent allies."
- **Through trainings, Web-based tools (see Appendix D), and other resources, increase partners' understanding of policymaking and, as appropriate, of legal processes and issues.** If possible, link early on with a "policy mentor" willing and able to help partners, including academic partners, to understand and better navigate the policy process.
- **Offer solutions to policymakers and decision makers, not just complaints:** Have relevant research readily available to show them why your solution is on target, practical, and affordable; include in your research some information on the "wallet angle" to show the cost effectiveness of your proposed solution; and provide them with the community support they need to advocate for change—e.g., helping to ensure strong community turnout at city council meetings, hearings, and other venues.
- **Plan for sustainability by seeking new funding streams, including those (e.g., some foundations) that actively support and encourage community-partnered research and action at the policy level, directed at promoting health equity.**
- **Take advantage of the university or health department partner's media office:** It can help draft and widely disseminate press releases. Make sure that community partners participate in decisions about content and timely use of such media, and that any media advocacy is a well-thought-out part of a bigger plan and campaign.
- **Recognize that policy change takes a long time, and commit to staying involved over the long haul:** Achieving policy change (and ensuring that a new measure or policy is in fact implemented) is likely to mean developing and implementing several strategies and working well beyond any funded grant period.

Finally, and beyond these recommendations to CBPR partnerships themselves, increasing the ability of such partnerships to help promote policy-level changes will require increased institutional support from foundations and the federal government. This funding must target CBPR partnerships focused on promoting healthy public policy and systems change to improve the public's health by promoting health equity.

Table 1. Sample Policy and Related Outcomes in which the Partnerships Appear to Have Played a Substantial Role*

West Harlem Environmental Action (WE ACT)/ Columbia Center for Children's Environmental Health

- Conversion of New York City bus fleet to clean diesel
- Establishment by the Environmental Protection Agency (EPA) of permanent air monitoring in Harlem and other "hot spots" locally and nationally
- Co-authoring and adoption of a statewide environmental justice policy

Concerned Citizens of Tillery/University of North Carolina School of Public Health

- Creation of the North Carolina Environmental Justice Network (NCEJN), which in turn helped re-invigorate a statewide environmental justice movement
- Through the NCEJN and drawing on study findings, passage and signing of a law in 2007 banning new hog facilities in the state and setting higher standards for waste treatment

Progress Center for Independent Living/Access Living/Departments of Disability Studies and Rehabilitation, University of Illinois, Chicago

- Passage of legislation and funding for a Senior Community Reintegration Program
- State reauthorization of a council to reassess the implementation of the Olmstead Act and to prepare a strategic plan for long-term care financing
- "Money follows the person" program provision funded in 2007 through a $55.7 million Phase I grant from the Centers for Medicare and Medicaid to the State of Illinois

The Southern California Environmental Justice Collaborative (South Los Angeles)

- Revision of a regulation (Rule 1402) that tightened emission standards and lowered acceptable cancer risk levels from existing facilities by 75 percent
- Changing of policy language used by the California Environmental Protection Agency (Cal/EPA) from individual to cumulative risk exposure
- Spearheading an organized environmental justice movement in Southern California

Literacy for Environmental Justice (LEJ)/San Francisco Department of Public Health

- Adoption by several city agencies of a voluntary policy creating the Good Neighbor Program to provide incentives for corner stores that increase access to healthy foods and decrease shelf space for alcohol and tobacco products (four stores had become "good neighbors" by 2007, with five more slated to do so in 2008–09)
- Passage and signing of AB 2384 in 2006, modeled on the Good Neighbor Program (albeit without funding appropriation), to establish a statewide Healthy Food Purchase pilot program to improve the supply of healthy choices in small corner stores

Tribal Efforts against Lead (TEAL)/Partnership among eight local tribes with the University of Oklahoma, Emory University, and the University of New Mexico

- Full implementation of blood lead screening and parental notification for young children by the Ottawa County Health Department and the Indian Health Service
- Halting the use of mine tailings in construction and on roads without proper containment

The Community Coalition /Imoyase Research Group/Loyola Marymount University

- Reopening by the Los Angeles Unified School District (LAUSD) of repair and construction contracts granted by a $2.4 billion school bond (Proposition BB), resulting in redirection of $100 million in school bond monies from wealthier schools to those in South Los Angeles
- Allocation of $153 million in new funds for additional schools in South Los Angeles and other inner-city communities.
- Successful lawsuit resulting in $750 million for new school construction

continued on next page

Indiana University School of Nursing/Healthy Communities of Henry County (HCHC)

- Passage and implementation of a bill restricting indoor smoking in public places
- Securing local government funding and support for a large new playground on public land that was then built by community members
- Securing government funding and approvals for an initiative to develop a network of trails throughout the county, promoting physical activity and cleaner air

Youth Link/University of New Mexico/New Mexico Department of Health (DOH)

- Passage by state legislature of a study bill (called a memorial) requesting the investigation of suspension and expulsion policies and their effects on high-school dropout rates
- City support and funding for a skate park in Las Cruces, New Mexico
- Passage of a citywide smoke-free ordinance in Albuquerque and restrictions on tobacco product placement in Santa Fe, and ultimately passage of a statewide ban on smoking in indoor workplaces and public spaces

Harlem Community and Academic Partnership

- Passage of a bill by the New York State Legislature that reinstated Medicaid benefits to inmates upon their release, replacing a policy that terminated benefits upon incarceration
- Passage by the New York City Council of Local Law 54 mandating the Department of Correction to provide expanded discharge planning services to people leaving jail
- Department of Correction decision to begin releasing many more inmates during daylight hours rather than after midnight

*Please note that none of these victories was attributed solely to the partnerships.

Introduction

The complexity of many of today's health and social problems—environmental injustice, obesity, HIV/AIDS, and pronounced racial/ethnic health disparities—often renders them poorly suited to traditional academically driven research and the sometimes disappointing intervention programs it spawns (1). Increasingly, too, there is a realization that to effect change, research in public health and related fields must be policy relevant. The field needs to move as researchers work *with* (rather than *on*) communities to study and address their issues and concerns, and collaboratively use the findings to influence policy and promote health equity. Community-based participatory research (CBPR) is the overarching name for a variety of research approaches that have as their centerpiece the three interrelated elements of community participation, research, and action (including sometimes policy-level action), to translate the findings of collaborative research in ways that improve health and help eliminate health disparities (1, 2).

Drawing on earlier seminal work (3, 4), the W. K. Kellogg Foundation's Community Health Scholars Program defines CBPR as "…a collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research 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."(5)

As suggested, a distinguishing feature of CBPR is its commitment to action as part of the research process—not something others do *after* the fact (1). Partnerships are typically formed with the close collaboration of a community partner (i.e., a community-based organization or group of community leaders/activists), an academic partner (i.e., researchers affiliated with a university), and/or professionals in a health department, a healthcare practice, or other such setting. Together, these partners decide on a research topic of interest to the community, collaboratively engage in the research, and ultimately use the research findings to inform program or policy-related change to improve community health and promote equity. By focusing on policy change as a potential action component, CBPR can have the potential for improving the health of large numbers of

Principles of CBPR

1. CPBR recognizes community as a unit of identity.
2. CBPR builds on strengths and resources within the community.
3. CBPR facilitates collaborative, equitable partnership in all phases of the research.
4. CBPR promotes co-learning and capacity building among all partners.
5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.
6. CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.
7. CBPR involves systems development through a cyclical and an iterative process.
8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.
9. CBPR involves a long-term process and commitment.

(Source: Israel et al. 1998)

Criteria for Inclusion in the Study

- Demonstrated excellence in CBPR process, living up to the core principles of CBPR practice
- Appeared to have impacted on health-promoting public policy or showed promise for contributing to policy change in the near future
- Brought diversity in terms of the range and scope of geography; racial/ethnic composition; topic areas of concern; and research methods employed
- Demonstrated a clear commitment to improving the public's health and promoting health equity

people, possibly having a major impact at the level of the city, region, state, or beyond.

CBPR partnerships have the potential for policy change through their structure and multiple functions. The policy tools of participatory decision making, education, and information dissemination fit well with CBPR principles. Other ways in which CBPR's structure and functions improve the potential for policymaking and change efforts have been outlined in a nationally distributed toolkit (6) generated by Community-Campus Partnerships for Health, an organization promoting effective "town-and-gown" collaborations throughout the United States. CBPR partnerships are typically composed of diverse partners and commonly reflect and manage multiple perspectives. Related features of CBPR partnerships are that they depend upon alliance building, involve members in participatory activities that enhance democratic decision making, and represent both research and community constituencies—all of which enhance the success of policymaking endeavors.

Little attention has focused to date on how CBPR partnerships may inform public policy at the local, regional, state, or national level. With a few notable exceptions (6, 7, 8), there is little guidance for those interested in leveraging CBPR at the policy level. This missed opportunity is due in part to the lack of a clear evidence base that demonstrates the policy impacts of CBPR. Although many CBPR studies now are reported in the literature, few appear directed at effecting broader level change. Those studies of CBPR partnerships that have had a focus on policy, moreover, tend neither to discuss their efforts in this regard nor to use a systematic approach in helping the reader understand what was accomplished and how.

This research project was designed to address this gap in the research on CBPR and its impact on public policy. We undertook a multisite case study analysis of partnerships that met the criteria for engaging in CBPR and also showed promise for influencing the development of healthy public policy through their collaborative efforts. Our goal was to demonstrate the utility of CBPR and share the successes and the challenges involved to help inform other CBPR partnerships' public health and community development policy processes to promote health equity.

Nearly 80 potential partnerships were considered for this analysis, and the final sample included a diverse group of 10 partnerships from around the country that demonstrated outstanding process and effectiveness in using CBPR to promote healthy public policy. Criteria for inclusion in the final sample were that the partnership appeared to live up to the principles of CBPR, have impacted on health-promoting public policy, or showed promise for

FROM WE ACT, NEW YORK
"Sometimes as scientists we make assumptions … community people, because they are looking at it from a fresh perspective, will question the assumptions in a way that actually improves the science. It may tailor things to the situation in a way we would not have thought of." —Academic Partner

FROM COMMUNITY COALITION, LOS ANGELES
"For us to go down there and protest and talk to people . . . the Community Coalition showed me I can make a difference around my neighborhood." — Community Youth

FROM CHICAGO
"The town hall forums have educated, motivated, and involved hundreds of people with disabilities and provided them with the necessary tools to advocate for full inclusion and opportunity for all." —Policymaker

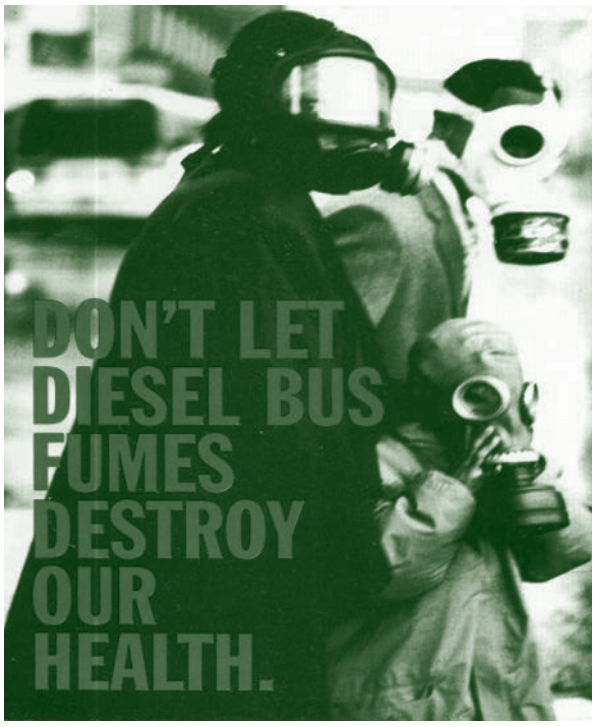
contributing to policy change in the near future. An attempt also was made to select partnerships that would capture the range and scope of CBPR efforts aimed at improving the public's health and promoting health equity through policy level action. As described in Appendix B, one or more research staff visited each partnership site. Visits included: interviews with community partner(s), academic partner(s), health department partner(s) (if applicable); focus groups with community partners and youth (if the partnership represented a youth-involved site); observation of partnership meetings and related events; and review of site-specific written materials related to partnership structure, history, and policy endeavors. Two or three research team members independently reviewed interview and focus group transcripts, and analysis based on findings was conducted using the qualitative software program ATLAS.ti (9). Finally, cross-site thematic analysis was conducted to explore common findings, success factors, and barriers. In the pages that follow, we profile each CBPR partnership, briefly describing its structure and evolution, research aims, methods and findings, and policy advocacy efforts and outcomes. We highlight the challenges faced by the partnerships and the factors that appear to contribute to their success. Major themes across all partnerships are presented, along with recommendations for other groups interested in using CBPR to identify, study, and address shared problems by promoting healthy public policy.

Ten Case Studies of Community-Based Participatory Research and Their Policy Efforts and Outcomes

Case Study #1:

Addressing diesel bus pollution and its health consequences in Northern Manhattan, New York:

West Harlem Environmental Action, Inc., and the Columbia Center for Children's Environmental Health



Asthma morbidity and mortality rates in the Northern Manhattan neighborhoods of Harlem and Washington Heights are among the highest in the nation, with one in four children in Central Harlem suffering from this disease (1). With its rich cultural history, Northern Manhattan is home to about 1.5 million mostly low-income African American and Latino residents. This densely populated 7.4-square-mile area also housed six of the city's eight diesel bus depots and 650 Port Authority buses when this project began. Residents had long believed that the diesel bus problem played a significant role in their high asthma rates (2–4). Their fears were well-founded. Diesel engines emit 30 to 100 times more particles than gasoline engines that have emission control devices (5); research has shown a significant association between high levels of diesel exhaust and elevated rates of respiratory ailments and asthma (5, 6). These studies also show that the largest contributor to area pollution is excessive bus idling in lots and in the streets around bus depots.

The Partnership: In 1996, West Harlem Environmental Action (WE ACT), a nonprofit organization that uses community-based action to advance environmental health policy, public health, and quality of life, formed a partnership with the Columbia Center for Children's Environmental Health (CCCEH) at the Mailman School of Public Health, Columbia University, to explore the possibility of excess pollution exposure in Northern Manhattan (2, 3) and to craft appropriate policy responses to their findings. The partnership was funded by an initial environmental justice grant from the National Institute of Environmental Health Sciences (NIEHS) and has continued to receive funding from this source and others, with some of the more recent grant support directed to WE ACT as the lead agency. This powerful community-academic collaboration has continued more than a dozen years, deepening its focus on air pollution as well as taking on additional areas of shared concern in the broad arena of place and health (3).

Research Methods: In the mid-1990s, the WE ACT partnership undertook detailed GIS mapping that graphically portrayed the disproportionate burden of asthma hospitalizations in Northern Manhattan, as well as the location of bus depots and other

"They [came] to us and…provided us with health information and local health studies that convinced us that there was a real problem here [and] that we ought to take the time and energy to help this community." —Policymaker

emission sources in relation to the public schools, hospitals, and other key sites. The signature aspect of the partnership's research, though, involved training high-school-aged youth to participate in investigations of exposure rates to fine particulate matter (PM2.5) commonly found in vehicle exhaust. In July 1996, WE ACT staff and summer interns (called "Earth Crew") identified neighborhood "hot spots" near the depots where vehicular and pedestrian traffic were particularly heavy, as well as possible confounders such as indoor smoking. The partnership's epidemiologist then trained the youth to do traffic and pedestrian counts in these areas and to calibrate and use backpack air monitors to test their personal exposures. CCCEH staff also used ambient air monitors in these locations to gather additional data (2, 7).

Findings: The study found that variations in concentration of fine particulate matter appeared to be related to the magnitude of local diesel sources. This reinforced community concerns about the disproportionate burden of diesel traffic and bus depots in Harlem. Results also showed that PM2.5 concentrations ranged from 22 to 69 $\mu g/m^3$ in eight hours (7)—well above the Environmental Protection Agency's (EPA) safety threshold, which at the time was 15.1 $\mu g/m.^3$ (7)

Getting to Action: WE ACT helped raise broad public awareness of the high exposure rates through a multilevel educational and advocacy campaign featuring the tag line, "If you live uptown, breathe at your own risk." The organization also experienced a deliberate planning process. In the words of a key community partner, "We would literally unfold charts of paper and start mapping the key actors: who is responsible for decision making, who is making policy, and what is the policy?… How does it play out in terms of impacting our community, our organization, and our allies?"

WE ACT also considered various potential policies and how they would have an impact on "our potential to establish policy goals" (e.g., obtaining 300 new buses powered by compressed natural gas (CNG) and having all new Metropolitan Transit Authority (MTA) depots converted for CNG). With its partners, sometimes including allies at the EPA, WE ACT also discussed how to use the study findings and the community's experience to effect its proposed policy and practice changes (4). In one instance, residents sent more than 10,000 postcards featuring a picture of two children in gas masks to two key policy targets: the governor and the head of the MTA. Dozens of bus shelter ads, widely distributed print media, and an effective media advocacy campaign were among the efforts undertaken to spread awareness. Despite this careful advance work, WE ACT often had difficulty getting a hearing with relevant officials, and it joined in filing a legal complaint against the U. S. Department of Transportation. Although the latter action was not expected to result in a win and did not, it was an important move politically in increasing the visibility of the issue and the community's commitment to seeking redress.

Policy Change Outcomes: WE ACT and its partners have been widely credited with playing a major role in securing the conversion of existing city buses to clean diesel. Although not yet reaching a key policy goal—getting 300 buses converted to compressed natural gas and requiring all new buses to use this technology—the partnership helped bring about tighter air quality standards that have withstood all legal appeals. EPA officials also cited WE ACT as the major force responsible for pressuring the agency to establish permanent air monitoring stations in Harlem and other "hot spots" locally and nationally (4). WE ACT's policy advocacy has expanded since the seminal Earth Crew study. Continuing its campaign to get the MTA to convert the city's buses to CNG, WE ACT now works closely with the Natural Resources Defense Council. It also played a key role in developing a statewide environmental justice policy: the organization's executive director, Peggy Shepard, chaired the task force that crafted the new policy and helped secure its adoption. Of equal importance, WE ACT has continued to build local capacity and amplify the community's voice through its role in spearheading the Environmental Leadership/ Mental Health Leadership Training Program and in co-chairing the Northeast Environmental

"There weren't many community-based studies that showed exposure to diesel particles at that time. From a scientific perspective, I think it played a role in [getting] the diesel exhaust controls." —Academic Partner

Justice Network. The scientists associated with the partnership have continued to see their work benefit from community partner perspectives.

Barriers and Success Factors: Several factors appeared to play a role in the partnership's effectiveness. Among them are WE ACT's strong community base, the scientific credibility of the partnership's research, strong policy and other organizational alliances, and the careful background work and strategic planning in which WE ACT is engaged. The deep mutual respect and trust among partnership members and WE ACT's strategic use of the mass media also appeared to contribute to its effectiveness and policy impacts. At the same time, the partnership struggled with different timetables and resource allocations as well as varying levels of commitment to the advocacy aspects of the work. Difficulties with simply getting meetings with key decision makers, especially in the early days of the project, were also a source of frustration.

New Directions: WE ACT sits on the steering committee of a new citywide coalition, the Campaign for New York's Future, which is working to ensure a sustainable, "greener" New York for all residents. The partnership between WE ACT and the CCCEH also has moved in new directions, with the partners collaborating on a citywide campaign, "Our Housing is Our Health," focused on indoor air quality. Together with nearly 30 organizational members, including tenant associations, housing groups, and community-based organizations, WE ACT is particularly focused on changing the city's policy on mold. Their goal: banning building materials that promote the growth of mold, and possibly even making mold a household violation. With the city's Public Advocate, they are now working to change the NYC Building Construction Code.

Summary Reflections: For more than a dozen years, the partnership between WE ACT and the Columbia Center for Children's Environmental Health has been characterized by mutual respect, trust, and a strong commitment to rigorous science and effective policy advocacy. Policymakers and others continue to point to the partnership's landmark Earth Crew study (7) as having provided key ammunition in the successful fight for tighter air quality standards and permanent air monitoring in hot spots in Harlem and similarly impacted neighborhoods around the country (4, 8). WE ACT continues to devote considerable effort to building individual and community capacity. And its continuing partnership with CCCEH and their allies demonstrates the power of CBPR and related policy advocacy to study and address problems at the intersection of place and health.

Contact Information:

Peggy Shepard,
Executive Director
WE ACT, Inc.
271 West 125th Street
Suite 308
New York, NY 10027
212.961.1000
peggy@weact.org

Patrick Kinney, ScD
Associate Professor of
Clinical Public Health
Columbia University Mailman
School of Public Health
Center for Children's
Environmental Health
60 Haven Avenue, B-116
New York, NY 10032
212.305.3663
plk3@columbia.edu

For Further Reading:

Breckwich Vásquez, V., M. Minkler, and P. Shepard. 2006. Promoting environmental health policy through community-based participatory research: A case study from Harlem, New York. *Journal of Urban Health* 83(1):101–10.

Brown, P., B. Mayer, S. Zavestoski et al. 2003. The health politics of asthma: Environmental justice and collective illness experience in the United States. *Social Science & Medicine* 57:453–64.

Kinney, P. L., M. Aggarwal, M. E. Northridge et al. 2000. Airborne concentrations of PM2.5 and diesel exhaust particles on Harlem sidewalks: A community-based pilot study. *Environmental Health Perspectives* 108:213–18.

Shepard, P., V. Breckwich Vásquez, and M. Minkler. 2008. Using CBPR to promote environmental justice policy: A case study from Harlem, New York. In *Community-Based Participatory Research for Health: From Process to Outcomes, 2nd Edition,* eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.

"We don't do policy, we just educate legislators!" —Community Partner

Case Study #2:

Tackling environmental injustice in industrialized hog production in rural North Carolina:

Concerned Citizens of Tillery and its partnership with the University of North Carolina, School of Public Health

Hog production in North Carolina more than tripled from the mid-1980s to the late 1990s, moving the state from the fifteenth- to the second-largest pork producer in the nation. By 2007, the state boasted more than 10 million hogs (1, 2). This thriving industry has come at a significant cost to the low-income, mostly African American communities where these intensive livestock operations (ILOs) are disproportionately located. By replacing local farms, harming local businesses by buying in bulk outside the community, and degrading the environment with their open hog-waste lagoons, the massive hog operations also were commonly believed to cause adverse health outcomes for local residents, including eye irritations, respiratory ailments, and diminished quality of life (3–6).

Almost 15 years ago, Concerned Citizens of Tillery (CCT) had begun doing "barefoot epidemiology" (in which residents conduct their own informal research looking into possible associations between exposures and adverse health outcomes) to study the ILO problem. CCT is a strong community-based organization that, for decades, had organized around concerns of the mostly low-income, African American residents of rural Halifax County. Suspecting the seeping of hog waste into their water supply, CCT members studied the dates of water well construction, their depth, and their proximity to the hog cesspools. CCT also reached out to neighboring communities to help found an environmental justice coalition, the Hog Roundtable, to address the regional nature of the problems. And their work was successful; CCT was heavily credited with helping secure the passage, in 1992, of a moratorium on industrial hog operations in southeast Halifax County as well as victories such as a new sewer line and the first local fire station (4–7).

The Partnership: In 1995, a journalist covering the work of CCT helped connect its executive director, Gary Grant, with epidemiology professor Steve Wing at the School of Public Health, University of North Carolina (UNC) at Chapel Hill, and a true CBPR partnership was born. This partnership originally included staff at the Halifax County health department and has received several environmental justice grants from the National Institute of Environmental Health Sciences (NIEHS) to support its work. For more than a decade, the partnership, which has also included UNC students in research, organizing, and advocacy work, has examined environmental racism in the placement of industrialized hog operations and the health and environmental effects of ILOs. The coalition eventually expanded its geographic scope and took the name Community Health and Environmental Reawakening (CHER) to reflect its statewide reach (4–7).

"…we have an intensive livestock ordinance in Halifax County due to the efforts of CCT…I don't recall the county commissioners or the Board of Health in any way being involved until we were brought into the issue by CCT." —Policymaker

Research Methods: The CCT/UNC partnership has utilized door-to-door surveys, ethnographic methods, water sampling and bacterial counts, and spatial analysis. In a seminal study in 1998 funded by the NIEHS, spatial analysis was used to compare the prevalence of ILOs in wealthier, predominately white census blocks with their prevalence in poorer, largely African American communities, adjusting for population density. Although the epidemiologist conducted this statistical research, it adhered to CBPR principles: the research question had emerged from the community's concerns; local residents helped evaluate the quality of the data on ILO locations based on their in-depth knowledge of these facilities; and the interpretation of findings was done collaboratively (3, 6–7).

Findings: The spatial analysis demonstrated that corporate-owned hog operations were far more common in low-income and African American communities, even after controlling for population density, and were also more common in areas where most residents depended on wells for drinking water (3). The partnership's interviews with members of more than 150 households revealed far more reports of headaches, sore throats, excessive coughing, and other respiratory and eye problems among people who lived closer to the ILOs (6–7).

Getting to Action: Working with UNC's News Service, the partnership developed and disseminated a press release about the study findings; the academic partner also presented these findings at a national scientific meeting. Several media outlets covered the study and its findings as well, and the lead community partner (who in 1996 and 1997 had appeared on the popular national news program, *60 Minutes*) was particularly adept at helping bring media coverage to the work. Results of the health survey were reported to the state health department, whose press statement in May 1999 led to immediate reprisal by the powerful North Carolina Pork Council, which demanded to see the investigators' confidential data (see "Barriers," following). Despite the multiple legal challenges that ensued, findings from the research have withstood the test of time and have been used by health departments, the Environmental Protection Agency, and the U. S. Department of Agriculture in strengthening the case against environmental racism (4–7). The roles of the community and academic partners in providing testimony based on the study findings at hearings and other venues also have figured into the growing awareness and calls for change (4–5).

Policy Change Outcomes: Well before the results of its first partnership study with UNC were released, the community partner, CCT, had used its own study findings and community members' testimony to help secure passage of the first Intensive Livestock Operation ordinance in 1997. Policy-related outcomes of the partnership's work are more difficult to tease out, in part because of partners' concerns about creating any perception that government funds were used to support policy advocacy endeavors. As a community leader with CCT was careful to point out, "We don't do policy, we just educate legislators." And educate they did! Several legislators and other stakeholders interviewed for this study emphasized the critical role that CCT played in achieving subsequent policy change. As one state policymaker recalled:

"…I have always said that we have an intensive livestock ordinance in Halifax County due to the efforts of CCT. They started it. I don't recall the county commissioners or the Board of Health in any way being involved until we were brought into the issue by CCT." (4).

The collective impact of diverse components of the CHER project, including community meetings, workshops, and presentations, was seen as having raised awareness about the impact of ILOs (4–7) and contributed to momentum for policy change. Results of the health survey also appeared to play a role in this process and were recently included in a policy paper prepared by the governor's office on the future of the hog industry in the state.

CCT further played a leadership role in organizing the North Carolina EJ Network (NCEJN), which helped invigorate a statewide environmental justice movement. In 2007, the NCEJN in turn helped form a coalition of grassroots and environmental

"CCT is my lifeline…When you come here, there are no big guys, no little geezers. Everybody is together… [W]hen there is unity, there is strength. I feel stronger after I leave the meeting." —Community Member

organizations to advocate for a ban on the lagoon and sprayfield technology "as a first step toward the complete elimination of this form of waste management" statewide (6). The rigorous research of the CBPR partnership—and the NCEJ Network's continued activism (e.g., holding a 51-hour vigil on the grounds of the state capitol that included construction of a mock hog factory complete with 40 gallons of pig waste)—helped get a law passed that would ban any new hog factories in the state (6, 8). Although this was seen as only a partial victory because it still allowed farmers to keep open-air lagoons indefinitely (8), it represented an important step forward.

Barriers and Success Factors: Although the studies—particularly the spatial analysis and resident survey—have been widely cited and used to help advocate for change, the partnership encountered formidable obstacles. Strong ties between the pork industry and the university's Board of Governors had what the academic partner called a "chilling effect," with the state's Pork Council's demand to see the researchers' confidential data posing threats to confidentiality and trust. Although these data were eventually released with potential individual and household identifiers removed (5), time had been lost and costs incurred in the process. A long history of institutionalized racism, concentrated land ownership, and a decade of legislation favoring pig production, often at the expense of public health and the environment, also worked against the partnership's efforts. The election to the state legislature of the state's biggest pork producer, who also headed the powerful North Carolina Pork Producers Association, further helped to promote the interests of the hog industry over those of residents (4). In the face of such realities, CCT's long history of community activism and trust, the "strong reciprocal relationship" between the community and academic partners (4, 5), and the high quality of the research they produced were important facilitators of change. The effective collaborative leadership of the community and academic partners, and their skillful and timely use of the mass media to create awareness and promote the positions being advocated, also played a key role in the successes observed.

New Directions: CCT and its academic partners continued to collaborate, most recently using a repeat-measures design in a mixed-methods CBPR study in 16 counties to collect data on the impacts of hog factory-related exposures on health and quality of life (9). The preliminary release of findings to the community and the mass media also helped galvanize change efforts (8). As previously noted, the community partner's seminal role in helping to create a statewide environmental justice network and grassroots coalition, and the latter's successful advocacy for legislation banning new hog factories in the state (6, 8), illustrate the ways in which this work, and the activism it has contributed to, have been taken to the state level.

Summary Reflections: Concerned Citizens of Tillery has been called "a textbook lesson in how to grow a healthier community from the ground up" (10). CCT's history as a powerful, autonomous community-based organization also positioned it to be a strong and equal partner in CBPR. The capacity and commitment of CCT and its UNC partners for genuine collaboration and collaborative leadership, and the high quality of their research and organizing, further contributed to these achievements. The partnership is widely cited as an example of the promise and practice of effective community-based participatory research (11). In its second decade, the partnership stands poised to continue its efforts to study, through well-designed mixed-methods research, and to help redress, through "educating legislators," environmental racism and its consequences in rural North Carolina and beyond.

Contact Information:

Gary Grant, Executive Director
Concerned Citizens of Tillery
P. O. Box 61
Tillery, NC 27887
252.826.3017
Tillery@aol.com

Steve Wing, PhD
Associate Professor,
Epidemiology
University of North Carolina, School of Public Health
2101F McGavern-Greenberg Hall
Chapel Hill, NC 27599
919.966.7416
steve_wing@unc.edu

For Further Reading:

Tajik, M., and M. Minkler. 2007. Environmental justice research and action: A case study in political economy and community-academic collaboration. *International Quarterly of Community Health Education* 26(3):213–231.

Tajik, M., S. Wing, and C. Grant. In press. Environmental Justice from the Roots: Tillery, North Carolina. In *Academics and Activists: Confronting Ecological and Community Crisis in Appalachia,* eds. Stephanie McSpirit, L. Faltraco, and C. Bailey. Lexington: Joyce Harrison University Press of Kentucky.

Wing, S. 2002. Social Responsibility and Research Ethics in Community-Driven Studies of Industrialized Hog Production. *Environmental Health Perspectives* 110(5):437–44.

Wing, S., R. A. Horton, N. Muhammad, and G. R. Grant. 2008. Integrating Epidemiology, Education, and Organizing for Environmental Justice: Community Health Effects of Industrial Hog Operations. *American Journal of Public Health* 98(8):1390–97.

Case Study #3:

Moving out of the nursing home and into the community:

The Departments of Disability and Rehabilitation at the University of Illinois – Chicago, Access Living, and the Progress Center for Independent Living

The U. S. Supreme Court *Olmstead* decision in 1999 challenged states to provide services to people with disabilities "in the most integrated setting appropriate" to their needs. Although many states had already moved away from institutionalization and towards community-based supports, others, including Illinois, had only begun the change needed to rebalance their long-term care systems. Indeed, the number of disabled people under age 60 who were living in Illinois nursing homes grew 25 percent from 1997 to 2003, and 80 percent of the state's long-term care funding went to nursing homes and other institutional care (1, 2). These figures,

"A researcher asked us about the definition of disability. At first we talked about personal limits, but now we talk about the power of voice." —Program Participant

the difficulties for individuals in moving back to the community once institutionalized, and the social barriers experienced by disabled people who have moved out of nursing homes, were a major impetus for the Chicago-based CBPR project, "Moving out of the nursing home and into the community."

The Partnership: The project was born in 2000 from a long partnership between two professors in Disability Studies at the University of Illinois and their community partners at two local Centers for Independent Living (CILs), Access Living and Progress Center, founded and operated by and for disabled people.[1] The topic grew out of conversation between the disability rights community and academic partners, who shared deep concerns about the number of disabled people in nursing homes in Illinois as well as the difficulties they experienced in leaving these settings and reintegrating into the community.

Funded by a grant from the National Institute on Disability and Rehabilitation Research (NIDRR), the project was designed to document the experiences and concerns of disabled people who attempted to move out of nursing homes, and to develop, implement, and evaluate an individual and a community empowerment and policy change intervention known as the Social Action Group (SAG) Program. Grounded in an empowerment model, the intervention included peer-led education about disability rights, help in accessing resources, and individual and community capacity building to promote systems change aimed at rebalancing long-term care funding in the state.

Research Methods: Initial focus groups with 30 disabled people transitioning out of nursing homes informed the development of the primary project intervention—a five-week SAG Program, which then was field tested through a controlled intervention trial. A 300-item baseline survey was administered to 140 participants who had been randomly selected from the lists of individuals involved in the state's community integration waiver program and were divided into a SAG intervention group and a waitlisted control group. Repeated measures were used at three months and 12 months post-intervention to test the effects of participation. Qualitative interviews and life narratives were used to gather additional process data. Ten follow-up focus groups averaging seven to 12 program participants each, and six town hall meetings ranging from 40 to 150 attendees, were conducted during and after the intervention. They enabled participants to "tell their stories," discuss preliminary study findings, and develop action plans focused in part on helping to effect policy change (3, 4). Members of the waitlisted control group also were invited to attend the post-SAG intervention town hall meetings.

Findings: By the end of the project, a significant difference was observed between the SAG intervention group and the control group in terms of the proportion who had successfully transitioned out of nursing homes (37 percent of SAG members vs. 20 percent of controls). By mid-October 2004, more than 200 disabled people had participated in the project through social action working groups, and many had developed skills as advocates for policy-level changes that could help address the bias toward institutionalization in long-term care funding and availability (3, 4). Focus group data also helped uncover key community concerns that then became the basis for subsequent policy-focused efforts. Among these were: a "Money Follows the Person" program, through which disabled consumers themselves would be enabled to select the support services they needed; emergency backup personal attendant services for people at risk of re-institutionalization without such support; and a community reintegration program for people over 60 who wanted to move out of nursing homes and often faced particularly difficult obstacles in doing so. These findings concerning disabled peoples' desired services and unmet needs in turn pointed to the need for new funding allocations and accompanying policy changes to support relevant programmatic interventions.

[1]Although "people with disabilities" often appears in the literature, "disabled people" and other "disability-centered" terms are preferred by many activists and scholars who promote positive disability identity as an act of resistance against disability oppression.

"We always had a lot of evidence before we walked into a room for a meeting with the state [including] a ream of facts and life stories of participants … to challenge them to move forward …" —Academic Partner

Getting to Action: Community and academic partners identified policy directions to pursue, drawing on the focus group data and policy-relevant information from key sources within and outside the state. For each policy objective (e.g., getting the above-mentioned Money Follows the Person program and emergency backup personal attendant services), academic and community partners, along with SAG members, testified at public hearings, contacted officials, wrote letters to the editor, and took part in town hall meetings, rallies, and demonstrations to increase public and policymaker awareness of and support for their positions. The partners did careful advance work prior to public meetings to determine the best strategies, the data needed, and the most effective ways to communicate information. In the words of an academic partner, "we always had a lot of evidence before we walked into a room for a meeting with the state [including] a ream of facts and life stories from participants… to challenge them to move forward."

The effective use of media advocacy—especially by the CIL partners, including opinion and editorial pieces and articles in the *Chicago Tribune* (5–7)—helped publicize Illinois' poor standing with respect to long-term care spending and highlighted the partners' stance on key issues. SAG participants added a human dimension to the facts and statistics by telling their stories to journalists as well. Building strong coalitions beyond the existing partnership also was a key policy-related activity. Partnership members were founding members of The Illinois Olmstead Coalition, for example, which advocated for Illinois to develop an effective action plan for moving disabled people out of institutional settings while providing the supports needed (e.g., a living wage for attendants) to facilitate community living.

Policy Change Outcomes: Increasing pressure on the state to comply with the *Olmstead* decision and the activities of many stakeholders precluded teasing out the effects of this CBPR effort on specific policy changes. However, several policymakers and leaders in the disability community described the partnership as having contributed substantially to important policy and systems change efforts and outcomes. One policymaker remarked, for example, that the partnership "was instrumental in providing evidence needed to change our policies and fund new demonstration projects like the Senior Community Reintegration Program and the Emergency Personal Assistant Program in Illinois." Other key outcomes for which the partnership was given some of the credit included the Money Follows the Person program provision, funded in 2007 through a $55.7 million Phase I grant from the Centers for Medicare and Medicaid to the state (3, 4). Illinois' earlier reauthorization of a statewide council to reassess *Olmstead* implementation and to prepare a strategic plan for rebalancing long-term care funding toward community-based care also was described by several stakeholders as an important intermediate step to which the partnership's research and advocacy contributed substantially. Finally, the programs helped nurture a new generation of disability rights mentors and advocates from among a highly marginalized population: disabled people in and transitioning out of nursing homes.

Barriers and Success Factors: The often formidable difficulties experienced in working through the state bureaucracy, coupled with the power of the nursing home industry, were major barriers to success. Discrimination against disabled people at every level in society also was noted. The tensions inherent in CBPR, which one partner called an "unholy matrimony" between scholarship and activism, and the lack of sufficient funding for community members also were raised. Despite these concerns, partners repeatedly pointed to success factors such as a long history of collaboration and strong mutual trust, deep commitment to the cause, an effective and a diverse local disability rights network, and federal legislation mandating the enforcement of the civil rights of disabled people.

Summary Reflections: By bucking the national trend toward deinstitutionalization and being slow to comply with the *Olmstead* decision mandating least restrictive alternative living environments for disabled people, Illinois may have presented the disability community and its allies with an important opportunity for research and action. The partnership was credited with having played a substantial role

"At strategic moments [the community partner] has been able to bring literally hundreds of community voices into the public decision-making process." —Academic Partner

in successful efforts to secure funding for several new initiatives, especially the historic allocation of more than $55 million for a Money Follows the Person program, which was among the partnership's signature issues. Equally important, the partnership has trained a new generation of disability activists and systems change advocates, many of whom continue to attend bi-annual town hall meetings. In the words of one policymaker, the SAG program and its town hall meetings helped create "a great influx of new voices carrying the message that it is time for a policy shift in Illinois…Policymakers are hearing this message and are reaching out to the disability community for additional collaboration."

Contact Information:

Marca Bristo,
President and CEO
Access Living
115 W. Chicago Avenue
Chicago, IL 60654
312.640.2100
mbristo@aol.com

Diane Coleman, JD, MBA
Executive Director
Progress Center for
Independent Living
7521 Madison St.
Forest Park, IL 60130
312.640.2100
NDYCOLEMAN@aol.com

Joy Hammel, PhD, OTR/L,
Associate Professor
University of Illinois
at Chicago
Departments of
Occupational Therapy
& Disability and Human
Development
1919 W. Taylor Street
Rm. 311
Chicago, IL 60612
312.996.3513
hammel@uic.edu

For Further Reading:

Hammel, J., S. Magasi, L. Fogg, T. Wilson, and E. Rodriguez. 2007. Moving out of the Nursing Home to the Community: Outcomes from the Participatory Social Action Group Project. Unpublished paper.

Minkler, M., J. Hammel, C. Gill, S. Magasi, V. Breckwich Vásquez, M. Bristo, and D. Coleman. 2008. Community-Based Participatory Research in Disability and Long-Term Care Policy: A Case Study. *Journal of Disability Policy Studies* 19 (2):114-126.

Case Study #4:

Using "data judo," community organizing, and policy advocacy on the regional level:

Southern California Environmental Justice Collaborative

Southeast Los Angeles is the site of more than 200 toxic hazards and 60 federally designated Superfund sites (1–3). The area is predominantly made up of communities of color that experience disproportionately high rates of cancer, asthma, learning disabilities, and other health problems (4). Although many environmental health and social justice organizations had been active in this area for years, a more coordinated, regional approach to environmental justice was needed, as were high-quality scientific data establishing the existence of environmental health inequities.

Since its founding more than a decade ago, the Southern California Environmental Justice Collaborative (the Collaborative) has focused on addressing these gaps through a three-pronged approach: community organizing, research, and philanthropy. The Collaborative played

"…we have already learned so many skills that we can ourselves go to the factories and demand public records. We know where to go, we know who to write to, we know how to go to their management… . We [know] how to motivate and gather people and mobilize them." —Community Member

a key role in helping to secure a 75 percent reduction in the maximum individual cancer risk standard—the number of risks per million allowed by a government body—for the area and advancing the concept of cumulative, rather than individual, risk exposure among regulators, policymakers, and other stakeholders.

The Partnership: The Southern California Environmental Justice Collaborative is a CBPR partnership made up of a community-based organization, Communities for a Better Environment (CBE); the Liberty Hill Foundation, a local philanthropy; and a multidisciplinary team of academic researchers from the University of California, Santa Cruz, Occidental College, and Brown University. Formally created in 1998 with the help of a $1.7 million grant from The California Endowment, the partnership was built on the foundation of strong prior working relationships among the partners. It maintains offices in Southeast Los Angeles and Northern California. Its goal is to improve the environmental health of low-income communities of color by generating sound scientific evidence, developing community capacity through grant-making and technical assistance to CBOs, and advocating and mobilizing for policy change.

The decision-making structure allows the community organization, CBE, to have the ultimate say on setting the partnership's research priorities and questions. Academic researchers then conduct studies based on the community's research questions while maintaining open communication with partners about the research design and methods. The Collaborative jointly interprets findings and makes decisions on dissemination. Liberty Hill provides technical, administrative, and financial support for the partnership. Placing great emphasis on research rigor, the Collaborative understands and accepts the possibility that research findings may not support advocacy needs.

Research Methods: The Collaborative employs secondary data analysis as its chosen research method, for two main reasons. First, using the data from state and federal government agencies such as the EPA, the National Cancer Institute, and the U. S. Census Bureau is more economical than primary data collection, allowing for broader coverage of research questions. Second, this approach is advantageous for building policy arguments. When the Collaborative does analysis based on government data to advocate for policy change, neither government agencies nor private industry are likely to challenge the quality or credibility of the data (4). The Collaborative's research methods include computer-based mapping, multivariate statistical analysis, environmental health risk assessment, and spatial statistics. Using such methods, the Collaborative examined whether there was a relationship between minority racial/ethnic status and residential proximity to toxic waste facilities. The partnership also developed an environmental health "riskscape" to illustrate the distribution of pollution burdens from a demographic and geographic perspective (5).

Findings: The Collaborative documented disproportionate exposure to toxic waste in communities of color and linked the exposure to a corresponding increased risk for cancer. Findings further demonstrated that polluting industries tend to locate in the areas where low-income minorities reside. These data, published in peer-reviewed journals in 1999 and 2001 (3, 5), were critical for challenging the "minority move-in theory," which suggests that minorities move into already heavily polluted areas because the property is cheaper, rather than the other way around (3, 5).

Getting to Action: The Collaborative used its research findings to further a key part of its policy agenda: getting a change in Rule 1402, which had been adopted by the California South Coast Air Quality Management District (SCAQMD) in 1994 and established an allowable lifetime cancer risk level for toxic air emissions of 100 risks per million. Not only was this level far above the one risk per million that the federal Clean Air Act recommended and that CBE and its allies had fought for; it was actually double the 50 per million limit that those representing the polluting industries had sought! CBE and its allies had long pressed for a revisiting of Rule 1402, and when an opportunity enabled a possible renegotiation of the rule in 2000, the Collaborative sprang into action.

"When you are dealing with agencies and you are analyzing their data and showing them your results, they are hard pressed to tell you your data sucks because it is their data." —Academic Partner

Calling a meeting of environmental groups and presenting its research findings and the opportunity at hand, the Collaborative helped motivate these groups to mobilize together on broader, regional issues, with Rule 1402 as a timely starting place. CBE did door-to-door outreach to inform community members and gave numerous presentations to schools and local groups, as well as Toxic Tours for policymakers, bringing the issues alive through visits to the affected communities. Through these venues, presentations at hearings, and in the media—including a strategically timed op-ed piece written by the partners and printed in the *Los Angeles Times* just before the decision meeting was to take place (6)—the Collaborative's research findings were shared and linked to Rule 1402 and to the concept of cumulative risk exposure. The Collaborative also brought attention to the powerful institutional forces driving the outcomes of prior decision making, helping bring further pressure on the air quality board to reconsider its earlier decision.

Policy Change Outcomes: The Collaborative's strong science, effective media advocacy, and powerful grassroots mobilization, together with the productive work of the coalition it helped create, have been given much credit for SCAQMD's decision to reduce the allowable cancer risk from pollution from 100 to 25 cases per million (7–8). Further, and with CBE taking the lead, the Collaborative succeeded in its campaign for the adoption by Cal/EPA of an environmental justice document to guide the agency's work in this area (4). Included in the document guidelines were the development of new methods for assessing cumulative risk and the integration of the precautionary principle—namely, being proactive "when scientific evidence strongly suggests, but does not yet fully prove" that an exposure is causing harm (4). Finally, the Cal/EPA guidance's call for the development of new programs and resources to increase authentic public participation in decision making around environmental health, particularly in communities of color, was an important step forward. CBE has been a key player in its implementation (9); e.g., serving on its Environmental Justice Advisory Committee, which, in turn, led to more systematic implementation of environmental justice programs in the state.

Barriers and Success Factors: The Collaborative encountered many obstacles, including the far greater resources of private industry, lack of sufficient understanding of relevant legal processes, and policymakers' lack of familiarity and comfort with environmental justice issues, particularly ones as complex as the precautionary principle and cumulative impact. On the positive side, however, were an improving political climate for environmental justice (10), CBE and its allies' ability to speak with a united voice and to mobilize needed "people power," and the Collaborative's effective use of both credible data and mass media. A stable and substantial funding base was another major advantage, enabling the Collaborative to focus on its research and organizing efforts without having to "chase the dollars." The opportunity to revisit Rule 1402 was, of course, a critical facilitating factor in this case study. But the partners were ready to capitalize on that opportunity with credible data and a strong facility for community organizing, policy advocacy, and media outreach.

Summary Reflections: The Southern California Environmental Justice Collaborative demonstrates the value of CBPR approaches in achieving policy goals in environmental health. The group's three-pronged model—community organizing, research, and philanthropy—played an early and important role in helping to unify the somewhat fragmented environmental justice efforts in the state. It brought groups together to mobilize around regional issues in ways that could in turn have an impact on the policy level. The Collaborative's experience suggests a need to build a popular base in advocating for policy change. The story underscores the benefits of organically developed relationships among partners and a deep collective commitment to sustain the movement, and the need for a long-term perspective on achieving change through community capacity building. The Collaborative's experience also demonstrates the value of philanthropic partners in enabling efforts like this one to focus on the work at hand without the distraction of funding pressures. Finally, the Collaborative's achievements with a relatively underutilized form of CBPR may hold an important lesson for the field. As articulated by several of the partners (4), "The achievements

"[The Collaborative] provided a model for how to work on environmental justice issues on a regional level and how to better integrate organizing efforts on EJ in a way that can push for policymaking." —Policymaker

of [the Collaborative] show that it is time to mainstream the marginal: academic-community collaboratives that emphasize secondary data analysis in their CBPR approach can be powerful agents for policy change without compromising the standards of rigorous scientific research."

Contact Information:

Bill Gallegos,
Executive Director
Communities for a
Better Environment
5610 Pacific Blvd. #203
Huntington Park, CA 90255
323.826.9771 X 109
billgallegos@cbecal.org

Rachel Morello-
Frosch, PhD, MPH
Associate Professor
University of
California, Berkeley
Department of
Environmental Science,
Policy and Management
& School of Public Health
128B Giannini
Berkeley, CA 94720
510.643.6358
rmf@nature.berkeley.edu

For Further Reading:

Morello-Frosch, R., M. Pastor, and J. Sadd. 2001. Environmental justice and southern California's "riskscape": The distribution of air toxic exposures and health risks among diverse communities. *Urban Affairs Review* 36:551–78.

Morello-Frosch, R., M. Pastor, J. Sadd, C. Porras, and M. Prichard. 2005. Citizens, science, and data judo: Leveraging secondary data analysis to build a community-academic collaborative for environmental justice in Southern California. In *Methods in Community-Based Participatory Research for Health*, eds. B. Israel, E. Eng, A. Schulz, and E. A. Parker. San Francisco: Jossey-Bass.

Petersen, D., M. Minkler, V. Breckwich Vásquez, and A. C. Baden. 2006. Community-based participatory research as a tool for policy change: A case study of the Southern California Environmental Justice Collaborative. *Review of Policy Research* 23(2):339–53.

Case Study #5:

Addressing food insecurity in San Francisco's Bayview Hunters Point:

The Literacy for Environmental Justice Partnership

In low-income, inner-city neighborhoods such as San Francisco's Bayview Hunters Point, high rates of obesity and food insecurity, or limited or uncertain access to nutritionally safe and adequate foods (1), often are intimately interconnected. Many such neighborhoods have experienced "supermarket flight," with large, full-service grocery stores moving out to more profitable locations. Together with transportation barriers, this phenomenon often leaves residents dependent

"The [LEJ partnership] decided on a voluntary policy because there are a lot of economic issues involved. They didn't want to go into the neighborhood and say, 'We're another group telling you what you should be doing.'" —Academic Partner

on fast-food outlets or small corner stores that are well stocked with liquor, tobacco, and processed foods heavy in salt, sugar, and fat, but offer little in the way of fresh fruits and vegetables (2, 3).

The Partnership: In 2002, a CBPR partnership linked a nonprofit youth empowerment and environmental justice education organization, Literacy for Environmental Justice (LEJ), with health educators at the San Francisco Department of Public Health and with an outside evaluator to address the food insecurity problem. Local high school youth, mostly from underserved racial/ethnic communities, worked five to 10 hours per week as paid LEJ interns studying and addressing the problem. Using the health department's five-step Community Action Model (CAM), health educators taught the youth critical thinking and research skills for understanding the root causes of problems, identifying contributing factors, gathering data, evaluating action-oriented change strategies, and developing policy solutions (4).

Because the health department's Tobacco Free Project funded the LEJ partnership, its work had to be related to smoking. But the partners readily found connections between the community's concerns with food insecurity and the problem of tobacco. For example, the youth soon learned that Philip Morris/Altria was the parent company of Kraft and Nabisco and was at that time the second-largest food conglomerate in the world (5). The partnership also benefited from the earlier work of other city agencies looking at the retail food environment and of a group of community elders who, in the early 1990s, began meeting to discuss their concern about the disproportionate sales of alcohol and tobacco in the local stores, which attracted loitering and vandalism. The proposed approach—providing incentives to stores that became "good neighbors" by offering healthier, fresh foods and reducing alcohol and tobacco advertising while promoting community safety—caught the attention of a charismatic local supervisor, who also had a long-standing interest in food insecurity in her community.

Research Methods: The research component of the partnership's work attempted to address several key questions: What was the reality of current access (or lack of access) to healthy foods in the neighborhood? Would increased access at the local stores translate into more residents shopping locally? Would local merchants consider making changes to increase their stock of healthy foods? What incentives would encourage this to happen?

With training by the evaluator and health department staff, the LEJ youth developed and conducted an initial community survey of 130 residents, asking about their needs and desires in relation to local markets, health and nutrition behaviors and habits, and what it would take to get them to shop locally instead of outside the community. The youth also used store-shelf diagramming to determine how much space in local stores was devoted to processed foods and to tobacco, liquor, and other products. The youth conducted in-depth interviews with merchants at five local stores and utilized Geographic Information Systems (GIS) mapping to display the location of corner stores, supermarkets, transportation routes, and relevant community demographics (6, 7).

LEJ worked with a student at UC Berkeley's School of Business to conduct a study of the economic feasibility for local stores of increasing their stocking of healthier foods, and of the potential economic incentive mechanisms available through the city and related programs. Finally, and because much local policy work involves being able to show what's worked in other communities, they collaborated with the local supervisor, Sophie Maxwell, to study related policies in different cities.

Findings: Store-shelf diagramming in 11 corner stores revealed that on average, close to 40 percent of shelf space went to processed foods, 26 percent to tobacco and alcohol, 17 percent to sodas and other beverages, and just two to five percent to fresh fruits and vegetables (6–8). The partnership's GIS mapping showed that it took residents (many of whom lacked reliable cars) approximately one hour and three bus transfers to get to the closest supermarket. Interviews with merchants and community surveys added

"[A lesson for other youth partnerships is] not being intimidated by people in suits…You are the one dealing with it every day in the community in which you are a part." —Community Member

other important information, including the fact that residents were favorable to increasing access to healthy foods and decreasing the availability of alcohol and tobacco advertising at the local stores (4, 6–8). Interviews with several merchants revealed that they were interested in the possibility of joining a "good neighbor" program if they could receive incentives that would make such changes economically feasible.

Getting to Action: Encouraged by these findings and working closely with Supervisor Sophie Maxwell, the LEJ partnership worked on establishing a Good Neighbor Program (GNP) in the Bayview neighborhood. Four city departments were quickly recruited as program co-sponsors, with the Redevelopment Agency now beginning to provide façade improvements to local stores that agreed to make specific health-promoting changes in their business practices. It is hoped that other concessions, such as discounted loans and energy-efficient appliances, can also be provided eventually.

The partnership developed detailed memorandums of understanding (MOUs), spelling out details such as how much space in the Good Neighbor stores would be devoted to fresh produce. City entities, including the Mayor's Office on Economic and Workforce Development, the Department of the Environment, and the Redevelopment Agency, joined the health department in contributing staff and resources to manage and sustain the program, with an eye to possible citywide expansion. LEJ continues to take a lead in the program by providing technical assistance and working with youth who help with taste testing and branding at the pilot store, Super Save Market, which became a "Good Neighbor" in December 2003. This pilot store saw an increase in produce sales from five percent to 15 percent, and a decrease in alcohol sales from 25 percent to 15 percent of total sales in the first seven months. Four years later, in 2007, these figures remained strong: Produce sales remained up 12 percent, alcohol and cigarettes down 10 percent, and overall profits up 12 percent (7, 8) compared to their pre-store conversion rates of sale. Based in part on the early success of the pilot store, other stores were encouraged to become "Good Neighbors." Finally, LEJ joined other stakeholders in helping to promote a state assembly bill that would establish healthy corner store programs statewide.

Policy Change Outcomes: Successful adoption of the voluntary municipal policy that promotes store conversions in the Bayview neighborhood resulted in four stores becoming "Good Neighbors" between 2004 and 2007; three additional stores converted in 2007. Five new stores will be recruited in 2008–2009 with additional funding from The California Endowment. On a larger scale, and with the support of the LEJ partnership and other groups, state Assemblyman Mark Leno introduced Assembly Bill 2384, supporting the establishment of a statewide "Healthy Food Purchase" pilot program modeled on the GNP and other corner-store conversion programs. The bill was passed and signed into law in 2006, albeit without a budgetary appropriation.

Barriers and Success Factors: Implementation of the Good Neighbor Program has sometimes proved challenging, with one of the early conversion stores recently reporting having trouble selling fresh produce and consequently needing to stock less than when it originally became a Good Neighbor. A special challenge lies in addressing price point; for example, coming up with innovative models to connect stores with local farmers and then providing produce at prices that local residents can afford and will purchase. Turnover among youth members and program staff posed another challenge and led to some incomplete data collection. Yet, the outcomes of this voluntary policy effort appear encouraging, whether measured in store recruitment and compliance, youth empowerment, or program growth and sustainability.

The long-term viability of this effort will depend in part on larger political and economic realities, among them the economic downturn and the fact that the first new supermarket in this neighborhood in over a decade is expected to open in 2010. Taking the work to scale statewide is also proving to be a challenge. Getting a budgetary appropriation by the 2011 deadline that would enable the

enactment of AB 2384 (supporting a statewide pilot program modeled in part on the GNP) does not seem likely in the current fiscal climate. But the bill's sponsors and supporters are continuing the fight while getting their message out nationally: LEJ is an active partner in a new national corner store network and hopes to use the San Francisco experiences to help communities in diverse parts of the country mount similar programs.

Summary Reflections: Literacy for Environmental Justice and its health department and other partners, with strong support from a local supervisor and a willing city government, have achieved an innovative partial solution to a persistent problem, with good potential for sustainability. LEJ youth have been fully engaged in many aspects of the work, utilizing technical assistance and the Community Action Model framework to help structure and formulate their partnership's research and policy strategy. Although the long-term viability of this ambitious effort will depend in large part on forces beyond the control of the partners, subsequent work on the state and national levels appears to hold potential for bringing the "good neighbor" concept to low-income communities on a far larger scale through participation in the Healthy Corner Stores Network and the sharing of a recently developed Good Neighbor Best Practices Kit.

Contact Information:

Gwendolyn Smith
GN Manager
Literacy for Environmental Justice
800 Innes Av. #11
San Francisco, CA 94124
415.282.6840
goodneighbor@lejyouth.org

Susana Hennessey Lavery, MPH
Health Educator
San Francisco Department of Public Health
Tobacco Free Project
30 Van Ness Avenue, Suite 2300
San Francisco, CA 94102
415.581.2446
Susana.Hennessey-Lavery@sfdph.org

For Further Reading:

Breckwich Vásquez, V., D. Lanza, S. Hennessey Lavery, M. Minkler, and H. S. Halpin. 2007. Addressing food security through public policy action in a community-based participatory research partnership. *Health Promotion Practice* 8(4):342–49.

Hennessey Lavery, S., M. L. Smith, A. A. Esparza, A. Hrushow, M. Moore, and D. F. Reed. 2005. The community action model: A community-driven model designed to address disparities in health. *American Journal of Public Health* 95(4):611–16.

Hennessey Lavery, S., M. L. Smith, and M. Moore. 2005. The community action model: Organizing for change in San Francisco's Tobacco Free Project. *Health Education and Behavior* 32(3):405–07.

"Community leaders know about us. We attend a lot of meetings in the community and community leaders know who we are. They know what we do and are in support of what we do." —Community Youth

"I believe the young people are driven by making a difference, by wanting to make a difference, and seeing that they do make a difference in their community, not just in their own lives." —Community Partner

"Tribes have a history of having been studied by outsiders in a negative way. You have to overcome that knowledge and maybe even personal experience with that history…You have to do things in person, not on the phone, until you have built trust. Go there and be there." —Academic Partner

Case Study #6:

Preventing lead exposure among children in Tar Creek, Oklahoma:
Tribal Efforts against Lead

Once at the heart of a vibrant lead and zinc mining industry, the Tar Creek region of Ottawa County, Oklahoma, has been of special concern to health workers and environmental activists since the mid-1990s because of contaminated soil and very high blood lead levels and anemia in the area's children (1, 2). Since the sale of lead-laden mine tailings was an important part of the local economy in this resource-poor community, environmental agencies had been slow to regulate its use. In the mid-1990s, however, Indian Health Service (IHS) data demonstrated that a high percentage of Native American children in the area were anemic and had blood lead levels high enough to increase their vulnerability to a host of problems, including lower intelligence quotient (IQ) scores, shortened attention span, and difficulties with coordination and fine motor skills (1, 3). These data provided the impetus for an ambitious new effort to address this problem, and Tribal Efforts against Lead (TEAL) was born.

The Partnership: Established in 1996 with funding from the National Institute of Environmental Health Sciences (NIEHS), the TEAL partnership includes members from nine Native American tribes and nations, academic researchers from three universities (University of Oklahoma Health Sciences Center, Emory University, and University of New Mexico), the Ottawa County Department of Health, the Oklahoma Department of Environmental Quality (DEQ), and a community-based environmental advocacy organization.

Research Methods: TEAL's centerpiece was the design and evaluation of a community-based lay health advisor intervention (2) for the prevention of lead poisoning among Native American children. Cross-sectional, population-based, blood lead screenings and detailed caregiver interviews were collected before and after the two-year lay health worker intervention. Organizational network interviews (n=21) and environmental assessments of 245 homes also were conducted (1, 4). Forty Clan Mothers and Fathers who were respected members of the local Native American community were hired and trained as lay health advisors. Although the research design and evaluation were undertaken primarily by the academic partners, community partners played key roles throughout; e.g., in broadening the intervention to include white as well as Native children in a second phase; helping to select and implement culturally relevant prevention activities; and serving as local supervisors, canvassers, phlebotomists, and interviewers. Academic partners took primary responsibility for data analysis and writing. Community members reviewed and commented on findings and co-authored publications when desired.

Findings: TEAL data demonstrated that soil and dust, rather than paint, are the primary residential sources of lead in the Tar Creek area and that the percent of children in the area with elevated blood lead levels was substantially higher than in comparable areas of the state and nation (1,

"It evolved pretty quickly that we couldn't just focus on individuals protecting themselves in this environment. We had to create change in the environment as well." — Academic Partner

2). TEAL's findings also indicated that even floor dust lead concentrations that are well below the EPA standard could result in elevated blood lead levels, particularly among children living in low-income households (2). They further demonstrated significant improvements in health knowledge, self-efficacy, and practices over the two years, in part as a result of the lay health worker intervention.

Getting to Action: TEAL's concrete and compelling data helped move lead poisoning prevention to a more prominent position on the community's agenda and promoted related public discussion. TEAL thus provided population-based blood lead and environmental data to the Governor's Task Force on Tar Creek, a major decision-making body charged with making recommendations for the future of Tar Creek.

To determine a course of action to suggest to the community, TEAL partners reviewed existing regulations on mining waste and examined enforcement issues. The partners also reviewed other states' blood lead screening policies and learned how people in other states achieved their policy change goals. Using visioning exercises and a brainstorming process, the partners discussed policy alternatives before agreeing to push for restrictions on the use of mine tailings, mandatory blood lead screening and reporting, and a state match to federal Superfund spending. But community buy-in was critical. As one participant noted, "TEAL identified potential policies but left it to the community to decide on which to pursue."

Although academic partners were careful not to make recommendations for specific policies because of the lobbying restrictions of their federal grant, TEAL community partners played a much more direct role, getting on the agenda of a county commission meeting and writing numerous letters to policymakers, several of which were published as letters to the editor in local newspapers.

Clan Mothers and Fathers visited each tribal government to urge passage of resolutions supporting mandatory screening. They then used these resolutions to persuade the Indian Health Service to fully implement IHS screening and reporting. The community partners volunteered to help IHS by sending letters notifying parents of blood lead testing results.

Policy Change Outcomes: TEAL is widely credited with helping the Ottawa County Health Department and Indian Health Services to fully implement mandatory blood lead screening and parental notification for young children. TEAL Clan Mothers and Fathers also played a major role in persuading the DEQ and county officials to restrict use of mine tailings on roads and in construction without proper containment. In addition to the fining structure imposed by the guidelines, TEAL helped to create local social pressure for guidelines to be followed.

TEAL helped spur the county health department to develop its own lead prevention efforts and hire a former TEAL project research coordinator as the lead educator for the department. More than 3,600 education and outreach activities, reaching close to 30,000 residents, were conducted over a two-year project period (5). TEAL also made important contributions to individual and community capacity building. In addition to the health educator previously mentioned, several TEAL staff have become leaders in health-related initiatives for tribal governments and other county and federal agencies working in the region.

TEAL findings were cited in a report about the Tar Creek site written by the Centers for Disease Control and Prevention (CDC)/Agency for Toxic Substance and Disease Registry (ATSDR) and presented to Congress (6). TEAL data were critical in getting the EPA to provide HEPA vacuum cleaners to the area's tribes and to continue remediation efforts. TEAL members served on the Governor's Task Force on Tar Creek, and TEAL academic partners served as expert witnesses in lawsuits on the health effects of mine tailings, all of which have since been settled. TEAL's voice, in short, was critical in helping pressure the state to provide matching cleanup funds for the Tar Creek Superfund site and in getting federal attention and action on this overlooked problem area.

"TEAL identified potential policies but left it to the community to decide on which to pursue." —Academic Partner

Barriers and Success Factors: Substantial time was needed to address the profound cultural differences between academic and community partners and to overcome the historical distrust of research that often is present in Indian Country. The fact that many residents earned a living selling the lead-rich mine tailings that TEAL hoped to contain also presented a substantial challenge, as did federal restrictions on lobbying that came with TEAL's NIH funding. On the plus side, however, the project's strong funding base enabled the hiring and training of community partners as local staff for long-term engagement with the work. Many of these individuals also acted effectively in their own citizen capacities in letter writing and other advocacy activities (7).

Central to TEAL's success was its reputation as a legitimate and an independent source of high-quality scientific data. Policymakers and local organizations said these data were "of critical importance in moving a number of policies forward." Other important success factors were demonstrated leadership among community and academic partners; and strategic alliances among tribal leaders, state and local health department personnel, and many local groups concerned about the lead issue. Ultimately, regional lead cleanup efforts stimulated community mobilization in the Tar Creek area as, in the words of an academic partner, the "sense of being ignored and abandoned [by government in the cleanup efforts] energized the community to action."

Summary Reflections: The TEAL partnership successfully implemented a broad community-based effort that collected critical data and used both behavioral and policy change strategies to prevent and control lead exposure in Ottawa County. TEAL has been particularly effective within the Native American community and among tribal organizations. Although the residents of one Tar Creek community, Picher, recently were forced to move after a federal study showed serious risks of subsidence (which was followed by a devastating tornado), actors well beyond TEAL are now involved in and committed to protecting those residents who remain in the area from the negative health effects of lead exposure, in terms of both education and remediation. This is a significant part of the project's legacy.

Contact Information:

Rebecca Jim
Executive Director
LEAD Agency, Inc.
19257 S. 4403 Drive
Vinita, OK 74301
918.256.5269
918.542.9399
rjim@neok.com

Michelle Kegler, DrPH
Associate Professor
Deputy Director, Prevention Research Center
Emory University, Rollins School of Public Health
Department of Behavioral Sciences and Health Education
1518 Clifton Road NE
Atlanta, GA 30322
404.712.9957
mkegler@sph.emory.edu

For Further Reading:

Kegler, M. C., and L. H. Malcoe. 2004. Results from a lay health advisor intervention to prevent lead poisoning among rural Native American children. *American Journal of Public Health* 94(10):1730–35.

Kegler, M. C., R. Stern, S. Whitecrow-Ollis, and L. H. Malcoe. 2003. Assessing lay health advisor activity in an intervention to prevent lead poisoning among Native American children. *Health Promotion Practice* 4(2):189–96.

Petersen, D., M. Minkler, V. Breckwich Vásquez, M. C. Kegler, L. H. Malcoe, and S. Whitecrow. 2007. Using community-based participatory research to shape policy and prevent lead exposure among Native children. *Progress in Community Health Partnerships* 1:249–56.

Singer, H., and M. C. Kegler. 2004. Assessing interorganizational networks as a dimension of community capacity: Illustrations from a community intervention to prevent lead poisoning. *Health Education and Behavior* 31(6):808–21.

"[The campaign's success] was a combination of good, solid, strategic community organizing backed by hard data they collected to substantiate the claim regarding the need for redistribution of funds." —Academic Partner

Case Study #7:

Improving school conditions by changing public policy in South Los Angeles:

The Community Coalition Partnership

With an estimated 694,000 students in a public school system second in size only to New York City's, Los Angeles, California, has long faced gross disparities in the physical environments in which youth receive an education (1). This disparity has rarely been more apparent than in a dramatic CBPR effort in the late 1990s to study and bring attention to the deplorable condition of schools in South Los Angeles, and the fact that a large, newly passed school bond would likely exacerbate the disparities between affluent and poor neighborhood schools.

Bordered on two sides by freeways and home to more than half a million people, South Central LA (now called South Los Angeles or South LA) is perhaps best known for civil unrest in the spring of 1992, following the acquittal of white police officers in the racially charged Rodney King beating case. The court's decision sparked the looting and burning down of some 200 of the area's 728 liquor stores (2). This tragedy also created a valuable opportunity for a community-based organization that had been established two years earlier to address alcohol and drug problems and to effect policy change in South LA through grassroots community organizing.

The Community Coalition for Substance Abuse Prevention and Treatment, or CCSAPT (now known simply as the Community Coalition), began the "Campaign to Rebuild South Central LA without Liquor Stores," which in turn was credited with preventing the rebuilding of 150 alcohol outlets and helping spur the conversion of 44 liquor outlets to community-friendly businesses such as laundromats. Most of these continue to thrive today (2). The campaign also helped establish the Community Coalition as a powerful voice for health-promoting public policy. Now boasting 5,000 dues-paying members, the Community Coalition frequently has combined CBPR with grassroots organizing to achieve larger policy change objectives (3). The successful Coalition-led campaign to study conditions in South LA schools and to get $153 million—most of it from a recent school bond—reallocated for repairs and other improvements in South LA schools exemplifies these efforts (4).

The Partnership: Since its founding in 1990, the Community Coalition has worked closely with an evaluation team at Imoyase Research Group Inc., a nonprofit program evaluation and consultation organization, and its CEO/founder, a professor of psychology at Loyola Marymount University. Community-based participatory research has been a central part of the partnership's mode of operation, with "community-driven research" described by the Coalition and its academic partners as central to the success of their collaborative work. The partners also share a commitment to youth development and empowerment, and the Coalition's youth group, South Central Youth Empowered through Action (SC-YEA), has played a key role in several partnership efforts.

Research Methods: The Community Coalition partnership has used a variety of research methods, including randomly sampled, door-to-door neighborhood needs assessments; GIS mapping; and secondary data analysis. The schools improvement project involved a survey administered by SC-YEA youth to 1,500 public school students, focus groups with parents, and a modified Photovoice project (5). As part of the data collection process, 60 students were given inexpensive cameras to document

"I think they have altered the process of decision making. When [policymakers] get ready to do things they say, 'What do you think the Coalition is going to say? Maybe we should run this by [the Coalition].'" —Academic Partner

risks in the school environment. The students then discussed the photos and selected pictures for later use in policy action (6). Taking advantage of the opportunity provided by a recently passed school bond measure, Proposition BB, in-house, policy-focused research was conducted as well to understand key city and state agencies responsible for implementing the legislation and the policy environment in which it would be implemented.

Findings: The survey of 1,500 teens was expected to identify racism, the quality of education, and teacher-student relationships as key areas of student concern. Instead, by far the greatest issue identified was the physical condition of the schools, many of which had leaky roofs and bathrooms with nonfunctioning sinks and toilets. In one high school, a single working toilet served the entire student body of 3,000. The "Photovoice" project, which produced more than 200 pictures, vividly portrayed many of these problems—overflowing toilets, exposed wires, missing cement tiles, and corroded water fountains (6). The youth conducted additional research in the schools and developed a detailed list of plant and grounds problems.

Lastly, the partnership's policy research revealed that, while most of the Proposition BB money had been allocated for air conditioning in the wealthier San Fernando Valley schools (leading critics to dub the measure "Proposition AC"), the small amount set aside for inner-city schools was earmarked mainly for security guards and window bars.

Getting to Action: Soon after the data-gathering phase of the project, the partnership used its findings to create public and policymaker awareness of twin issues: the terrible condition of South LA schools and the grossly inequitable resource distribution under the new school bond measure. Many of the 200 pictures from the SC-YEA Photovoice project were displayed as part of a demonstration at a meeting of the school district's oversight committee. In the words of a local political figure overseeing the meeting, "The students were very effective. They were angry, but they didn't come across as angry. They created a presentation, and they did it very respectfully" (4).

Since part of the Coalition's strategy was, in the words of a journalist, "to shame the school district into doing the right thing," the group reached out to the media by writing numerous press releases and arranging school "walk-arounds" for a *Los Angeles Times* columnist accompanied by SC-YEA students. The Photovoice project garnered national coverage of the issue when it was featured in *People* magazine (6). Numerous meetings with government officials or staffers were held to share study findings and advocate for change. Coalition staff and SC-YEA youth testified more than a dozen times at hearings and committee and school board meetings.

The Coalition and its partners' policy advocacy was effective in part because of the careful preparatory research that preceded it. They consequently did a careful mapping of the policy environment, along with key players and pressure points. Although the academic partners' role was less visible in the policy advocacy aspects of the work, they held trainings for Coalition staff and youth members throughout the process, participated in a detailed strategic planning process, collected needed policy-related information that was sometimes difficult for community partners to gather, and used a detailed archiving system to compile relevant information from newspapers and other sources. The academic partners also worked with the Coalition to develop short-, middle-, and long-term goals to guide the organization's future work.

Policy Change Outcomes: The Coalition and its partners' documentation of the deteriorating conditions in South LA schools, together with their background research on the planned use of Proposition BB monies, effective organizing, and media and policy advocacy, was widely credited with the reopening of repair and construction contracts made in conjunction with the $2.4 billion bond. Roughly $100 million was reallocated for repairs in schools in South LA and other inner-city neighborhoods, supplemented by $153 million from other sources. Media accounts and local political figures cited the role of the Coalition and teenagers involved in the partnership's project as having played a major role in bringing about this investment (5). Approximately 1,800 repairs

"[The Coalition] did a lot of investigative work to understand who the key players were in the process, where there were points of potential impact from a policy perspective, [and] what needed to be done both from an organizing standpoint and from a research standpoint to make some type of inroad into that pressure point." —Academic Partner

were made to address the problems brought to light by the Coalition study. These efforts in turn helped lay the groundwork for a subsequent bond measure and a successful lawsuit that brought $750 million to low-income communities in and around Los Angeles for new school construction.

The Coalition's victories also contributed to youth empowerment. In the words of one SC-YEA participant, "For us to go down there and protest and talk to people…the Community Coalition showed me I can make a difference around my neighborhood."

The school district also made changes in its operating procedures in the wake of the campaign, hosting an annual gathering of hundreds of interested students and also regularly having students present their concerns at school board meetings (3). In the end, the successful schools campaign enhanced the perception of the Coalition as a major player in the local political arena. As one observer commented, "When [policymakers] get ready to do things, they ask, 'What do you think the Coalition is going to say? Maybe we should run this by the Coalition.'"

Barriers and Success Factors: The Coalition's work was not without obstacles. "Publicly available" information (e.g., municipal budget allocations) was sometimes withheld from the community partner despite repeated efforts to obtain it; sometimes access to information required the intervention of the academic partner. Several students involved in exposing poor conditions at their school faced retaliation by their principal, and in one case, a senior's transcripts were held up, potentially jeopardizing his admission to college. Although adult intervention ended this standoff in the student's favor, the incident was a reminder of the personal obstacles that may be confronted in such work.

Counterbalancing such challenges, however, was the very visible and powerful role of the Coalition, its history of success on important community-driven issues (2, 7), its large membership base, and increasingly, its youth program. Several policymakers, prominent business leaders, and the mass media commented on the significant role of the SC-YEA youth in the budget reallocation decision and the school improvements that followed (4). Regular youth involvement at city council meetings and in other venues and the Coalition's adept use of media advocacy also contributed to the group's success.

Summary Reflections: Education and school quality have strong links to health, with recent studies suggesting that education is indeed even more important than income as a contributor to adverse health outcomes, including lower life expectancy (8). The Community Coalition's efforts to improve the deteriorating South LA schools for and with youth helped improve the physical environments in which children grow up and learn, in the process improving their chances for leading healthy and productive lives.

The Coalition continues to work in a variety of areas, from kinship care policy through land use to social services delivery, welfare reform, and community economic development. Further, and as a testament, in part, to its broad base of community support, the organization's former executive director, Karen Bass, stepped down to run for State Assembly—and was elected by a wide margin in November 2004. Assemblywoman Bass, who went on to become the first African American woman Speaker of the House in 2008, stated that her decision to run for public office signaled not only her belief in the strength and sustainability of the Coalition, but also in the need to provide another avenue for the organization and the broader community to have access to power and to keep lawmakers' "feet to the fire" in being responsive to their base.

Contact Information:

Marqueece Harris-Dawson
Executive Director
Community Coalition
8101 S. Vermont Avenue
Los Angeles, CA 90044
323.750.9087
marqueece@southla.org

Cheryl Grills, PhD
Professor
Loyola Marymount University
University Hall 4747
310.338.3016
cgrills@lmu.edu

"The [Coalition] wanted to be a player at the table…in order to ensure that the community voice was part of any discourse on issues that would impact the community. I think they have accomplished that." —Academic Partner

For Further Reading:

Foege, A., and V. Sheff-Cahan. 1999. Picture imperfect. *People*, November 29.

Lopez-Garza, M. 2001. *State of South Los Angeles 1990–2010: A Community Coalition Perspective*. Los Angeles: Community Coalition.

Saurwein, K., and K. A. Haynes. 1999. Schools have no trouble identifying the LA school district's most pressing problems. *Los Angeles Times*, October 15, p. 2.

Case Study #8:

Making the Healthy Choice the Easy Choice:

A Healthy Communities CBPR Partnership in New Castle, Indiana

Best known for many years as a center of automobile parts manufacturing, New Castle, Indiana, is a rural community that experienced economic hardships with the declines in the American automobile industry. However, New Castle also "has a history of helping itself and using the resources available" (1). This attitude is reflected in its formation, 25 years ago, of a Healthy Cities Committee (HCC). Part of a statewide Healthy Cities initiative, the HCC was designed to promote the health of the town through multisectoral collaboration. With representatives from health and social services, government, business, the arts, environmental concerns, the media, and transportation, as well as ordinary citizens, the HCC attempted to build on local assets to address shared health problems in ways that were tailored to the local community.

The Partnership: In the mid-1990s, funded through an initial grant from the W. K. Kellogg Foundation, the HCC began a community-based participatory research collaboration with four faculty members at

"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?" —Academic Partner

the Indiana University School of Nursing. 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 the town's decision makers and the general public to think about the potential health impacts of any policies or programs being considered. Rather than crafting specific policy goals, the partnership hoped to undertake research and action that would help catalyze a host of "small p" policy changes that didn't necessarily require legislative change but would still broadly and cumulatively improve the health of the community.

Research Methods: The academic partner conducted secondary analysis of Census data to compare New Castle's morbidity and mortality rates and other health indicators to national figures. A door-to-door survey then was distributed to 1,000 households identified through non-probability quota sampling. HCC members helped with the wording of survey questions, data collection, and interpretation and use of findings. The partners presented findings at town hall meetings and sought community input on the meaning and significance of the survey and Census data analyses. A follow-up survey two years later used many of the same questions, and an additional survey of sixth and 11th graders was undertaken to involve young people in the process. To help build capacity as well as broadly disseminate study findings, focus groups and a statewide workshop were held with sessions on data interpretation, priority setting, and policy-structured actions (1, 2).

Findings: The survey of close to 500 residents revealed a troubling portrait of health problems and unhealthy behaviors in New Castle, including high rates of smoking (32.2 percent—twice the National Health Promotion Objective of below 15 percent)—and unhealthy dietary choices. While study participants scored well in a few areas (e.g., 36.6 percent reported regular and vigorous exercise), considerable room for improvement was apparent. Almost 27 percent of study participants reported getting no regular exercise, close to 40 percent failed to seek medical care when needed because of the cost, and many people reported depressive symptoms. Finally, Census data analysis showed New Castle's rates of cancer, heart disease, and stroke to be above the national average. After the survey and public discussion of its findings, the academic partner commented that "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."

Getting to Action: Based on their discussion of the findings and insider knowledge of other health issues of importance to the community, HCC took the lead in identifying five priority health issues for action (1). To reduce smoking rates, it led a successful effort to get an ordinance banning indoor smoking in public buildings. To promote children's exercise in a safe environment, HCC mobilized 1,200 residents who, with support from the Department of Parks and Recreation, worked for seven eight-hour days to replace a deteriorating play structure and build a beautiful new park. The community partner (later renamed Healthy Communities of Henry County, or HCHC) also played a major role in a comprehensive land use planning effort, including an ambitious plan, supported in part by a new food and beverage tax, to build a "web of trails" crisscrossing the county (3) to encourage walking and biking.

In each of these efforts, the partners did their homework. With respect to the anti-smoking ordinance, for example, they moved incrementally, considering "what would work in our idiosyncratic community." And before mounting the web of trails initiative, HCHC members studied a similar effort in Ohio to learn from that experience.

Policy Change Outcomes: In addition to successfully advocating for the indoor smoking ban, the partnership raised $950,000 from the state Department of Transportation and other government grants, totaling more than$1.3 million in support of the trails initiative. Under the leadership of the HCHC, town residents have planted more than 5,000 trees along the trails and other locations to help improve air quality and promote outdoor activity (2, 3).

"Getting teenage boys to a city council meeting; to care what mayor got elected this year; to care what was happening at the city council…that was engaging citizens. I think it is so much a part of healthy communities." —Community Partner

Barriers and Success Factors: The difficulties inherent in getting change in environments like New Castle were well summarized by one partner who remarked, "In Indiana, you can't tell people what to do. That's why we have no motorcycle helmet law." Geographic factors also proved challenging, with the academic partner taking a job at a considerable distance from New Castle soon after the research project had been completed. The community partner operated on a very small budget, with no paid staff for most of the time this work took place. Finally, and inevitably, not all of the action efforts succeeded, causing some discouragement among people who had worked hard on these issues. An attempt to get a new skate park in an area favored by local teenage boys failed to pass the city council despite a large turnout and the active engagement of a number of the town's youth.

On the positive side, a strong sense of community and the fact that much work "happens informally" in a town this size were major contributors to project success. Strong awareness and appreciation of the community partner and its work also were evident, with elected officials, the media, and others pointing to the role of the HCHC, and its early community-academic partnership, in catalyzing health-promoting legislation and action that may lead to improved health outcomes down the line. Perhaps as important, these efforts have led to a more engaged citizenry. In recounting the effort to get approval for the skate park, for example, a community 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."

Summary Reflections: The New Castle case study offers a fascinating example of the kind of sustainable change that can take place long after an official community-academic partnership has completed its work. Although most of the action outcomes described fall under the heading of "small p" policy changes, the HCHC has clearly been effective in working with other community members and to get government entities to make or support changes conducive to health. More than a decade after the original community-academic partnership completed its formal work, the action component of this effort continues to thrive.

Contact Information:

Doug Mathis, Administrator
Henry County Health Department
1201 Race Street, Suite 208
New Castle, IN 47362
765.521.7060
dmathis@henryco.net

Joanne Rains Warner, PhD
Dean, School of Nursing
University of Portland
5000 N. Willamette Boulevard
Portland, OR 97203
503.943.7509
warner@up.edu

For Further Reading:

Minkler, M., V. Breckwich Vásquez, J. Warner, H. Steussey, and S. Facente. 2006. Sowing the seeds for sustainable change: A community-university research and action partnership in Indiana and its aftermath. *Health Promotion International* 21(4):293–300.

Rains, J. W., and D. W. Ray. 1995. Participatory action research for community health promotion. *Public Health Nursing* 12:256–61.

"We met with the mayor. He tried to meet with us once a month, which I think was a good thing, an important one because from the get-go you feel you are actually important." —Youth Participant

Case Study #9:

Empowering New Mexico's Young People in Public Policymaking:

Youth Link and Masters in Public Health Program, University of New Mexico

New Mexico is a highly diverse state where two-thirds of counties are rural and more than half the population lives in underserved communities of color, principally Hispanic (44 percent) and Native American (9.7 percent) (1). Ranked 40th among states in per capita income, almost 14 percent of New Mexico's people live in poverty, and 21.5 percent have no health insurance (2, 3). Arrest rates for driving while intoxicated (DWI) and for teenage pregnancy are also among the highest in the country.

Over the past 14 years, members of the statewide Youth Link leadership program have identified drunk driving, teenage pregnancy, and poverty, along with tobacco and substance abuse, violence, crime, youth-police relations, gangs, and other school-related problems, as key concerns to the state's youth. While youth voices often remain unheard or unrepresented in important policy decisions and processes, Youth Link participants have helped to change this culture in New Mexico. The program's young people have taken part in policy advocacy trainings, conducted research, and influenced state and local policies to improve their communities and promote youth health across the state.

The Partnership: Youth Link began in 1994 with funding from the W. K. Kellogg Foundation, establishing 14 youth Community Action Teams (CATs) representing New Mexico's diverse communities of youth ages 12–21 and focused on issues of key concern to local youth. Although the number of CATs was later reduced to just four because of a funding hiatus and changes from foundation to public funding, the organization of a statewide Youth Town Hall had already enabled Youth Link to establish itself. In its role as a statewide leadership program, it aims to help youth become "active, aware, and concerned citizens who are engaged in the political process" and mobilized around state and local policy issues, with a recent focus on tobacco control and violence prevention (4).

During its first few years of operation, Youth Link was engaged with academic partners at the University of New Mexico's Masters in Public Health Program in an in-depth participatory evaluation that focused both on youth capacity building and empowerment and on policy outcomes on the state and local levels. That seven-year multi-method evaluation, along with subsequent tracking of the project's policy-focused research and accomplishments, offered an excellent window into the processes and outcomes of this unique statewide program and its academic partnership. In the form of CBPR known as participatory evaluation, the academically trained evaluator acts as a coach, mentor, and facilitator in helping community partners think through their goals and objectives, including policy goals and objectives; identify and build their skills and capacities (e.g., in public speaking and strategic planning); and use these to help carry out research and action plans. In Youth Link, UNM worked collaboratively with program staff to develop the overarching evaluation logic model (a conceptual model showing how an intervention is expected to achieve desired outcomes), and coached the CATs to develop their own goals and objectives. At annual retreats

"The community began seeing these young people as positive forces instead of just being the problem. They could see these young people out there creating a solution for themselves instead of just asking for people to do something for them."
—Community Partner

and statewide training sessions, the participating CATs engaged with the academic partner in collaborative analysis and evaluation of their and the partnership's effectiveness in achieving their goals and objectives to reflect on their successes and challenges and to develop the next year's plans.

Research Methods: With the assistance of adult volunteer coordinators, the CATs researched their communities' problems and met in regional trainings and statewide gatherings to analyze policy issues that affected New Mexican youth. The CATs began by conducting focus groups with their peers to identify the priority issues facing New Mexico's young people. Additional policy-focused needs assessment data were collected through the three-day town hall that followed, and in which 145 youth and 20 adults participated (5). Youth Link members conducted secondary analysis of KIDS Count Data and data from the state Department of Health. They have also developed, implemented, and analyzed surveys over the years to better understand the concerns of youth as well as of businesses and other community members.

The participatory evaluation that was central to Youth Link's work in the early years of the project explored three levels of program effectiveness: changes in the political efficacy and civic behaviors of youth participants, capacity changes in the CATs to engage their communities, and policy impacts at the local and state levels. Multiple evaluation methods were used to assess the research question of how this Youth Link model could create policy change, through empowering youth in policy advocacy processes. A detailed evaluation instrument was developed by program staff, youth, and their academic partners and used to survey youth members at the beginning of the program and after two years. Other evaluation activities included annual focus groups with Youth Link CAT participants, adult interviews of local CAT mentors, review of project documents, and tracking of program accomplishments at the annual retreats (6).

Findings: Youth Link's regional focus groups highlighted a number of issues about which New Mexico's youth were particularly concerned, among them substance abuse, violence, crime, gangs, school issues, and teen pregnancy. The focus groups also probed perceived root causes of these problems, including racism and discrimination, lack of adult support and role models, poor environments and poverty, youth self-esteem, and relationship violence. These findings were corroborated at the statewide Youth Town Hall meeting that took place at the end of year two, and at which participants developed a series of recommendations based on their findings.

Participatory evaluation with the academic partner pointed to the importance of the Youth Town Hall as a catalyzing experience for youth policy action; the role of supportive adults; the creation of a state-level group identity; and education in policy skills. Youth Link participants experienced an increase in their sense of efficacy, community, voice, and leadership and demonstrated greater levels of involvement in political processes.

Getting to Action: At the end of the second year, youth facilitators from the Albuquerque CAT led a three-day residential Youth Town Hall, whose outcomes framed Youth Link's policy and action agenda for the next several years. The youth identified several action areas on which they wanted to work for policy and other systems change: increased youth presence on school boards; reform of suspension and expulsion policies; increased condom distribution in schools; more drug-, alcohol-, and tobacco-free alternative activities; and a lowering of the voting age to 16.

To translate their recommendations into action, several CATs developed "study bills" or memorials for the state legislature, formally requesting, for example, that the health department be charged with studying the relationship between school sex education and teen pregnancy rates. Also at the state level, Youth Link worked both one-on-one and in testimony before the legislature to educate elected officials on the importance of maintaining funding levels for youth prevention programs that were being threatened by budget cuts.

In addition to working within their own statewide network, the Youth Link partnership was actively involved in numerous youth and issue coalitions,

"Youth are so often disenfranchised, and this program created opportunities for them, with the aid of supportive adults, to find and study their issues, come up with policy objectives, work for those objectives, and have their voices heard by policymakers."
—Academic Partner

including Youth Empowerment Advocacy Heroes (YEAH! Coalition), for which it publishes a semi-annual newsletter that covers the policy and service activities of coalition groups across the state (4). Through this collaborative work and its own efforts to educate legislators and work for municipal and state level changes, it helped achieve a number of impressive victories.

Policy Change Outcomes: On the local level, Youth Link CATs and their partners helped get a citywide smoke-free ordinance in Albuquerque and restrictions on tobacco product placement in Santa Fe. In Las Cruces, Youth Link members were similarly instrumental in persuading the mayor's office to support the public funding of a skate park. On the state level, one of the three memorials put forward (requesting research on alternatives to student suspension and expulsion and their effects on dropout rates), was commissioned and conducted, and Youth Link was credited with playing a major role in the decision (5, 7). Additionally, the partnership has helped get bills introduced before the legislature on a range of issues, including teen DWI offenders, restrictions on tobacco, homeless youth resources, gun safety, suicide prevention, and school safety. In 2006, Youth Link and coalition partners experienced a major win in getting a statewide ban passed on smoking in indoor workplaces and public spaces (4).

Barriers and Success Factors: The sheer logistics of coordinating a statewide effort in a largely rural state, particularly when the project is youth driven, posed substantial challenges to Youth Link and its academic partners and adult allies. Turnover of youth and adult program staff and mentors also led to some discontinuities and setbacks (5–7). Finally, a substantial cut in funding after the first few years, coupled with the categorical nature of new state funding, circumscribed somewhat the areas in which the partnership could focus. However, substantial early foundation funding—including support for an evaluator/coach who could work closely with the youth over several years and engage them in participatory evaluation from the outset—greatly contributed to the partnership's ability to receive continuous feedback, track impacts, and help attract additional funding. The interest, commitment, and leadership skills of a core group of youth in diverse parts of the state were also of seminal importance to the project's success, as were a number of adult allies and mentors and supportive policymakers.

Summary Reflections: Now entering its 15th year, Youth Link is viewed by policymakers as a key partner in developing youth policy. Although its funding today somewhat restricts the policy areas in which it can focus (e.g., tobacco and substance abuse prevention), the statewide leadership organization continues to thrive and provide new training opportunities for members.

Youth Link today has member groups in 46 communities across the state (4). Some youth participants have become well-known at the capital and take pride in the fact that state legislators call them by name. Lessons from the Youth Link experience include the central roles played by adult allies, youth dialogue and reflection, and measurement of youth political development as well as policy outcomes. With the impressive gains in collective and political efficacy among participating youth and substantial policy successes, Youth Link is well on its way to developing the "next generation of advocates" for New Mexico.

Contact Information:

Kwaka Sraha, BA,
Program Manager
Youth Link
New Mexico Voices
for Children
2340 Alamo Road SE, #120
Albuquerque, NM 87106
505.244.9505 x20
ksraha@nmvoices.org

Nina Wallerstein, DrPH, MPH
Director, Center for
Participatory Research and
Professor, MPH Program
Department of Family and
Community Medicine
University of New Mexico
Health Sciences Ctr.
MSC09 5040
1 University of New Mexico
Albuquerque, NM 87131
505.272.4173
nwallerstein@salud.unm.edu

"I think I would attribute the success [of the Harlem Community and Academic Partnership] to tenacious people who really care about this issue." —Academic Partner

For Further Reading:

Springett, J., and N. Wallerstein. 2008. Issues in Participatory Evaluation. In *Community-Based Participatory Research for Health: From Process to Outcomes, 2nd Edition*, eds. M. Minkler and N. Wallenstein. San Francisco: Jossey-Bass.

Wallerstein, N. 2002. Empowerment to reduce health disparities. *Scandinavian Journal of Public Health* 30:72–77.

Case Study #10

Reintegrating Drug Users Leaving Jail and Prison:
Harlem Community and Academic Partnership

The communities of Central and East Harlem have been deeply affected by the reintegration of community members who have served time in jail or prison. An estimated 6,000 to 7,500 inmates are released back into these communities every year, and half of them are re-incarcerated within a year (1). The intersection of reentry issues with substance abuse—the long-time focus of the Harlem Urban Research Center (URC)—led its Policy Work Group (PWG) to identify reintegration of drug users after incarceration as a priority concern. Reflecting on barriers to reintegration and their connections to larger issues of poverty, unemployment, addiction, education, and mental health, the PWG undertook a broader policy approach to address these deeper problems. The group, now called the Harlem Community and Academic Partnership, reframed the issue of reentry in a public health light and focused on changing harmful policies and developing programs to support successful reintegration and prevent re-incarceration (1, 2).

The Partnership: In 1996, the Center for Urban Epidemiological Studies (CUES) in New York received a CDC Urban Research Center grant that supported the development of "innovative strategies to improve the health of urban and

"By moving from the individual and community to the municipal policy level, we have been able to make jail reentry a policy issue in New York, if not on the front burner then at least in the middle of the stove rather than way back."
—Academic Partner

low-income populations." Eventually renamed the Harlem Urban Research Center and more recently, the Harlem Community and Academic Partnership (HCAP), it was composed of partner organizations including the New York City Department of Health, the New York Academy of Medicine (NYAM), and a Community Action Board (CAB) with representatives from local service providers, city health organizations, advocacy groups, and residents.

When the grant was first awarded, CUES' academic and health department partners had few connections to the Harlem community. However, as the group's leadership evolved and through the development and subsequent activism of the CAB, the collaboration adopted a CBPR partnership approach and decided to focus on substance abuse in the Harlem community. To ensure that the partnership's research was translated into action, the CAB developed its own PWG. After extensive research and reflection on substance abuse and related issues, the PWG decided to focus on reintegrating former inmates into the community. Although the PWG was defunded in 2004, it has continued to meet and help translate its findings into changes in programs, practices, and policies.

Research Methods: The PWG and URC went through several phases of research and planning to identify the problem and define their focus for policy change. The PWG conducted a review of the literature and media coverage and undertook secondary analysis of public data on substance use and incarceration. The PWG also gathered background information from CAB members and policy experts to understand the issue from lay and policy perspectives. Next, the PWG conducted focus groups with 36 substance users and former inmates and a survey of 79 substance abuse service providers. This research revealed key policies and release procedures that could be targeted for change. Later, the PWG used public opinion research, adding a question on reentry to an existing poll of New York City residents (3).

Findings: Focus groups with former inmates suggested that people leaving jail or prison were not adequately prepared for release or provided with the necessary support to reenter their communities as healthy and productive members of society. The service provider survey revealed consensus on the positive and negative effects of specific policies affecting substance users and inmates. More than half of the participating providers pointed to 11 policies they believed harmed their clients. These policies involved drug treatment, correctional system processes, and Medicaid benefits. The PWG's other research approaches also provided greater understanding of health issues; incarceration trends; the legal requirements in providing services and benefits to former inmates; the state of public opinion on reintegration; and the willingness of policymakers to support the PWG's policy goals (1, 2).

Getting to Action: Through community forums and facilitated discussions with community members and other stakeholders, the PWG shared its findings, reinforcing strong community interest in reintegration and helping the partnership hone its goals and policy targets. The PWG reframed substance abuse and inmate reentry as a public health issue and brought together a broader citywide coalition, the Community Reintegration Network (CRN), which pushed for action from the New York City Council and the mayor.

Because much effective policy work requires addressing funding, the PWG advocated for and used a cost study from the city government to better understand the public finance of incarceration. The findings from this study allowed the PWG to argue that the city would save money by providing better support for inmate reintegration.

Partnership members used their data and the city's findings to discuss potential cost savings and promote their proposals. By speaking at city council hearings, producing and distributing policy reports, and developing 12 key recommendations for change, the PWG and its allies made a strong case for realistic and doable changes in programs, policies, and practices.

Policy Change Outcomes: The Policy Work Group and the Community Reintegration Network it helped create are credited with having played a major role in several key victories. They were

"This was the first time reentry and health-related consequences had been put together. It was definitely a unique perspective and a more comprehensive perspective. They (HCAP) have in-depth knowledge of the issue. They knew the system and what was going on. They offered recommendations on how to fix it." —City Council Member

instrumental in persuading the Department of Correction to release many more inmates during daylight hours rather than at 3:00a.m. and offering people leaving jail "a bus ride to a drug treatment, housing, or employment program rather than release in a subway stop frequented by drug dealers, prostitutes, and a Dunkin' Donuts outlet" (3). The PWG indeed played a key role in helping to get a 2004 law requiring the department to provide discharge planning services to people leaving New York City jails. Additional provisions enacted the following year expanded services to assist people leaving jail to find housing, drug treatment, and employment; the provisions also allocated city funds to community organizations to provide these services. Despite inadequate funding, advocates believed the law set an important precedent.

Finally, the PWG figured prominently in helping secure the passage of a bill by the New York State Legislature that reinstated Medicaid coverage to inmates upon their release, replacing the previous policy that terminated benefits upon incarceration. Representatives of the Policy Work Group and the CRN have remained active as part of a three-year municipal Strategic Planning Initiative and in other ways continue to work for policy and practice changes that can make a difference in improving the odds for recently released inmates to return successfully—and lead full and productive lives in the community.

Barriers and Success Factors: Federal budget cuts, which resulted in defunding the Harlem URC and its Policy Work Group in 2004, posed a strong challenge to the partnership since several of the project's policy goals and activities had yet to come to fruition. However, these funding constraints were counterbalanced by the group's commitment to continuing to meet and work, as well as by individuals and partner institutions donating time, space, and supplies. Finally, the partnership benefited from external pressures. For example, banking giant Citibank, which wanted to redevelop the area where inmates were traditionally released, also pressured the city to change to daylight release, as a means of enabling the former inmates to more easily disperse to other parts of the community.

Summary Reflections: As previously suggested, the PWG and Harlem URC's impressive research and policy accomplishments are all the more notable because many were achieved after formal funding had ended. When asked how they were able to sustain their partnership efforts, participants responded that they believed in the work, lived in Harlem, cared about one another, and supported the process and long-term goals of the group. Their work provides a good example of the need for committing to CBPR efforts over the long haul, often beyond a budgeted project period, if the goal is to effect policy and systems change. This case study, however, also is a reminder of the need to forge untraditional alliances in policy-focused work.

Contact Information:

Ann-Gel S. Palermo, MPH
Associate Director
of Operations
Center for Multicultural
& Community Affairs
Mount Sinai School
of Medicine
1 Gustave Levy
Place - Box 1035
New York, NY 10029
212.241.8886
ann-gel.palermo@mssm.edu

Nicholas Freudenberg,DrPH
Distinguished Professor
of Urban Public Health
Hunter College/City
University of New York
425 East 25th Street,
New York, NY 10010
212.481.4363
nfreuden@hunter.cuny.edu

For Further Reading:

Freudenberg, N., M. A. Rogers, C. Ritas, and M. Nerney. 2005. Policy analysis and advocacy: An approach to community-based participatory research. In *Methods in Community-Based Participatory Research for Health,* eds. B. A. Israel, E. Eng, A. J. Schulz, and E. A. Parker. San Francisco: Jossey-Bass.

van Olphen, J., N. Freudenberg, S. Galea, Ann-Gel Palermo, and C. Ritas. 2003. Advocating policies to promote community reintegration of drug users leaving jail: A case study of first steps in a policy change campaign guided by community-based participatory research. In *Community-Based Participatory Research for Health*, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.

Contributions of CBPR Partnerships to Promoting Healthy Public Policy: What Can (and Can't) We Conclude?

This monograph provided 10 illustrative case studies of community-based participatory research partnerships that appear to have contributed to policy- or systems-level change in their communities or regions. These outcomes ranged from helping to achieve a 75 percent reduction in allowable cancer risk from toxic emissions (in South Los Angeles) to reinstating Medicaid for prisoners in New York immediately after their release and helping ensure their release is during daylight hours rather than in the middle of the night.

The changes observed also included subtle victories, such as getting New Castle, Indiana, to enact a series of "small p" policy changes designed to promote a healthy community. Healthy Communities of Henry County used its CBPR study results and years of follow-up work to secure substantial funding and widespread political and community support for creating a web of walking and biking trails that would connect key points of interest in this sprawling rural community and promote physical fitness and environmental improvements.

Changes in the policy environment, including a change in the economy; the opening of a window of opportunity in the wake of a natural disaster or media exposé; or the election or appointment of a new policymaker or other key decision maker who shares the partnership's goals may greatly impact on the likelihood of a policy victory.

Additionally, the very nature of CBPR work, with its emphasis on building alliances and frequently working in coalition with numerous actors and stakeholders, makes singling out the role of the community, academic, or health department partnerships in helping to achieve a policy victory all but impossible. Although we have attempted in this monograph to highlight the ways in which CBPR partnerships appear to contribute to one or more policy or systems changes, we do so cautiously, underscoring in each case that we are *analyzing connections and contributions* and not *attributing contributions* to the partnership's efforts alone.

Our task in this regard was sometimes made more difficult by challenges faced in studying the partnership's potential contributions to policy change efforts. Among these challenges was the reluctance of some of those involved in partnerships to talk about their potential policy-level work, since federal or other funding was seen as precluding this type of work because of funding restrictions on lobbying. The media's tendency to single out one contributor (often a politician), together with the potential for over- (or under-) stating the partnership's role or give credit to a policymaker ally, further compounded the difficulty of analyzing contribution. Despite these difficulties, our multi-method investigation allowed us to conclude with some confidence that efforts highlighted by the 10 CBPR case studies did indeed play a substantial role in helping to promote healthy public policy or other systems-level change. Table 2 summarizes these varied policy and related outcomes to which the 10 partnerships contributed.

Table 2. Sample Policy and Related Outcomes in which the Partnerships Appear to Have Played a Substantial Role*

West Harlem Environmental Action (WE ACT)/Columbia Center for Children's Environmental Health

- Conversion of New York City bus fleet to clean diesel
- Establishment by the Environmental Protection Agency (EPA) of permanent air monitoring in Harlem and other "hot spots" locally and nationally
- Co-authoring and adoption of a statewide environmental justice policy

Concerned Citizens of Tillery/University of North Carolina School of Public Health

- Creation of the North Carolina Environmental Justice Network (NCEJN), which in turn helped re-invigorate a statewide environmental justice movement
- Through the NCEJN and drawing on study findings, passage and signing of a law in 2007 banning new hog facilities in the state and setting higher standards for waste treatment

Progress Center for Independent Living/Access Living/Departments of Disability Studies and Rehabilitation, University of Illinois, Chicago

- Passage of legislation and funding for a Senior Community Reintegration Program
- State reauthorization of a council to reassess the implementation of the Olmstead Act and to prepare a strategic plan for long-term care financing
- "Money follows the person" program provision funded in 2007 through a $55.7 million Phase I grant from the Centers for Medicare and Medicaid to the State of Illinois (CMS, 2007)

The Southern California Environmental Justice Collaborative (South Los Angeles)

- Revision of a regulation (Rule 1402) that tightened emission standards and lowered acceptable cancer risk levels from existing facilities by 75 percent
- Changing of policy language used by the California Environmental Protection Agency (Cal/EPA) from individual to cumulative risk exposure
- Spearheading an organized environmental justice movement in Southern California

Literacy for Environmental Justice (LEJ)/San Francisco Department of Public Health

- Adoption by several city agencies of a voluntary policy creating the Good Neighbor Program to provide incentives for corner stores that increase access to healthy foods and decrease shelf space for alcohol and tobacco products (four stores had become "good neighbors" by 2007, with five more slated to do so in 2008–09)
- Passage and signing of AB 2384 in 2006, modeled on the Good Neighbor Program (albeit without funding appropriation), to establish a statewide Healthy Food Purchase pilot program to improve the supply of healthy choices in small corner stores

Tribal Efforts against Lead (TEAL)/Partnership among eight local tribes with the University of Oklahoma, Emory University, and the University of New Mexico

- Full implementation of blood lead screening and parental notification for young children by the Ottawa County Health Department and the Indian Health Service
- Halting the use of mine tailings in construction and on roads without proper containment

The Community Coalition /Imoyase Research Group/Loyola Marymount University

- Reopening by the Los Angeles Unified School District (LAUSD) of repair and construction contracts granted by a $2.4 billion school bond (Proposition BB), resulting in redirection of $100 million in school bond monies from wealthier schools to those in South Los Angeles
- Allocation of $153 million in new funds for additional schools in South Los Angeles and other inner-city communities.
- Successful lawsuit resulting in $750 million for new school construction

Indiana University School of Nursing/Healthy Communities of Henry County (HCHC)

- Passage and implementation of a bill restricting indoor smoking in public places
- Securing local government funding and support for a large new playground on public land that was then built by community members
- Securing government funding and approvals for an initiative to develop a network of trails throughout the county, promoting physical activity and cleaner air

Youth Link/University of New Mexico/New Mexico Department of Health (DOH)

- Passage by state legislature of a study bill (called a memorial) requesting the investigation of suspension and expulsion policies and their effects on high-school dropout rates
- City support and funding for a skate park in Las Cruces, New Mexico
- Passage of a citywide smoke-free ordinance in Albuquerque and restrictions on tobacco product placement in Santa Fe, and ultimately passage of a statewide ban on smoking in indoor workplaces and public spaces

Harlem Community and Academic Partnership/ The Center for Urban Epidemiological Studies, Community Reintegration Network

- Passage of a bill before the New York State Legislature that reinstated Medicaid benefits to inmates upon their release, replacing a policy that terminated benefits upon incarceration
- Passage by the New York City Council of Local Law 54 mandating the Department of Correction to provide expanded discharge planning services to people leaving jail
- Department of Correction decision to begin releasing many more inmates during daylight hours than after midnight

*Please note that none of these victories was attributed solely to the partnerships.

Success Factors and Challenges Faced Across Sites

Success Factors across Sites

Many factors contributing to the success of the 10 case studies we examined were context specific and unique to the particular projects and partnerships examined. At the same time, several factors emerged in our cross-site analysis as facilitators of effective functioning and outcomes. These include:

- The presence of a strong, autonomous community partner organization prior to the development of the partnership
- A high level of mutual respect and trust among the partners, and an appreciation of the complementary skills and resources that each partner brought to the table
- Appreciation by all partners of the need for solid scientific data as a prerequisite for making the case for policy action
- Commitment to "doing your homework"—finding out what other communities have done, who holds decision-making authority, key leverage points, etc.
- Facility for and commitment to building strong collaborations and alliances with numerous and diverse stakeholders beyond the formal partnership
- Knowledge of and facility for attending to a variety of "steps" in the policy process, *whether or not the language of policy was spoken*

The last point in particular is worthy of note. Although many partnerships acknowledged that they needed to learn much more about the policymaking process, each also appeared to have a sense of the kinds of policy steps necessary, from reframing issues and policy goals to identifying policy targets, finding and using windows of opportunity, and effectively using the mass media to help carry their message and pressure for change.

Challenges Faced across Sites

Each partnership also faced unique challenges, grounded in the historical, political, economic, interpersonal, and other realities surrounding their research, organizing, and policy work. These challenges ranged from the strong opposition of powerful corporate interests (e.g., the hog industry in North Carolina and the nursing home lobby in Chicago) to problems posed by high staff turnover (Youth Link) and severe funding cutbacks mid-project (Harlem Community and Academic Partnership and Youth Link). In addition, several challenges were nearly universal, mentioned by all or most partnerships as having impeded their efforts to promote policy or systems change:

- Differences in the research timetable of the community and academic partners, with the former often anxious for a quicker execution of the data analysis and release of findings in the interests of using them to promote change. The tightrope walk involved in balancing what has been called "the necessary skepticism of science" with the "action imperative of communities" often came to mind in relation to this aspect of the work.
- Different perspectives on policy work held by academic/health department and community partners, with the latter often more clear from the outset about the need for and nature of policy goals and objectives
- Funding constraints and/or termination of funding or changes in sources of project support that in turn delayed or changed the nature of what could be studied and achieved
- Perceptions among partnership members that they lacked sufficient understanding of policymaking processes and avenues for systems change
- Difficulty talking in terms of policy goals and activities because of real or perceived funding prohibitions and constraints
- Difficulty measuring the longer-term impacts of project or policy change: who follows up when the money runs out?

Recommendations

The partnerships in this study were selected in part because of their perceived effects on health-promoting public policy. Based on their experiences and shared concerns, the following recommendations are offered to other CBPR partnerships interested in including a policy component in their work or increasing their effectiveness in advocacy.

1. **Build leadership and a strong base of support by being genuinely community driven: Start where the people are by having the community partner and its base determine the "hot-button" issue that needs to be studied—an issue they are committed to helping to research and to mobilize around.**

By inviting each partner to contribute ideas for potential studies with policy relevance, but giving its community partner veto power and the ultimate say on issues chosen, the Southern California Environmental Justice Collaborative well illustrated this principle. And so did New Mexico's statewide Youth Link organization, whose Community Action Teams used focus groups and surveys among youth to determine a range of desired place-based changes requiring either municipal action or statewide change (e.g., enacting a study bill to explore student suspension and expulsion policies and their impacts on high-school dropout rates). Although adult mentors and academic partners at the University of New Mexico played a key role as coaches and facilitators, it was the youth-driven nature of project decision making and issue selection that resulted in high level youth engagement in the organization's policy-focused work.

2. **Where possible, use a variety of research methods: Both people's stories (captured in qualitative data) and the facts and statistics that emerge from more quantitative approaches are needed for moving policymakers and effectively using the media. Different forms of data may help to reach different audiences.**

The Concerned Citizens of Tillery partnership in North Carolina used door-to-door surveys, ethnographic methods, water sampling and bacterial counts, and spatial analysis to demonstrate both the disproportionate prevalence of intensive livestock operations in poorer, largely African American communities and the negative health and quality-of-life outcomes for residents. The diverse audiences to which the partnership reached out, from county commissioners to the U. S. Department of Agriculture, and from local to national media, responded to different types of data, as well as to the combination of personal stories and "hard science" backing their claims and helping to effectively tailor the messages presented.

3. **Produce high-quality research that can stand up to careful scrutiny, but make results easily accessible and highlight their policy relevance: Policy briefs, short reports with pie charts and other graphics, and talking points, as well as "quotable quotes" from focus groups or interviews should all be made widely available to relevant audiences.**

The high-quality air monitoring data collected by WE ACT youth trained and supervised by epidemiologists at Columbia University produced results that merited publication in rigorous scientific journals. But their research also won the respect of policymakers and EPA officials, who in turn paid attention to the partnership's calls for permanent air monitoring in Harlem and other "hot spots" as well as other changes. At the same time, WE ACT's education and advocacy campaign, which featured easy-to-understand articles in the *Uptown Eye* newspaper, 75 bus shelter ads, and the sending of 10,000 postcards to the governor and the head of the Metropolitan Transit Authority, effectively told the story of residents choking on polluted air and WE ACT's policy change goals.

4. Use approaches and processes that reflect the local community culture and ways of doing things (even if it slows down the process).

The Tribal Efforts against Lead (TEAL) project in rural Oklahoma required that substantial time be spent up front to address the profound cultural differences between academic and community partners and to overcome the historical distrust of research that often is present in Indian Country. Making this time and showing respect for tribal culture and structure (e.g., by hiring indigenous Clan Mothers and Clan Fathers who visited Tribal Governments and urged them to pass resolutions supporting mandatory screening for lead) not only increased the local relevance of the work, but also resulted in tribal support. In turn, this support was critical in persuading the Indian Health Service to fully implement lead screening and reporting for young children.

5. Remember that "research" includes not only the partnership's original study of the problem but also subsequent investigation of the policy considerations involved: Community partners should be helped to research whether policy-level work is the best route for achieving the change they seek; who has the power to make the change(s) being sought; and what sorts of policy-relevant data need to be collected, from whom, and how (this is all part of "data collection").

West Harlem Environmental Action's staff indicate that they will literally map out the playing field, highlighting who has decision-making power, what policies they've supported, and what the impact of their prior policies have been on their neighborhood, their organization, and their allies. CBPR partners in Chicago studied what disability rights activists had done in other states to help bring about the kinds of systems-level changes they sought regarding community integration of people in nursing homes.

6. Make sure all partners, including academics, understand that advocacy is different from "lobbying": Gain an understanding of the advocacy activities allowed of nonprofit organizations, including universities and community partner organizations. And don't be surprised if this is more than you might expect.

When the opportunity opened for renegotiating a weak regional air quality rule governing allowable cancer risk, Communities for a Better Environment and its academic partners used their research findings to galvanize a regional coalition that could fight to change the regulation. Members of the partnership did door-to-door outreach, conducted Toxic Tours for policymakers, presented at hearings, and published a strategically timed op-ed piece in the *Los Angeles Times.* Could their activities be considered "lobbying?" To the extent that they were educating community members and policymakers about their research and potential ways to mitigate cancer risk, perhaps. But all of these activities were within the appropriate boundaries of nonprofit and academic institutions.

7. Decide on a policy goal and identify the relevant policy targets and change strategies, but always have at least one "Plan B," and be open to compromise.

The Literacy for Environmental Justice partnership in San Francisco's Bayview District at first explored crafting a city ordinance to promote their "Good Neighbor" concept, and then the idea of getting legislation that would make their neighborhood a "restricted use district" for incoming merchants. When neither option was deemed viable, however, the partnership turned to a third alternative—a voluntary policy targeted at local stores and involving working with merchants to improve food security. The Good Neighbor Program born of this third option had both legs and wings, taking off to become a model program involving several city departments and a growing number of local stores with promising results.

8. Build strong linkages with organizational allies and other stakeholders, and be strategic in your choice of partners. But remember that in policy work, as in community organizing, there are "no permanent enemies, no permanent allies." That means looking for allies in sectors to achieve your goals.

The WE ACT partnership well embodied this recommendation: members alternated between pressuring the Environmental Protection Agency to make changes and partnering with the agency as a strategic ally to achieve cleaner air in Northern Manhattan and other hot spots. In another example, the Harlem Community and Academic Partnership was surprised to find that a global corporation, Citibank, was pressuring officials for one of the changes *it* sought—namely, the release of prisoners during daylight hours rather than at 3:00 a.m.—albeit for entirely different motivations: The banking giant wanted the area where the prisoners were released to be safer and primed for redevelopment. Strange bedfellows can sometimes help leverage the pressure needed to help push for a mutually desired change.

9. Through training, Web-based tools, and other resources (see Appendix D), increase partners' understanding of the policymaking process and, as appropriate, of legal processes and issues. If possible, link early on with a "policy mentor" willing and able to help partners, including academic partners, understand and better navigate the policy process.

The partnership between two Centers for Independent Living (CILs) in Chicago and their academic partners at the University of Illinois clearly benefited from its broad network of existing disability rights activists, who then partnered with project "newcomers" in Social Action Groups and town hall meetings. In part through the effective involvement of more seasoned activists, the program helped nurture a new generation of disability rights mentors and advocates from among a highly marginalized population: disabled people in and transitioning out of nursing homes (see appendix D for a short list of relevant policy tools available on the Web, including former Harlem URC member Cassandra Ritas' booklet, *Speaking Truth, Creating Power*, written specifically for policy-focused CBPR partnerships).

10. Offer solutions to policymakers and decision makers, not just complaints: Have relevant research to show them why your solution is on target, practical, and affordable; include in your research information on the "wallet angle" to show the cost effectiveness of your proposed solution; and provide community support to advocate for change.

The Harlem Community and Academic Partnership's request for a study by the New York City's Independent Budget Office documenting the annual cost for one incarceration revealed this figure to be $92,500 in 2002—and made the *New York Times*. With additional data from a partnership member on the cost savings of one of the alternatives to incarceration programs the PWG supported, this information helped make a strong case for a new policy allocating funds for, and expanding, such alternative programs.

11. Plan for sustainability by seeking new funding streams, including those that actively support and encourage community-partnered research and action at the policy level.

Several of the partnerships reported new funding streams from foundations and other sources that actively supported policy-focused research and action and, in the process, provided freedom to pursue work that would link place-based efforts with local or regional policy advocacy. For both the

LEJ partnership in the Bayview and the Southern California EJ Collaborative in Los Angeles, generous new funding from The California Endowment allowed them to pursue their goals. Fundraising for even a small pot of unrestricted funds can be helpful, as can negotiating with funders for a broad interpretation of issue areas they support.

12. Enlist the university or the health department partner's media relations office to help write and widely disseminate press releases. But make sure community partners participate in decisions about content and timely use of such media and that any media advocacy is a well-thought-out part of a bigger plan and campaign.

In Tillery, North Carolina, partners utilized UNC's News Service, and a press release highlighting study findings was developed and disseminated in conjunction with a presentation of the findings at a national academic meeting. After the story was carried by several mass media outlets, partnership members presented the findings before the General Assembly's agriculture committee. Results of the health survey were reported to the state health department, which issued its own press statements. The large amount of local media coverage that followed, together with earlier exposure of the issue by the community partner on the TV news program, *60 Minutes*, helped bring broader attention to the issue. But a cardinal rule of effective policy-focused work is to engage the media strategically for the purposes of policy change (e.g., highlighting a *policy solution*) and not simply for broad "awareness" of the problem—a critical distinction. Community partners may be particularly helpful in getting media to cover not only the problem, but also community and partnership perspectives on what can be done about it.

13. Recognize that policy change takes a long time, and commit to staying involved over the long haul: Getting to policy change (and ensuring that a new measure or policy is in fact implemented) is likely to mean developing and implementing several strategies and working well beyond any funded grant period.

When federal budget cuts resulted in the termination of funding for the Harlem URC's Policy Work Group, the partnership faced major challenges, particularly because the cuts came before the project had achieved several policy goals and activities. Because of their deep commitment to the cause, however, members continued to meet with individuals and partner institutions and to donate time, meeting space, and supplies to pursue their objectives. Most of the impressive policy changes achieved by this group took place after funding ended. The Policy Work Group continues to meet and to study and advocate for new policies and practices that can ease community reentry among recently released inmates.

These recommendations are directed to CBPR partnerships themselves and were culled from the combined wisdom of the partnership members and policymakers interviewed for this project. Beyond these recommendations, however, increasing the ability of such partnerships to help promote policy-level changes will require increased institutional support in the form of federal and foundation funding. Such funding should specifically target CBPR partnerships focused on promoting healthy public policy and systems change to improve the public's health. Interested funders should also communicate to their grantees, and particularly those doing CBPR, both the value of working on the policy- and systems-change levels and the parameters around doing so where federal and foundation funding is concerned.

References Cited

Introduction

1. Minkler, M., and N. Wallerstein. 2008. Introduction to Community-Based Participatory Research: New Issues and Emphases. In *Community-Based Participatory Research for Health: From Process to Outcomes*, 2nd Edition, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.
2. Israel, B. A., E. Eng, A. J. Schulz, and E. A. Parker, eds. 2005. *Methods in Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass.
3. Israel, B. A., A. J. Schulz, E. A. Parker, and A. B. Becker. 1998. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health* 19:173–202.
4. Green, L. W., M. A. George, M. Daniel, C. J. Frankish, C. P. Herbert, W. R. Bowie, and M. O'Neill. 1995. Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada. Vancouver, British Columbia: Royal Society of Canada.
5. W. K. Kellogg Community Health Scholars Program. 2001. *Stories of Impact: Community Health Scholars Program*. Ann Arbor: University of Michigan.
6. Ritas, C. Speaking Truth, Creating Power: A Guide to Policy Work for Community-Based Participatory Research Practitioners. http://depts.washington.edu/ccph/pdf_files/ritas.pdf.
7. Morello-Frosch, M., M. Pastor, J. L. Sadd, C. Porras, and M. Prichard. 2005. Citizens, Science and Data Judo: Leveraging secondary data analysis to build a community-academic collaborative for environmental justice in southern California. In *Methods in Community-Based Participatory Research for Health*, eds. B. A. Israel et al. San Francisco: Jossey-Bass.
8. Themba-Nixon, M., M. Minkler, and N. Freudenberg. 2008. The Role of Community-Based Participatory Research in Policy Advocacy. In *Community-Based Participatory Research for Health: From Process to Outcomes*, 2nd Edition, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.
9. Minkler, M., V. Breckwich Vásquez, M. Tajik, and D. Petersen. 2008. Promoting Environmental Justice through Community-Based Participatory Research: The Role of Community and Partnership Capacity. *Health Education and Behavior* 35(1):119–37.

Addressing diesel bus pollution and its health consequences in Northern Manhattan, New York

1. Nicholas, S., B. Jean-Louis, B. Ortiz et al. 2005. Addressing the childhood asthma crisis in Harlem: the Harlem Children's Zone Asthma Initiative. *American Journal of Public Health* 95(2):245–9.
2. Perera, F., S. Illman, P. Kinney et al. 2002. The challenge of preventing environmentally related disease in young children: Community-based research in New York City. *Environmental Health Perspectives* 110(2):197–204.
3. Shepard, P., M. Northridge, S. Prakash et al. 2002. Preface: Advancing environmental justice through community-based participatory research. *Environmental Health Perspectives* 110(suppl 2):139–40.
4. Breckwich Vásquez, V., M. Minkler, and P. Shepard. 2006. Promoting Environmental Health Policy Through Community Based Participatory Research: A Case Study from Harlem, New York. *Journal of Urban Health* 83(1):101–10.
5. McClellan, R. 1987. Health effects of exposures to diesel exhaust particles. *Annual Review of Pharmaceutical Toxicology* 27:279–300.
6. Diaz-Sanchez, D. 1997. The role of diesel exhaust particles and their associated polyaromatic hydrocarbons in the induction of allergic airway disease. *Allergy* 52(suppl 38):52–56.
7. Kinney, P. L., M. Aggarwal, M. E. Northridge et al. 2000. Airborne concentrations of PM2.5 and diesel exhaust particles on Harlem sidewalks: A community-based pilot study. *Environmental Health Perspectives* 108:213–18.

8. Corburn, J. 2005. *Street Science*. Cambridge, MA: MIT Press.

Tackling environmental justice in industrialized hog production in rural North Carolina

1. Furuseth, O. 1997. Restructuring hog farming in North Carolina: Explosion and implosion. *Professional Geographer* 49:391–403.
2. Agricultural Statistics—Hogs: Inventory and Value. http://www.ncagr.com/stats/livestock/hoginv.htm.
3. Wing, S., D. Cole, and G. Grant. 2000. Environmental Injustice in North Carolina's Hog Industry. *Environmental Health Perspectives* 108:225–31.
4. Tajik, M. and M. Minkler. 2007. Environmental Justice Research and Action: A Case Study in Political Economy and Community-Academic Collaboration. *International Quarterly of Community Health Education* 26(3):213–31.
5. Tajik, M., S. Wing, and C. Grant. In press. Environmental Justice from the Roots: Tillery, North Carolina. In *Academics and Activists: Confronting Ecological and Community Crisis in Appalachia*, eds. Stephanie McSpirit, L. Faltraco, and C. Bailey. Lexington: Joyce Harrison University Press of Kentucky.
6. Farquhar, S. and S. Wing. 2008. Methodological and ethical considerations in environmental justice research. In *Community-Based Participatory Research for Health, 2nd Edition,* eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.
7. Wing, S. 2002. Social Responsibility and Research Ethics in Community-Driven Studies of Industrialized Hog Production. *Environmental Health Perspectives* 110:437–44.
8. Rawlins, E. 2008. Eastern NC residents say they're sick of smelling swine. *Fayetteville (NC) Observer,* June 19.
9. Wing, S., R. A. Horton, N. Muhammad, G. R. Grant, M. Tajik, and K. Yhu. 2008. Integrating epidemiology, education, and organizing for environmental justice: Community health effects of industrial hog operations. *American Journal of Public Health* 98(8): 1390-97.
10. Flower, B. 1993. Bridges, not walls—building healthier communities. *Healthcare Forum J* 65.
11. Brugge, D. and P. H. Hynes. 2005. *Community Research in Environmental Health: Studies in Science, Advocacy, and Ethics*. Burlington, VT: Ashgate.

Moving out of the nursing home and into the community

1. MEDSTAT. 2005. *Medicaid long-term care expenditures in Federal Fiscal Year 2004*. Washington, DC: Centers for Medicare and Medicaid Services.
2. Illinois Department of Public Health. 2005. *Long-Term Care Facility Profiles*. Springfield, IL: Illinois Department of Public Health.
3. Hammel, J., S. Magasi, L. Fogg, T. Wilson, and E. Rodriguez. 2007. Moving out of the Nursing Home to the Community: Outcomes from the Participatory Social Action Group Project. Unpublished paper.
4. Minkler, M., J. Hammel, C. Gill, S. Magasi, V. Breckwich Vásquez, M. Bristo, and D. Coleman. 2008. Community-Based Participatory Research in Disability and Long-Term Care Policy: A Case Study. *Journal of Disability Policy Studies* 19(2):114–26.
5. Bristo, M., and Z. Naiditch. 2004. Stop segregating people with disabilities. Voice of the People, *Chicago Tribune*, July.
6. Adler, J. 2006. Projects for disabled aim to encourage independence. *Chicago Tribune*, February 19.
7. Tsouderos, T. 2005. Disabled push for care aid at home. *Chicago Tribune*, February 27.

Using "data judo," community organizing, and policy advocacy on the regional level

1. Los Angeles Department of City Planning. 2005. Los Angeles Department of City Planning. *City of Los Angeles: Population*

and Housing Profile. http://cityplanning.lacity.org/DRU/Locl/LocPfl.cfm?geo=cp&loc=SeL.

2. Kelly, W. 2003. Noxious Neighborhoods. *California Journal* 20–23.
3. Sadd, J., M. Pastor, J. T. Boer, and C. D. Snyder. 1999. Every breath you take … The demographics of toxic air releases in southern California. *Economic Development Quarterly* 13(2):107–23.
4. Morello-Frosch, R., M. Pastor, J. Sadd, C. Porras, and M. Prichard. 2005. Citizens, science, and data judo: Leveraging secondary data analysis to build a community-academic collaborative for environmental justice in southern California. In *Methods in Community-Based Participatory Research for Health,* eds. B. Israel, E. Eng, A. Schulz, and E. A. Parker. San Francisco: Jossey-Bass.
5. Morello-Frosch, R., M. Pastor, and J. Sadd. 2001. Environmental justice and southern California's "riskscape": The distribution of air toxic exposures and health risks among diverse communities. *Urban Affairs Review* 36:551–78.
6. Pastor, M., C. Porras, and R. Morello-Frosch. 2000. The region's minorities face major health risks from pollution: Justice demands that the AQMD cut emissions. *Los Angeles Times,* p. 9.
7. Brugge, D., and P. H. Hynes. 2005. *Community Research in Environmental Health: Studies in Science, Advocacy and Ethics*. Burlington, VT: Ashgate.
8. Petersen, D., M. Minkler, V. Breckwich Vásquez, and A. Baden. 2006. Community-based participatory research as a tool for policy change: A case study of the Southern California Environmental Justice Collaborative. *Review of Policy Research* 23(2):339–53.
9. California Environmental Protection Agency, Advisory Committee on Environmental Justice. 2003. *Recommendations of the California Environmental Protection Agency (Cal/EPA) Advisory Committee on Environmental Justice to the Cal/EPA Interagency working group on environmental justice*. http://www.calepa.ca.gov/EnvJustice/Documents/2003/Final Report.pdf
10. 1Executive Order 12898. 1994. Federal actions to address environmental justice in minority populations and low-income population. *Federal Register* 59(32), Title 3. February 11. http://www.hud.gov/offices/fheo/FHLaws/EX)12898.cfm.

Addressing food insecurity in San Francisco's Bayview Hunters Point

1. Anderson, S. 1990. Core indicators of nutritional state for difficult-to-sample populations. *Journal of Nutrition* 120(suppl 11):1557–1600.
2. Baker, E. A., M. M. Metzler, and S. Galea. 2005. Addressing social determinants of health inequities: Learning from doing. *American Journal of Public Health* 95(4): 553–5.
3. Morland, K., S. Wing, A. Diez-Roux, and C. Poole. 2002. Neighborhood characteristics associated with the location of food stores and food service places. *American Journal of Preventive Medicine* 22(1):23–29.
4. Hennessey Lavery, S., M. L. Smith, A. A. Esparza, A. Hrushow, M. Moore, and D. F. Reed. 2005. The Community Action Model: A community-driven model designed to address disparities in health. *American Journal of Public Health* 95(4):611–6.
5. Altria. 2008. Kraft Spin-off (Completed). http://www.altria.com/about_altria/1_7_2_spinoffempinfo.asp.
6. Hennessey Lavery, S., M. L. Smith, and M. Moore. 2005. The community action model: Organizing for change in San Francisco's Tobacco Free Project. *Health Education and Behavior* 32(3):405–7.
7. Breckwich Vásquez, V., D. Lanza, S. Hennessey Lavery, M. Minkler, and H. S. Halpin. 2007. Addressing food security through public policy action in a community-based participatory research partnership. *Health Promotion Practice* 8(4):342–9.
8. Breckwich Vásquez, V., D. Lanza, S. Hennessey Lavery, H. S. Halpin, and M. Minkler. 2008. Addressing food security through policy promoting store conversions: The role of

a CBPR partnership. In *Community-Based Participatory Research for Health: From Process to Outcomes, 2nd Edition*, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.

Preventing lead exposure among children in Tar Creek, Oklahoma

1. Malcoe L., R. A. Lynch, M. C. Kegler, and V. J. Skaggs. 2002. Lead Sources, Behaviors, and Socioeconomic Factors in Relation to Blood Lead of Native American and White Children: A Community-Based Assessment of a Former Mining Area. *Environmental Health Perspectives* 10(suppl 2):221–31.
2. Kegler, M. C., and L. H. Malcoe. 2004. Results from a lay health advisor intervention to prevent lead poisoning among rural Native American children. *American Journal of Public Health* 94(10):1730–5.
3. Lanphear, B., K. Dietrich, P. Auinger, and C. Cox. 2000. Cognitive deficits associated with blood lead concentrations <10µg/dL in U. S. children and adolescents. *Public Health Reports* 115:521–9.
4. Singer, H., and M. C. Kegler. 2004. Assessing interorganizational networks as a dimension of community capacity: Illustrations from a community intervention to prevent lead poisoning. *Health Education and Behavior* 31(6):808–21.
5. Kegler, M. C., R. Stern, S. Whitecrow-Ollis, and L. Malcoe. 2003. Assessing lay health advisor activity in an intervention to prevent lead poisoning among Native American children. *Health Promotion Practice* 4(2):189–96.
6. Gerberding, J. 2004. *Report to Congress: Tar Creek Superfund Site; Ottawa County, Oklahoma.* Centers for Disease Control and Prevention and Agency for Toxic Substances and Disease Registry, October. http://www.atsdr.cdc.gov/sites/tarcreek/index.html.
7. Petersen, D., M. Minkler, V. Breckwich Vásquez, M. C. Kegler, L. H. Malcoe, and S. Whitecrow. 2007. Using community-based participatory research to shape policy and prevent lead exposure among Native children. *Progress in Community Health Partnerships* 1:249–56.

Improving school conditions by changing public policy in South Los Angeles

1. Los Angeles Unified School District. *Fingertip Facts 2007–2008*. http://www.lausd.k12.ca.us.
2. Lopez-Garza, M. 2001. *State of South Los Angeles 1990–2010: A Community Coalition Perspective*. Los Angeles: Community Coalition.
3. The Community Coalition. http://www.cocosouthla.org/.
4. Saurwein, K., and K. A. Haynes. 1999. Schools have no trouble identifying the LA school district's most pressing problems. *Los Angeles Times*, October 15, p. 2.
5. Wang C. C., and M. Burris. 1997. Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior* 24:369–87.
6. Foege, A., and V. Sheff-Cahan. 1999. Picture imperfect. *People* Magazine*,* November 29.
7. Stewart, G. 2002. Business has learned to let the community lead. *Los Angeles Business Journal*, April 4–8.
8. Meara, E. R., S. Richards, and D. M. Cutler. 2008. The gap gets bigger: Changes in mortality and life expectancy, by education, 1981–2000. *Health Affairs* 27(2): 350–60.

Making the healthy choice the easy choice

1. Rains, J.W., and D. W. Ray. 1995. Participatory action research for community health promotion. *Public Health Nursing* 12:256–61.
2. Minkler, M., V. Breckwich Vásquez, J. Warner, H. Steussey, and S. Facente. 2006. Sowing the seeds of sustainable change: A community-university research and action partnership in Indiana and its aftermath. *Health Promotion International* 21(4):293–300.
3. Healthy Communities of Henry County. http://hchcin.org/.

Empowering New Mexico's young people in public policymaking: Youth Link

1. U. S. Factfinder. 2006. *2006 American Community Survey: New Mexico*. http://factfinder.census.gov/servlet/ACSSAFFFacts?_submenuId=factsheet_1&_sse=on.
2. National Association of Counties Rural Action Caucus, County Data. 2005. http://www.naco.org/RuralTemplate.cfm?Section=RAC_County_Data&Template=/cffiles/rac/state_srch.cfm.
3. New Mexico Human Services Department. 2006. *New Mexico's Uninsured Rate Moving in the Right Direction Despite Rapidly Rising Healthcare Costs*. http://www.hsd.state.nm.us/pdf/2005UninsuredRateNR.pdf.
4. http://nmvoices.org/youthlink.htm.
5. Wallerstein, N. 2002. Empowerment to reduce health disparities. *Scandinavian Journal of Public Health* 30:72–77.
6. Springett, J., and N. Wallerstein. 2008. Issues in Participatory Evaluation. In *Community-Based Participatory Research for Health: From Process to Outcomes, 2nd Edition*, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.
7. Blackwell, A. G., M. Minkler, and M. Thompson. 2005. Using Community Organizing and Community Building to Influence Policy. In *Community Organizing and Community Building for Health, 2nd Edition*, ed. M. Minkler. New Brunswick, NJ: Rutgers University Press.

Reintegrating drug users leaving jail and prison

1. Freudenberg, N., M. A. Rogers, C. Ritas, and M. Nerney. 2005. Policy analysis and advocacy: An approach to community-based participatory research. In *Methods in Community-Based Participatory Research for Health*, eds. B. A. Israel, E. Eng, A. J. Schulz, and E. A. Parker. San Francisco: Jossey-Bass.
2. van Olphen, J., N. Freudenberg, S. Galea, A.-G. Palermo, and C. Ritas. 2003. Advocating Policies to Promote Community Reintegration of Drug Users Leaving Jail: A Case Study of First Steps in a Policy Change Campaign Guided by Community-Based Participatory Research. In *Community-Based Participatory Research for Health*, eds. M. Minkler and N. Wallerstein. San Francisco: Jossey-Bass.
3. Freudenberg, F. 2008. Changing municipal policies to promote health and reduce disparities: What's the role of community-based participatory research? Presentation to the Kellogg Health Scholars Program Networking Meeting, May 20, in Washington, DC.

Appendix A: Project Staff and National Advisory Board Members

Project Staff

Meredith Minkler, DrPH, MPH (PI)
Professor, Health and Social Behavior
School of Public Health,
50 University Hall #7360
University of California, Berkeley
Berkeley, CA 94720-7360
Phone: 510.642.4397
Fax: 510.643.8236
mink@uclink.berkeley.edu

Victoria Breckwich Vásquez, DrPH, MPH
Chief, Community Health Action and Assessment Section
City of Berkeley Public Health Division
1947 Center Street, #2
Berkeley, CA 94704
Phone: 510.981.5362
Fax: 510.981.5345
VBreckwich-Vasquez@ci.berkeley.ca.us

Angela Glover Blackwell (Consultant)
Founder and CEO, PolicyLink
1438 Webster Street, Suite 303
Oakland, CA 94612
Phone: 510.663.2333
Fax: 510.663.9684
ablackwell@policylink.org

Judith Bell (Consultant)
President, PolicyLink
1438 Webster Street, Suite 303
Oakland, CA 94612
Phone: 510.663.2333
Fax: 510.663.9684
info@policylink.org

Mildred Thompson, MSW (Consultant)
Senior Director and Director,
PolicyLink Center for Health and Place
1438 Webster Street, Suite 303
Oakland, CA 94612
Phone: 510.663.2333
Fax: 510.663.9684
info@policylink.org

Victor Rubin, PhD (Consultant)
Vice President for Research, PolicyLink
1438 Webster Street, Suite 303
Oakland, CA 94612
Phone: 510.663.2333
Fax: 510.663.9684
info@policylink.org

Additional Project Staff

Mansoureh Tajik, PhD
Assistant Professor
Department of Community Health and Sustainability
School of Health & Environment
University of Massachusetts at Lowell
3 Solomont Way, Suite 3
Lowell, MA 01854-5121
Phone: 978.934.4482
Mansoureh_tajik@uml.edu

Dana Petersen, PhD, MPH
Research Social Scientist
Policy Division, SRI International
333 Ravenswood Avenue, BS113
Menlo Park, CA 94025
Phone: 650.859.4518
Fax: 650.859.5258
dana.petersen@sri.com

Shelley Facente, MPH
Coordinator for HIV CTL Evaluation
and Quality Assurance
HIV Prevention Section, AIDS Office
San Francisco Department of Public Health
25 Van Ness Avenue, Suite 500
San Francisco, CA 94102
Phone: 415.554.9136
Fax: 415.934.4868
Shelley.Facente@sfdph.org

Andrea Corage Baden, PhD (cand)
UCSF Department of Social Behavioral Sciences
3333 California Street #455
San Francisco, CA 94118
Phone: 206.329.1737
corage@umich.edu

Advisory Board Members

Makani Themba-Nixon
Executive Director
The Praxis Project
1750 Columbia Road, NW
Second Floor
Washington, DC 20009
Phone: 202.234.5921
Fax: 202.234.2689
mthemba@thepraxisproject.org

Lorenda Belone, MPH, PhD (cand)
Program Manager/Research Scientist, MPH Program
University of New Mexico
2400 Tucker, NE, Room 145
Albuquerque, NM 87131-0001
Phone: 505.272.3634
Fax: 505.272.4494
ljoe@salud.unm.edu

Pamela Tau Lee
Coordinator of Public Programs
School of Public Health
Labor Occupational Health Program
University of California – Berkeley
2223 Fulton Street, 4th Floor
Berkeley, CA 94720-5120
Phone: 510.643.7594
Fax: 510.643.5698
ptlee@berkeley.edu

Gary Tang
Adult and Aging Services Director
Asian Counseling and Referral Services
720 8th Avenue S., #200
Seattle, WA 98104
Phone: 206.695.7526
Fax: 206.695.7606
garyt@acrs.org

Lucille Webb
President
Strengthening Black Family, Inc.
1509 Tierney Circle
Raleigh, NC 27601
Phone: 919.834.8862
Fax: 919.856.6575
webb@handtechisp.com

Alex J. Allen, III
Vice President
Community Planning & Research
Isles, Inc.
10 Wood Street
Trenton, NJ 08618
Phone: 609.341.4701
Fax: 609.393.9513
aallen@isles.org

Cassandra Ritas, MPP, BA
Consultant
8510 34th Avenue, #621
Jackson Heights, NY 11372
Phone: 212.744.7664
critas@gmail.com

Appendix B: Study Methods and Analysis

Site Selection Process

To be included in this study, partnerships had to meet strict criteria of CBPR (Israel et al., 1998) and to have either showed evidence of having contributed to a policy change or showed promise for doing so in the near future. An initial group of 12 potential projects was identified in conjunction with a major concurrent study by the Research Triangle Institute/University of North Carolina's Center for Evidence Based Public Health, which was examining the evidence base for CBPR in English-speaking North America.

Additional literature reviews and calls to approximately two dozen relevant Internet listservs, such as Campus Community Partnerships for Health (CCPH), the Community Health Scholars Program, and relevant American Public Health Association (APHA) caucuses, increased the total number of potential cases to 77. Projects were summarized along dimensions including health policy area of interest, population and geographic area involved, and type of research methods employed.

To assist in selecting the final case studies for this analysis, as well as to provide input on subsequent stages in the research, an eight-member national community advisory board (CAB) was formed. Members of the CAB had all been engaged in CBPR typically as community partners, and in two cases as bridging persons or liaisons between academic and community partners. CAB members were drawn from diverse parts of the country and brought diversity as well in terms of their race/ethnicity, age, gender, and social class. Diversity was also evident in the health-related areas with which their CBPR partnerships had been engaged.

PolicyLink staff worked with the CAB and the University of California-Berkeley researchers in the selection process. The Principal Investigator (PI) and Project Director prescreened all 77 of the cases under review, removing those that were conducted outside the United States; had little policy involvement to date; focused solely on private sector policy; or had not resulted in peer review publications and/or abstracts, unless there was other major written evidence of activities and accomplishments (e.g., reports to the National Institutes of Health). In many cases, the partnership's PI was contacted to gain further information before deciding whether to keep their projects in the pool.

A final group of 27 potential case studies was summarized on an Excel spread sheet (which subsequently formed the basis for an extensive FileMaker contact database) and presented to the CAB for review. The advisory board in turn fine-tuned selection criteria to include the following: (1) the need for projects that represented diversity of health problem areas being addressed; (2) racial/ethnic, urban, rural, and geographic diversity; and (3) a range in types of research conducted by the partnerships.

The CAB, consultant, and research team narrowed the final list to 14. One of these had ceased its work after achieving its policy goals and chose not to be included, while another was too busy to participate; a third never responded despite repeated outreach attempts. A final project under consideration proved not to meet the CAB's criteria of action in the public policy arena. The remaining 11 sites were enthusiastic about participating, with one serving as a pretest site for the study, and the rest included in in-depth case study and cross-site analyses.

Data Collection

After receiving approval from the UC Berkeley Institutional Review Board and after substantial revision based on pretests, key source interview guides and focus group guides were finalized for use at the selected sites. Three of the 10 partnership sites involved significant youth participation, and separate source interview and focus group guides were created to highlight and measure key outcomes related to youth.

To help defray the costs of their participation, $250 was offered to each participating community-based agency, as well as an honorarium of $50 (cash or gift certificate) to each individual who participated in an individual or a focus group interview. Site

visits, typically two to three days in length and attended by one to two team members, were completed at all 10 sites and involved the following:

- Confidential key source interviews, lasting 90 minutes on average, were conducted with 60 community and academic and/or health department partners and were taped with their permission and transcribed.
- Twelve focus groups, lasting one hour on average, were conducted with community residents and also were taped and transcribed.
- Twelve phone interviews were conducted with policymakers/decision makers or external stakeholders, which lasted 45 minutes on average.
- Relevant newsletters, reports, or other documents were collected for review, with subsequent Internet searches, etc., used to track additional published information.
- Where applicable and feasible, at least one tour of the area in which the project took place was conducted by visiting team members.
- At some sites, participants were observed at special events, such as town hall meetings, board meetings, and local conferences sponsored by the partnership project.

Data Analysis

The PI, Project Director, and a graduate student assistant independently reviewed each of the transcripts and coded key domains using a numerical coding schema developed for the project. Team members then met to reconcile their findings and agree on distinctions between and among domains. Transcripts and numerical codes were entered into the qualitative data analysis program, Atlas.ti, to generate both inter-rater reliability scores and summaries of all of the relevant transcript data on given themes and research questions under investigation. The data analysis program was then used to develop a computerized grouping of all responses by domain and by site, and these key domain reports were reviewed independently by research team members. Key themes for each domain and for each site emerged.

Preliminary themes present across all sites were then analyzed and shared with the project consultant and CAB. These were subsequently developed into a comprehensive list. Analysis also produced ranked-order listings of success factors and lessons learned in each partnership, ranked by how often they were mentioned across all partners we interviewed.

Although this was a study of CBPR projects rather than a participatory research project itself, we were committed to honoring participatory research principles and invited partnerships to review and correct any inaccuracies in the project summaries we developed in relation to their sites. We also invited partnership members to serve as co-authors on relevant publications and/or to participate in subsequent presentations about the work (see Appendix C).

Appendix C: List of Project Publications

Breckwich Vásquez, V., D. Lanza, S. Hennessey Lavery, S. Facente, H. Halpin, and M. Minkler. 2007. Addressing food security through public policy action in a community-based participatory research partnership. *Health Promotion Practice* 8(4):342–9.

Breckwich Vásquez, V., M. Minkler, and P. Shepard. 2006. Promoting environmental health policy through community-based participatory research: A case study from Harlem, New York. *Journal of Urban Health* 83(1):101–10.

Minkler, M., V. Breckwich Vásquez, M. Tajik, and D. Petersen. 2008. Promoting environmental justice through community-based participatory research: The role of community and partnership capacity. *Health Education and Behavior* 35(1):119–37.

Minkler, M., V. Breckwich Vásquez, J. Warner, H. Steussey, and S. Facente. 2006. Sowing the seeds for sustainable change: A community-university research and action partnership in Indiana and its aftermath. *Health Promotion International* 21(4):293–300.

Minkler, M., J. Hammel, C. Gill, S. Magasi, V. Breckwich Vásquez, M. Bristo, and D. Coleman. 2008. Community-based participatory research in disability and long-term care policy: A case study. *Journal of Disability Policy Studies* 19 (2): 114–26.

Petersen, D., M. Minkler, V. Breckwich Vásquez, and A. C. Baden. 2006. Community-based participatory research as a tool for policy change: A case study of the Southern California Environmental Justice Collaborative. *Review of Policy Research* 23(2):339–53.

Petersen, D., M. Minkler, V. Breckwich Vásquez, M. C. Kegler, L. H. Malcoe, and S. Whitecrow. 2007. Using community-based participatory research to shape policy and prevent lead exposure among Native children. *Progress in Community Health Partnerships* 1:249–56.

Tajik, M. and M. Minkler. 2006–07. Environmental justice research and action: A case study in political economy and community-academic collaboration. *International Quarterly of Community Health Education* 26(3):213–31.

Appendix D: Web and Other Resources

Advocating for Change, PolicyLink. http://www.policylink.org/AdvocatingForChange.

Center for Third World Organizing. www.ctwo.org.

The Community Tool Box. http://ctb.ku.edu.

The Environmental Defense Fund's *Environmental Scorecard*. www.scorecard.org.

NetAction (including self-guided course on Internet organizing and advocacy). www.netaction.org.

Networking for Policy Change. POLICY, 1999: www.policyproject.com.

Organizer's Collaborative. www.organizerscollaborative.org.

The Praxis Project. www.thepraxisproject.org.

Speaking Truth, Creating Power: A guide to policy work for community-based participatory research practitioners. C. Ritas. Community-Campus Partnerships for Health. http://futurehealth.ucsf.edu/pdf_files/Ritas.pdf.

Strategic Concepts in Organizing and Policy Education (SCOPE). www.scopela.org.

Sites for addressing the digital divide:

Community Technology Centers. www.ctcnet.org.

Digital Divide Network. www.digitaldividenetwork.org.

Tech Soup. www.techsoup.org.

Table 3. CBPR Partnership Summaries

Partnership	Research Aim	Research Methods	Policy Approaches	Key Policy Outcomes*
Community Coalition Partnership South Los Angeles, CA • Community Coalition • The Imoyase Group/ Loyola Marymount University	Study conditions of schools in South LA	Youth survey (n=900) Photovoice (n=60 participants) Focus groups	Media advocacy Partnering with other stakeholders Community organizing and mobilization Lawsuit	Reopening by LAUSD of repair and construction contracts granted by school bond Redirection of $100 million to South LA schools $153 million in new funds for additional school repairs in South LA and other inner-city communities $750 million for new school construction via successful lawsuit
CCT Partnership Tillery and Southeast Halifax County, NC • Concerned Citizens of Tillery (CCT) • Univ. of North Carolina, Chapel Hill • Halifax County Health Department (initially)	Quantify industrial hog operations in low-income/ mostly African American communities and their health effects	Spatial statistics GIS mapping Household water source study and survey	Public involvement in hearings Organizational alliances Outreach to legislators	Created NC Environmental Justice Network, which re-invigorated statewide EJ movement Helped get passage of law banning new hog facilities in state and setting standards for waste treatment (2007)
Harlem Community and Academic Partnership East and Central Harlem, NY • New York Academy of Medicine – Ctr. for Urban Epidemiological Studies • Harlem Urban Research Center (URC) • Hunter College, City University of New York	Study the barriers faced by reentry populations and examine policies that limit their access to related services	Focus groups In-depth interviews Surveys with substance users and service providers Public opinion research	Policy advocacy Community symposium Survival Guide for Substance Users Web-based resource guide for service providers Development of parallel citywide network for sustainability	Passage of state bill reinstating Medicaid benefits to inmates upon release Passage by NYC Council of law mandating Dept. of Correction to provide expanded discharge planning services to people leaving jail Dept. of Correction move to release many more inmates during daylight hours
HCHC Partnership New Castle and Henry County, IN • Healthy Communities of Henry County (HCHC) • Indiana University School of Nursing • Henry County Memorial Hospital	Develop a health profile of Henry County to inform community and environmental policy interventions	Census data analysis Door-to-door surveys Focus groups	Statewide workshop with sessions on data interpretation, priority setting, and policy-structured changes 15-week leadership training Partnerships with local policymakers	Crafting and passage of region's first indoor smoking ordinance Securing of local government support and funding for playground Securing inter-sectoral governmental funding, including a new food and beverage tax, for a "web of trails" initiative

Partnership	Research Aim	Research Methods	Policy Approaches	Key Policy Outcomes*
LEJ Partnership Southeast San Francisco, CA • Literacy for Environmental Justice (LEJ) • San Francisco Dept. of Public Health • Independent evaluator	Study food insecurity in Bayview Hunters Point community	Community surveys Store shelf diagramming Merchant interviews Economic incentives study GIS mapping	Followed Community Action Model focused on policy action Media advocacy Local outreach campaign Partnerships with local policymakers and food distributors	Enactment of a voluntary municipal policy (Good Neighbor Program) incentivizing corner stores that increase access to healthy foods and decrease advertising of alcohol and tobacco Passage of AB 2384 in 2006, modeled on GN Program, to establish statewide Healthy Food Purchase pilot program (w/ out funding appropriation)
Moving out of the Nursing Home and into the Community Chicago, IL • University of Illinois, Chicago Occ. Therapy/Disability and Human Development • Access Living • Progress Center for Independent Living	Examine change in community living status, community participation, disability identity, and individual and collective power among those transitioning out of nursing homes	Focus groups Controlled intervention trial with baseline and repeated measures survey Interviews	Quarterly town hall meetings Mobilization of disabled community Social Action Groups Media advocacy Testifying Class action lawsuit	Passage of legislation and funding of a Senior Community Reintegration Program State reauthorization of a statewide council to reassess Olmstead Act implementation and plan for rebalancing long-term care financing Allocation of $55.7 million from state in 2007 for new "Money Follows the Person" program
Southern California Environmental Justice Collaborative South Los Angeles, CA • Communities for a Better Environment • Liberty Hill Foundation • Researchers at UC Santa Cruz, Occidental College, Brown University	Examine environmental inequality in air quality and toxic exposure levels in southern CA	Secondary data analysis using spatial statistics, multivariate, GIS Creation of regional "health riskscape"	Tripartite approach of credible research, community organizing, and policy advocacy/law	Revision of a regulation (Rule 1402) tightening emission standards and lowering MICR by 75 percent Changing of policy language used by Cal/-EPA from individual to cumulative risk exposure Spearheading EJ movement in southern CA

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Partnership	Research Aim	Research Methods	Policy Approaches	Key Policy Outcomes*
Tribal Efforts against Lead (TEAL) Tar Creek, Northeast Ottawa County, OK • Clan Mothers and Fathers from eight tribes • Univ. of Oklahoma, Univ. of New Mexico, and Emory University • Ottawa County Health Department	Assess lead exposure levels among local children and evaluate a lay health worker model	Childhood blood lead level screenings Lay health worker intervention Home environmental assessments	Garnering community support for routine lead screening Getting tribal resolutions for mandatory testing Working with County Commission to pass mine tailings use regulations	Full implementation of blood lead screening and parental notification for young children by Ottawa County Health Dept. and Indian Health Service Policy action to halt use of mine tailings in construction and on roads without proper containment
WE ACT Partnership Northern Manhattan, New York City, NY • West Harlem Environmental Action • Columbia University Center for Children's Environmental Health	Study community-level exposure to diesel exhaust emissions and related air pollution	Traffic and pedestrian counts Personal air monitoring GIS mapping	Media advocacy Testifying and briefing officials Filing legal complaints	Conversion of NYC bus fleet to clean diesel Establishment by EPA of permanent air monitoring in Harlem and other "hot spots" Co-authoring and adoption of statewide environmental justice policy
Youth Link New Mexico • Youth Link • University of New Mexico • New Mexico Department of Health (DOH)	Study youth-identified and geographically based health issues and evaluate youth participation	Youth surveys Interviews with youth Secondary analysis of KIDS Count Data and DOH data	Youth policy training Bill development Policy advocacy Media advocacy Visits to state capitol	State legislature's passage of study bill to investigate suspension policies and their effects on high-school dropout rates City support and funding for skate park in Las Cruces citywide smoke-free ordinance in Albuquerque, and restriction on tobacco product placement in Santa Fe Passage of statewide ban on smoking indoor workplaces and public spaces

* Please note that victories were not attributed entirely to the partnerships; rather, the partnerships were perceived to have had a significant impact on these policy outcomes.

PolicyLink
1438 Webster Street
Suite 303
Oakland, CA 94612
Phone: 510 663-2333
FAX: 510 663-9684
Web: www.policylink.org

School of Public Health
University of California, Berkeley
50 University Hall #7360
Berkeley, CA 94720-7360
Phone: 510 642-6531
Web: sph.berkeley.edu

W.K. Kellogg Foundation
One Michigan Avenue East
Battle Creek, MI 49017-4012
Phone: 269 968-1611
FAX: 269 968-0413
Web: www.wkkf.org