Successful Models of Community-Based Participatory Research

Meeting hosted by the NIEHS
March 29-31, 2000 – Washington, DC

Final Report

Edited by Liam R. O'Fallon, Frederick L. Tyson, Allen Dearry

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Acknowledgments

We would like to thank the Office of Research on Minority Health, National Institutes of Health for its generous support of this meeting.

Executive Summary

In the last ten years, traditional population-based biomedical research methods have been challenged due to limited community participation. Proponents for change explain that community participation, as an active partner in the research process, provides numerous benefits to research findings and public health intervention outcomes. In addition, community participation builds and strengthens the capacity of community residents to address future health risks, through education, outreach and training. As an increasing number of researchers utilize community-based participatory research (CBPR), the need for demonstrating successful models becomes ever more important, especially for institutions that support such research.

Over this same time period, the National Institute of Environmental Health Sciences (NIEHS) has assumed a leadership role in developing and implementing novel CBPR programs that address a broad range of social and physical environments, health outcomes, and intervention strategies. Based upon the success of such programs, the NIEHS seeks to expand the acceptance, use, and applicability of CBPR as a valuable tool in improving the public health of the nation.

On March 30-31, 2000, the Chemical Exposures and Molecular Biology Branch, Division of Extramural Research and Training (DERT) at the NIEHS brought together representatives from schools of public health, state and local departments of health, and public and private funding agencies along with researchers in CBPR. Fifty-five people participated, representing a variety of public and private agencies and institutions, including among others the Environmental Protection Agency, the Department of Housing and Urban Development, the National Cancer Institute, W.K. Kellogg Foundation, Maryland Department of Health and Mental Hygiene, King County/Seattle Department of Health, University of Iowa School of Public Health, and the Texas A&M School of Rural Public Health (a more comprehensive list is provided in the "Participants" section of this document).

The purpose of the meeting was to promote the use of and support for CBPR by the above institutions by presenting them with successful models of CBPR. Presentations and discussions emphasized the importance and value of CBPR and how it can be used to achieve a given organization's goals.

To provide participants with a perspective of CBPR and its application to their institutional missions, the meeting was structured around two themes: *Community-Based Participatory Research Methodology* and *Uses of Community-Based Participatory Research*. Within these two overarching themes, speakers presented on six key topics. Methodology topics addressed Partnership Building, Process, and Evaluation. Topics for discussion on the uses of CBPR were Research & Intervention, Health Care Delivery & Services, and Social Capital & Policy.

To set the appropriate stage for discussions, keynote speakers addressed CBPR in its historical context, outlined policy recommendations and emphasized the benefits it has for communities. In her keynote presentation, Barbara Israel outlined nine principles of this research approach and the rationale for utilizing it. In addition, she highlighted several policy recommendations to strengthen and enhance current efforts in CBPR. Peggy Shepard emphasized how increased

awareness of CBPR has benefited her community-based organization. She explained how the partnerships formed with schools of public health and health care providers offered her organization and communities of Northern Manhattan with added credibility in their fight against environmental injustices.

Presentations and discussions elucidated a range of themes regarding the strengths and challenges of CBPR. The summaries in this report synthesize both the presentations and comments from the breakout sessions. The sections from **Community-Based Participatory Research Methodology** reflect the development, maintenance, and evaluation of successful community-based partnerships. In the *Partnership Building* section, Loretta Jones discusses the essential components that must be considered when establishing a working relationship with underserved communities. She highlights the common threads between projects where researchers work in partnership with communities. In the *Process* section, Thomas Arcury conveys four essential elements for ensuring the continued success of a community partnership. Finally, in the *Evaluation* section, Linda Silka describes how evaluation techniques should be used to demonstrate the effectiveness of CBPR.

The three presentations and discussion themes from **Uses of Community-Based Participatory Research** focused on the application of CBPR. In a co-presentation on *Research and Intervention*, Wilma Caldwell-Brakefield and Edith Parker, speak to the benefit of community participation in research and intervention projects. Increased participation and compliance in research are cited as two significant strengths of partnering with the community. Marshall Chin, in the *Health Care Delivery & Services* section, delineates several mechanisms through which the community makes special contributions. Lastly, Rosalind Wright speaks to an old but re-emerging topic of *Social Capital*. After establishing a correlation between social capital and human health, she explains how CBPR may possess a positive outcome in fostering and strengthening this social cohesion.

Participants identified several key benefits of CBPR and recommendations for its continued success and enhancement. In the section on **Conclusions and Recommendations**, these conclusions are categorized by four separate, but overlapping themes: (1) Overall Benefits, (2) Benefits for Schools of Public Health, (3) Benefits for State and local Health Departments, and (4) Benefits for Public and Private Funding Institutions.

Overall Benefits of CBPR:
- **Enhances data quality and quantity, by establishing trust.**
- **Moves beyond categorical approaches**.
- **Improves research definition and direction.**
- **Enhances translation and sustainability of research findings.**
- **Improves the community's health, education and economics, by sharing knowledge obtained from projects.**

Benefits to Schools of Public Health
- **Fulfills missions of schools of public health.**
- **Brings together disciplines that have historically operated in their own research silo**.
- **Increases student interest and participation in research**.

Benefits to State and local Health Departments
- **Increases patient contact, primary care, and self-management.**
- **Facilitates development and implementation of more effective public health interventions.**
- **Enhances behavioral change and decreases costs to health departments.**

Benefits to Public and Private Funding Institutions
- **Cost effectiveness of CBPR.**
- **Increased trust from communities.**
- **Non-categorical nature allows for greater flexibility in support.**

In addition to outlining benefits of CBPR, the Conclusions and Recommendations section highlights challenges facing CBPR and offers possible solutions to overcome them. Three principal challenges identified by participants included: **development of university-community partnerships**, **institutional commitment**, and **training**.

National Institute of Environmental Health Sciences,
Division of Extramural Research and Training

Successful Models of Community-Based Participatory Research
Preliminary Meeting Agenda

Washington, DC
29-31 March 2000

Wednesday, March 29

6:00 - 6:30 PM   **Registration**

6:30 - 9:00 PM   **Plenary Dinner**

7:30 PM   **Welcome & Keynote Speakers**

- **Introduction**
  Allen Dearry, Chief
  Chemical Exposures and Molecular Biology Branch,
  National Institute of Environmental Health Sciences

- **Welcome**
  Sam Wilson, Deputy Director,
  National Institute of Environmental Health Sciences

- **Keynote Address**
  "Community-Based Participatory Research: Principles, Rationale and Policy Recommendations."
  Barbara Israel, Professor,
  University of Michigan

- **Keynote Address --**
  "Achieving Environmental Justice Objectives & Reducing Health Disparities Through Community-Based Research & Interventions."
  Peggy Shepard, Executive Director,
  West Harlem Environmental ACTion, Inc.

9:00 PM   **Adjourn for Day**

Thursday March 30

7:30 - 8:00 AM	**Continental Breakfast**

8:00 – 8:30 AM   **Welcome and Orientation**
Frederick Tyson, Program Administrator,
Chemical Exposures and Molecular Biology Branch,
National Institute of Environmental Health Sciences

8:30 – 9:30 AM   **Plenary Session**:
Community-Based Participatory Research Methodology

In this session, participants will hear from representatives of three different CBPR projects that exemplify successful models of each of the following three topic areas.

- **PARTNERSHIP BUILDING**
  Loretta Jones, Executive Director
  Healthy African American Families, Los Angeles, CA

- **PROCESS**
  Thomas Arcury, Professor
  Wake Forest University, Winston-Salem, NC

- **EVALUATION**
  Linda Silka, Professor
  University of Massachusetts, Lowell, MA

9:30 – 10:00 AM   **Break**

10:00 – 11:45 AM   **Breakout Session**

The purpose of these discussions is to explore in greater depth the value that community-based participatory research adds to a given institution's public health objectives. Groups will consider other successful models and the commonality between them, in addition to gaps yet to be addressed. Using questions provided in the meeting packet, plenary session speakers will moderate the discussions. Each group will report back to the larger audience on March 31 and the summary of these discussions will be used to develop a report.

- **PARTNERSHIP BUILDING**

Partnerships between researchers and community members can be challenging to build, yet the benefits to a successful relationship can be immeasurable. This group will examine different models for partnership building.

- **PROCESS**

Once a partnership is established there must be certain mechanisms in place to nurture, strengthen, and sustain it. A variety of methods may be employed to achieve the aims of the partnership.

- **EVALUATION**

Demonstrating the positive impact of a project is essential for continued funding and sustainability. Prominent methods of evaluation, including qualitative and quantitative approaches, will be discussed.

| 12:00 – 2:30 PM | **Plenary Lunch:** |
| | **Uses of Community-Based Participatory Research** |

In this session, participants will hear from representatives of three different CBPR projects that exemplify successful models of each of the following three topic areas.

- **RESEARCH & INTERVENTION**
  Edith Parker, Assistant Professor
  University of Michigan, Ann Arbor, MI

  Wilma Brakefield-Caldwell, Community Member
  Detroit, MI

- **HEALTH CARE DELIVERY & SERVICES**
  Marshall Chin, Assistant Professor of Medicine
  University of Chicago, Chicago, IL

- **SOCIAL CAPITAL & POLICY**
  Rosalind Wright, Instructor in Medicine
  Beth Israel Deaconess Medical Center, Boston, MA

| 2:45 - 4:45 PM | **Breakout Session** |

- **RESEARCH & INTERVENTION**

This group will reflect on how community-based research and intervention improves public health outcomes.

- **HEALTH CARE DELIVERY & SERVICES**

Health care delivery affects the well-being of every community, but has traditionally been decided upon without community input. This group will discuss how community participation can enhance access to and quality of health care services.

- **SOCIAL CAPITAL & POLICY**

Social capital represents features of social organization beyond the level of the individual -- such as collective efficacy, psychological sense of community, and neighborhood cohesion -- which act as resources for individuals and facilitate collective action. This group will examine how CBPR can influence social capital and impact social, economic, or political policy.

4:45 PM   **Adjourn for Day**

Friday, March 31

8:00 – 8:30 AM   **Continental Breakfast**

8:30 – 10:30 AM   **Report Backs** (20 minutes each section)

10:30 – 11:15 AM   **Presentations**
- **Report on Guidelines for Community-Based Research**
  Douglas Taylor,
  Loka Institute
  Madeleine Scammell,
  Loka Institute

- **Report on GIH Annual Meeting on Health Philanthropy**
  Kathy Sessions,
  Health and Environmental Funders Network

11:15 AM -- 12:00 PM   **Summary and Adjourn**

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National Cancer Institute (NCI)
National Institute on Aging (NIA)
Office of Research on Minority Health (ORMH)

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University of Illinois, Chicago
New York State Psychiatric Institute

Health Departments
King County Health Department, Seattle, WA
Wisconsin Health Department
California Department of Health
Maryland Community & Public Health Administration
New Mexico Department of Health

Meeting Structure and Overview

To provide participants with a global perspective of CBPR and its application to their institutional missions, the meeting was structured around two central themes: *Community-Based Participatory Research Methodology* and *Uses of Community-Based Participatory Research*. Within these two overarching themes, discussions focused on the following six topics: Partnership Building, Process, Evaluation, Research & Intervention, Health Care Delivery & Services, and Social Capital & Policy.

To assure quality, relevance, and variety, the NIEHS established an interagency planning committee of federal, university, and non-governmental organization representatives with experience in CBPR. The following people participated on this committee: (1) Donna Higgins, CDC; (2) Barbara Israel, University of Michigan; (3) Victor Rubin, HUD; (4) Susan Scrimshaw, University of Illinois, Chicago, and (5) Susan West, NEETF. Through a series of conference calls, committee members identified presenters for the six topics based upon their assessment of who was conducting model CBPR projects. Each presenter was matched with the most appropriate topic given the focus of his/her project. Selected researchers were grantees from the NIEHS, CDC, and HRSA.

The hybrid meeting organization included plenary and breakout sessions to allow meeting participants to learn about all topics and yet participate actively in focused discussions. Each presenter gave a 20-minute overview of his/her topic as it related to their project as a means to set the stage for discussions during the breakout session. Immediately following presentations, presenters moderated breakout discussions on the topic about which they had just spoken. Participants were preassigned to breakout groups based upon their background and institutional affiliation. In addition, a balance of knowledge of and experience with CBPR was sought to facilitate productive dialogue.

Overarching questions used during breakout sessions were:
1. In addition to the project discussed during the plenary presentation, what are other examples of successful models that pertain to this theme?
2. What are the common threads/features of these models?
3. What is the benefit to CBPR of: Relationship Building, Process, Evaluation? AND/OR What value does CBPR add to: Research & Intervention, Health Care Delivery, Social Capital & Policy?
4. Are there major gaps, or issues, yet to be addressed? If so, what are some approaches to deal with them?
5. Why is this particular CBPR breakout theme of interest to Schools of Public Health? State or local health agencies? Public and private funding agencies?

In addition, the above questions served as the foundation for developing this final report. The following sections of this report consist of summaries from the six breakout sessions as well as the two keynote presentations. Presenters/moderators synthesized breakout discussions by spotlighting major themes, and when possible, related issues back to their presentation.

COMMUNITY-BASED PARTICIPATORY RESEARCH:
PRINCIPLES, RATIONALE AND POLICY RECOMMENDATIONS[*]

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INTRODUCTION[1]

       Historically, the field of public health has examined environmental and social determinants of health status (1-8) and involved the public itself in identifying and addressing public health problems (4, 9-10). Over time, greater emphasis has been placed on research aimed at creating knowledge about determinants of health that has tended to stress individual rather than social or environmental risk factors, and to separate researchers and public health practitioners from the public at-large as the health "experts" (2-3, 5, 11-14). The emphasis on individual level risk factors tends to obscure the contributions of social and environmental conditions to health and disease, most visible in the growing gap between the health status of rich and poor, white and non-white, urban and non-urban (2, 15-17).

       More recently, researchers have called for a renewed focus on an ecological approach that recognizes that individuals are embedded within social, political and economic systems that shape behaviors and access to resources necessary to maintain health (2, 5, 13, 16-19, 20-24). Emphasis has also been placed on the need for more translation and integration of basic, intervention, and applied research (25-26). Greater community involvement in processes that shape research and intervention approaches, e.g., through partnerships between academic, health services and community-based organizations (27-33) is one means towards these ends, and also increases sensitivity to and competence in working within diverse cultures (34-37).

       These calls for a more comprehensive and participatory approach to research and practice in public health have been voiced in major national reports (e.g., *The Future of Public Health*, *Healthy People 2000*, and *Health Professions Education for the Future: Schools in Service to the Nation*). They have also been translated into funding initiatives

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by a number of private foundations and federal agencies (e.g., NIEHS' Initiative "Community-Based Prevention Intervention Research" (38), CDC's Urban Centers for Applied Research in Public Health" (39), W.K. Kellogg Foundation's "Community-Based Public Health" (40)).

This combination of critical reflection within public health and new opportunities for funding has given rise to a number of partnership approaches to research and practice, variously called "community-based/involved/participatory/ collaborative/centered-research" (27, 32-33, 41-52). At the same time, a large literature spanning the social sciences has examined approaches to research in which participants are actively involved in all aspects of the research process. Examples include "participatory research" (29, 53-59), "participatory action research" (60-61) "action research" (62-67), and "empowerment evaluation" (68). Despite differences among these approaches (e.g., 57-58, 69), each is explicitly committed to conducting research that will benefit the participants either through direct intervention or by using the results to inform action for change.

The purpose of this presentation is to provide a synthesis of key principles or characteristics of community-based participatory research; discuss the rationale for its use; and provide several policy recommendations at the organizational, community and national levels aimed at advancing the use of CBPR.

COMMUNITY- BASED PARTICIPATORY RESEARCH: OVERVIEW[2]

Community-based participatory research in public health is a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute their expertise and share responsibilities and ownership to enhance understanding of a given phenomenon, and to integrate the knowledge gained with action to improve the health and well-being of community members (27, 46, 51, 70-71).

The label "community-based participatory research" (CBPR) is used to acknowledge the fundamental characteristic that emphasizes the participation, influence and control of non-academic researchers in the process of creating knowledge and change. This approach is also often referred to as "community-based research". However, those of us involved in the Detroit Community-Academic Urban Research Center Partnership decided to use the label of CBPR because it represents a critical distinction from what is a somewhat different use of the term "community-based research", that emphasizes conducting research in a community as a place or setting, in which community members have only limited involvement, if any, in what is primarily a researcher-driven enterprise. Such an approach might be more appropriately referred to as "community-placed research". By comparison, community-based participatory research involves conducting research which recognizes the community as a social and cultural entity with the active engagement and influence of community members in all aspects of the research process (51, 71). Furthermore, the inclusion of the term "participatory" more clearly aligns CBPR with its roots in participatory research approaches (54-55, 57, 59).

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[2] This section drawn 27.

KEY PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH[3]

The following presents a set of principles or characteristics that seek to capture the key elements of this approach based on the present state of knowledge in the field. These principles will continue to evolve as further CBPR is conducted and evaluated. They are presented with the recognition that the extent to which any research endeavor can achieve any one or a combination of these principles will vary depending on the context, purpose, and participants involved in the process. While presented here as distinct items, community-based participatory research is an integration of these elements.

1. *Recognizes community as an unit of identity*. The concept of community as an aspect of collective and individual identity is central to community-based participatory research. Units of identity, for example, membership in a family, friendship network, or geographic neighborhood, are all socially constructed dimensions of identity, created and recreated through social interactions (71-73). Community is characterized by a sense of identification and emotional connection to other members, common symbol systems, shared values and norms, mutual influence, common interests, and commitment to meeting shared needs (30, 73-75). Communities of identity may be centered on a defined geographic neighborhood or a geographically dispersed ethnic group with a sense of common identity and shared fate. A city or other geographic area may not be a community in this sense of the term, but rather an aggregate of people who do not share a common identity, or may contain several different and overlapping communities of identity within its boundaries. CBPR endeavors attempt to identify and to work with existing communities of identity, and/or to strengthen a sense of community through collective engagement (30, 67).

2. *Builds on strengths and resources within the community*. Community-based participatory research seeks to identify and build on strengths, resources, and relationships that exist within communities of identity, and seeks to support or expand social structures and social processes that contribute to the ability of community members to work together to improve health.

3. *Facilitates collaborative, equitable involvement of all partners in all phases of the research*. Community-based participatory research involves a collaborative partnership in which all parties participate as equal members and share control over all phases of the research process (29, 34, 47, 50-51, 56, 67, 71, 76-79, 80-83). These partnerships focus on issues and concerns identified by community members (29, 67, 71, 76, 79, 83-86), and create processes that enable all parties to participate and share influence in the research and associated change efforts.

4. *Integrates knowledge and intervention for mutual benefit of all partners.* Community-based participatory research seeks to build a broad body of knowledge related to health and well-being while also integrating that knowledge with intervention efforts that address the concerns of the communities involved (29-30, 51, 55-56, 67, 69, 82, 87). Information is gathered to inform interventions, and new understandings emerge as participants reflect on the interventions conducted. CBPR may not always incorporate a direct intervention component, but there is a commitment to the translation and

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[3] This section has been adapted from 27.

integration of research results to intervention and policy efforts (51), with the intention that all partners will benefit (29, 51, 69, 76, 86, 88).

5. *Promotes a co-learning and empowering process that attends to social inequalities.* Community-based participatory research is a co-learning and empowering process that facilitates the reciprocal transfer of knowledge, skills, capacity, and power (30, 34, 48, 51, 67, 76, 79, 82-83, 89-91, 83). For example, researchers learn from the knowledge and "local theories" (92) of community members, and community members acquire further skills in how to conduct research. This process involves giving explicit attention to the knowledge of community members, and an emphasis on sharing information, decision-making power, resources, and support among members of the partnership (30, 34, 90-91, 93-94).

6. *Involves a cyclical and iterative process.* Community-based participatory research involves a cyclical, iterative process that includes partnership development and maintenance, community assessment, problem definition, development of research methodology, data collection and analysis, interpretation of data, determination of intervention and policy implications, dissemination of results, intervening (as appropriate), specification of learnings, and establishment of mechanisms for sustainability (30, 59, 67, 71, 95-99).

7. *Addresses health from both positive and ecological perspectives.* Community-based participatory research addresses the concept of health from a positive model (100-102) that emphasizes physical, mental, and social well-being (103). It also emphasizes an ecological model of health (2, 13, 18-19, 21-22, 30, 47, 101, 104) that encompasses biomedical, social, economic, cultural, historical, and political factors as determinants of health and disease.

8. *Disseminates findings and knowledge gained to all partners.* Community-based participatory research seeks to disseminate findings and knowledge gained to all partners involved, in language that is understandable and respectful, and "where ownership of knowledge is acknowledged" (84 pg. 186) (29, 36, 46, 51, 55, 84-85, 105-106). The ongoing feedback of data and use of results to inform interventions are integral to this approach (77, 96, 107). This dissemination principle also includes researchers consulting with participants prior to submission of any materials for publication, acknowledging the contributions of participants and, as appropriate, developing co-authored publications (51).

9. *Involves a long-term commitment by all partners.* Given the emphasis in community-based participatory research on an ecological approach to health, and the focus on developing and maintaining partnerships that foster empowering processes and integrate research and action, CBPR requires a long-term commitment by all the partners involved (51-52, 71, 77, 81, 108). Establishing trust and the skills and infrastructure needed for conducting research and creating comprehensive interventions necessitates a long time frame (77, 108). Furthermore, communities need to be assured that outside researchers are committed to the community for the long haul, after initial funding is over.

RATIONALE FOR COMMUNITY-BASED PARTICIPATORY RESEARCH

The rationale for and key advantages of community-based participatory research include: [4]

- Enhances the relevance and use of the research data by all partners involved (51, 109-111);

- Joins partners with diverse skills, knowledge, expertise, and sensitivities to address complex problems (64, 105, 111-113);

- Improves quality and validity of research by engaging local knowledge and local theory based on the experience of people involved (37, 46, 55, 76, 84-85, 92, 95, 105, 111);

- Knowledge gained can be used by all partners involved to direct resources and influence policies that will benefit the community (46, 55, 59, 76, 105, 113);

- Increases possibility of overcoming understandable distrust of research on part of communities that have historically been "subjects" of such research (52, 71);

- Has potential to "bridge the cultural gaps that may exist" (109, p. 211) between partners involved (34, 37, 52, 71, 84);

- Overcomes fragmentation and separation of individual from culture and context that are often evident in more narrowly defined, categorical approaches (22, 29-30, 98);

- Provides resources (e.g., funds, training) and possible employment opportunities for communities involved (52, 82, 95); and

- Aims to improve health and well-being of communities involved, both directly through examining and addressing identified needs and indirectly through increasing power and control over the research process (29, 51, 71, 76, 114-116).

POLICY RECOMMENDATIONS FOR ADVANCING THE USE OF COMMUNITY-BASED PARTICIPATORY RESEARCH

There are numerous challenges, and barriers, as well as facilitating factors in conducting community-based participatory research (27). It was beyond the scope of this presentation to provide an in-depth discussion, rather a few of the key issues were highlighted in conjunction with several policy recommendations aimed at advancing the use of CBPR. These recommendations are based upon our experience and conversations with members of the Detroit Community-Academic Urban Research Center Board. The discussion focused on three key interrelated areas for policy change (117): (1) funding research partnerships (e.g., planning grants, long-range funding, initial and ongoing funding for infrastructure, funding directly to community-based organizations, funding for comprehensive approaches, and grant application and review process); (2) capacity building and training for CBPR partners (e.g., pre and post-doctoral training, training

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[4] Adapted from 27.

programs for community members, and educational opportunities for members of traditionally marginalized communities); and (3) benefits and reward structures for CBPR partners (e.g., tenure and promotion process, and roles, responsibilities and recognition of community partners). This was not intended to be a comprehensive coverage of policy implications, but rather highlighted those that were of particular relevance for those of us attending the meeting.

CONCLUDING REMARKS

The past several decades have seen a resurgence of interest in partnership approaches to involving the public in public health research and practice. In order for community-based participatory research to continue to expand and improve there is a need for greater:

- Awareness and recognition of the meaning and value of community-based participatory research;

- Funding support from public and private funding institutions;

- Emphasis on capacity-building and training to enhance knowledge and skills needed to conduct CBPR;

- Benefits and reward structures for CBPR partners; and

- Use of multiple case study evaluations to assess the context, process and outcomes of community-based participatory research endeavors.

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Achieving Environmental Justice Objectives and Reducing Health Disparities Through Community-Based Participatory Research and Interventions

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West Harlem Environmental ACTion, Inc.

Minority populations live and work in polluted environments because of their race and color, whether they are African-Americans, Latinos, Asians, Native Americans or Pacific Islanders. Residents of these communities are exposed to greater health and environmental risks than is the general population. Government has done little to correct the environmental injustice that exists in this country, in fact, governmental action, as well as its inaction, and inequitable environmental enforcement, has often exacerbated the problems (e.g. zoning -- the chief device for regulating land use). Clearly, all Americans do not have the same opportunities to breathe clean air, drink clean water, attend environmentally safe schools, work in a clean, safe environment, and enjoy clean parks, open space and access to revitalized waterfronts.

People of color bear the brunt of the nation's pollution problem, according to a growing body of studies and reports. For instance, a PCB landfill was sited in a rural, poor, African-American community of Warren County, N.C.   The location was selected not because it was the environmentally sound choice, but because that community seemed powerless to resist. During a 1982 protest of this landfill, more than 500 people were arrested, and the term "environmental racism" was coined. The protesters believed this new action was just an extension of the racism they had encountered in housing, employment, education, municipal services, and law enforcement.

Environmental Racism is, as my colleague Norma Ramos says, a civil rights analysis of environmental decision making. It is discrimination in the enforcement of regulations and laws, in the deliberate targeting of communities of color for toxic waste disposal and waste transfer stations, permitting of polluting facilities in overburdened communities, and in the exclusion of people of color from the staff and boards of mainstream environmental groups, decision making boards, commissions and regulatory bodies. No one region has a monopoly on this problem. It is national and international in scope.

A number of strategic initiatives and interactions by environmental justice (EJ) leaders at the grassroots and federal levels have created steps toward change. They include:

1. The mobilization that culminated in the 1991 National People of Color Environmental Leadership Summit in Washington that drew 300 delegates and 1,000 participants from the grassroots, major environmental groups, foundations

and government. The delegates recognized a commonality that cut across geography, race, ethnicity, and culture. They left Washington with a draft of 17 Principles of Environmental Justice and a mandate to organize regional and national networks to democratize environmental decision making and empower communities of color to speak and act for themselves.

2. In 1993, these expressions became reality when the National Institute of Environmental Health Sciences (NIEHS) announced its *Environmental Justice: Partnerships for Communications* and later its *Community-Based Prevention/ Intervention Research* grant programs. These programs are unique because they include mechanisms for involving the public in both the identification and investigation of environmental health concerns, and ultimately facilitate communication between scientists, researchers, clinicians and community residents.

3. The 1994 Presidential Executive Order on Environmental Justice which directed relevant federal agencies to develop new policies and procedures to address the disproportionate impact of environmental hazards in communities of color and low income.

4. The 1994 *Interagency Symposium on Health, Research and Needs to Ensure Environmental Justice* hosted by the NIEHS in Crystal City, Va. was an important moment in EJ history. Attended by 1,100 people -- including 400 EJ advocates -- the importance of community involvement in setting and implementing research agendas was at the forefront of the discussion. Recognizing the meeting's momentous nature, the White House convened a signing ceremony of the Executive Order on Environmental Justice on the second day of the symposium.

Few of the 400-plus EJ groups around the country led by people of color receive government or foundation funding. Most of them are small and operate with resources generated from the local community -- as WE ACT did when it was founded in 1988. It has been mostly women who have emerged as grassroots leaders who see their families, homes, and communities threatened by polluting facilities and unresponsive government policies. WE ACT emerged from these types of community struggles here in New York City, in Northern Manhattan -- over the siting and operations of the North River sewage treatment plant and the siting of another diesel bus depot.

More than 500,000 mostly African-American and Latino residents live in Northern Manhattan, specifically in the neighborhoods of East, West and Central Harlem and Washington Heights, an area of 7.4 square miles. Northern Manhattan also houses over one-third of the city's 4,200 buses, in addition to the Port Authority's 650 diesel buses. The heavily trafficked Westside Highway and the George Washington Bridge (50 million truck crossings per year) bound these neighborhoods on the west, and the FDR Drive and the nearby Triborough Bridge (14 million truck crossings in 1998) bound them to the

east. Since neither highway allows truck traffic, neighborhood streets have become major truck routes.

On Harlem's westside, a dilapidated Hudson River waterfront, housing a marine transfer station, has temporarily halted operations. As a result, over 200 sanitation trucks are queuing up to dump their garbage. Next door to that dilapidated facility is the North River Plant where WE ACT organized civil disobedience by mobilizing residents for seven years. As a result of these actions, the mayor appropriated $55 million to fix the plant, which now operates better but still emits odors, pollutants that exacerbate asthma, and volatile organic compounds (VOCs) like perc. On Harlem's eastside the aging Wards Island sewage treatment plant emits hydrogen sulfides and nitrogen oxides that exacerbate respiratory disease.

In 1988, recognizing the need for data to make present a credible case to policymakers regarding the North River and the Metro Transit Authority's bus depots, WE ACT reached out to Jean Ford at Harlem Hospital for data and advice. From Dr. Ford's study, we learned that asthma mortality and morbidity in Harlem was three to five times that of other communities. Dr. Ford introduced WE ACT to his colleagues at the Harlem Health Promotion Center where we discussed our concerns about diesel particulates. A year later, Dr. Ford called to say that Dr. Graziano at Columbia's NIEHS Center had granted funds to his colleagues to conduct a pilot study on the effects of diesel on adolescents in Harlem schools. It took us two years to convince the local school board to allow the study. Although the school board approved the study, the school principal said no. Consequently, we implemented the study in an alternative school with 50 junior high school students. The study published in WE ACT's Uptown Eye newspaper two years ago was published in the June 1999 publication of the American Journal of Public Health. Results from urine analysis found biomarkers for diesel exposure in 75 percent of the youth in the control school.

Again through the NIEHS Center working with Patrick Kinney and our Earth Crew youth group we performed car, truck, bus and pedestrian counts at key intersections in four neighborhoods where the EPA was already monitoring for PM 10 and 2.5. In addition, the youth wore personal air monitors to gauge their personal exposures. We found that at four key intersections, the level of PM 2.5 measured 200 percent above EPA's new contested standards for small diesel particles. This data has been helpful in getting the EPA to fund community-based monitoring in the state DEC's air monitoring network. We believe that credible data on hot spots and community-level exposures are important if we are to impact public policy on these issues. This study was published to the community by WE ACT last year and was published in the March 2000 edition of Environmental Health Perspectives.

WE ACT often initiates foundation grants with Columbia as a sub contractor. For example, Dr. Kinney and his assistant work on our GIS project by providing training and assistance to our GIS coordinator, when needed, to produce maps that illustrate polluting facilities and health data.

Four years ago, WE ACT became principal investigator of an NIEHS Environmental Justice grant and is a partner on an NIEHS Community-Based Prevention/Intervention Research grant. Columbia's Harlem Health Promotion Center directed by Al Cohall and the NIEHS Center For Environmental Health In Northern Manhattan directed by Joe Graziano are partners. During the four years of one grant, we trained 60 community leaders primarily from Northern Manhattan in a two-month, six-course environmental health curriculum. We trained leaders on issues identified by the community at a series of three neighborhood-specific town hall meetings. And we began training clinicians during grand rounds on community environmental exposures. The intervention project headed by Dr. Kinney, director of the Exposure Assessment Core, will become potentially more significant when it is expanded next year to include the homes of 400 mothers and newborns participating in the Children's Center study.

Three years ago, Dr. Frederica Perera asked me to join the team of researchers who would be meeting to develop a proposal for one of these centers. We spent hours working together through the fall up to Christmas and in committees to develop a center proposal that was funded.

The Center's mission reflects a key concern of community residents and a demand that they made to the city 15 years ago: a comprehensive, community-based assessment of environmental risks to infants and children, and to develop strategies for reducing, and ultimately preventing those risks. Significant time was spent crafting an organizational plan that would ensure community involvement and ensure the effective use of the Community Advisory Committee. As a result, I serve as a member of the Administrative Core that provides overall coordination, guidance, and review of the Center's work. That review includes ethics involved in learning confidential information because the study includes meeting and working in people's homes; cultural sensitivity issues; issues like will all participants get real benefits like the educational intervention or the developmental tests which will be administered to all participants with feedback to the mother on her child's development.

As co-director of the Community Outreach and Education Program, I work with my colleagues to ensure community participation in the Center and its activities and to disseminate information about the Center to local and national audiences. The goals of the program are (1) to create awareness of the Center in targeted communities of Northern Manhattan and the South Bronx (2) to disseminate information about specific environmental factors under study by the Center (3) to engage community partner agencies and advisors in guiding Center projects and (4) to support the outreach effort of the Community Education Campaign called Healthy Home, Healthy Child, a 15-month educational outreach campaign to inform residents on actions they can take to reduce risks to their children at home.

More resources are needed for the creation and sustainability of partnerships between academic institutions and community based organizations that have a long-term commitment to environmental health and safety. It is through innovative programs such as the NIEHS Environmental Justice, Community-Based Prevention/Intervention

Research, and Community Outreach and Education Programs that environmental health scientists and community members come together to address environmental health concerns in an effective and culturally relevant manner. Though no one organization can speak for all members of a community, many are actively engaged in listening to, educating and representing area residents. Effective collaborations move us all toward a healthier and safer community using strategies arrived at through consensus of informed experts, community leaders and residents.

Partnership Building

Loretta Jones
Healthy African American Families

This paper reflects upon the processes for partnering and identifies key factors for establishing strong and effective relationships between researchers and communities. The first section discusses the lessons learned from the Healthy African American Families (HAAF) project in Los Angeles, California. The next section summarizes the discussion from the breakout session on partnership building. It considers a variety of projects that have been successful in developing partnerships between researchers and communities, and examines the similarities of these projects. Benefits of relationship building for community-based participatory research are outlined in this section. In addition, it identifies some major gaps, or issues that need to be addressed. Most importantly, it offers recommendations on the value of partnership building to Schools of Public Health, state and local health agencies, and public and private funding agencies.

Healthy African American Families, Los Angeles, California

HAAF over the course of five years has become a successful model by developing a strong partnership with the funding agency, the community and university. This process required a paradigm shift that meant putting aside bureaucratic rules, community hesitancy and academic superiority to agree that all participants should have an equal voice. This partnership succeeded by nurturing value and respect for each partner, being flexible, and trusting one another. In addition, community residents were hired in leadership positions. The project was housed in the community for increased visibility, as well as to foster community understanding of the research, and to encourage resident participation in this new paradigm of CBPR. This section highlights the major lessons learned and key issues that must be considered to ensure an effective partnership.

When embarking on the development of partnership and collaboration on applied health research and disease prevention and health promotion it is important to factor in the effect that information collected will have on the community that it serves.

In the past, investigators sometimes gathered information without full disclosure and without a sense of the communities involved. These data were recorded, stored, analyzed but not picked up again until (in the perception of the community) they were used to establish the inferiority of a community, its lack of motivation and/or intelligence, or to perpetuate divisive attitudes. In this context, the HAAF project was initiated on the following premises:

- All African American families have a right to health.
- African American families have some area in their existence, whether is it social, spiritual, educational, physical, economic or cultural on which to build and take charge.
- By overriding differences from past projects, health is seen as positive, proactive and productive.
- Health will not be viewed as lack of disease (although this is part of the definition) but a "Healthy African American Family" will be seen as reclaiming extended care and social support necessary.
- Through deep spiritual beliefs, African Americans have developed and nurtured an overwhelming sense of community and extended support system. Within the African American bloodline is survival, forgiveness, a deep spiritual faith and connection to a higher power, love and caring and the talent to achieve.

These premises serve as the groundwork upon which the HAAF based its prevention and intervention programs. The project strives to rewrite the phrase "beauty is in the eyes of the beholder" to "health is in the eyes of the community." This notion is very important because when a community believes it can accomplish something, it will. Therefore, the HAAF mandate is to turn the beliefs from thirty-second negative media sound bites to a lasting appreciation of the intrinsic value and worth that each family member and community member possesses.

In the process of developing a functional partnership, HAAF found that the following aspects require attention.

Equal Partners -- With the new paradigm of equal partnership, comes the shift of power and the necessity to listen to one another and to respect different perspectives. The new partnership establishes an agreement as to process/procedure, perspective, and time parameters. The shift takes place when the process is valued equal to the proposed research activities. Thus the process builds relationships and trust. The process creates its own synergy and energy, becoming a vibrant process creating living, breathing, and evolving outcomes.

Defining Community -- It is important not to consider the community as the "subject" of research. In CBPR, the community must be a partner. Sometimes a particular field of study (behavioral, clinical, medical, organizational, and professional) defines the research community. In so doing, the investigator may not obtain a realistic image of the community being studied.

University -- One of the most important steps in forming the partnership is choosing a university willing to participate in building the communities' capacity for understanding and benefiting from research. It is important to find a university that is committed to the community it serves. This means that they must have the ability to change rules, attitudes and beliefs to fit the new paradigm of "community involvement."

Community members may not possess academic credentials, but they are resident experts with "life experiences" in special areas. As such, their contributions to research should not be overlooked. With an increasing number of universities coming into the community-partnered research, each university will need to address employment practices to allow for the hiring of community members in leadership positions. By opening its doors to the community, the university can increase community access to resources, help interested community members learn research protocols, and facilitate linkages with different departments to build skills, and most of all place a value on the voices that come from the community.

Funder -- Commitment to a community-partnered research model is a commitment by the funding source to maintain close contact throughout the length of the project. Frequent site visits, after orientation to the project, to meet with project leaders and participants can serve to demonstrate the agency's commitment to these efforts.

Challenges -- HAAF discovered that partnering with the community can be challenging. Researchers should not assume that the community will immediately jump at the opportunity to collaborate in a community-based research project. This hesitancy results from a history of mistrust of the research community, an uncertainty of the direction the research or partnership may take, and a doubt of their status as partners, in particular, whether or not their abilities will be valued by the investigators. In addition, the community may hesitate if they believe they are not privy to the whole picture.

Joint Decisions -- To foster mutual respect and value of individual perspectives in issues, CBPR requires that these issues be addressed. It may be that what is an issue for the funding agency or the university may not be an issue for the community. Such issues include:

- Location of project.
- Hiring practices and procedures
- Roles of all partners and who defines them.
- Development of a system of communication for decision-making that allows for all involvement of all partners.
- Individual perspectives of project.

Value -- *Social bonding* is the core value from which the community operates. The elements of social bonding include attachment to other persons, commitment and involvement in the community, and the belief an expectation that opportunities for information sharing and the development of methods for providing technology transfer occur through attachment.

By utilizing the social bonding approach to dealing with serious health problems or diseases, partnerships move from control and compliance to a new skills set of continuous involvement and improvement on how we function as equal partners. In addition, the rewards for positive social involvement increase the likelihood that the

research outcomes will make a difference in the practice and behaviors of the community partners.

<u>HAAF Recommendations</u>

To make the process smooth the following elements must be present. Community-Based Participatory Research requires that staff must build "roots" within the community. Researchers and funders must be visible in the community, attend community meetings on a regular basis, establish offices within the neighborhoods, convene meetings in the community and provide opportunities for a wide range of opinions to be voiced. In addition, they should provide funding for community members who work on the project.

Not only should they be seen as researchers, they must also attempt to achieve the following:

- Adapt to various situations throughout the community.
- Serve as a resource to the community.
- Demonstrate an attitude of comfort in their surroundings.
- Actively participate in community events – providing the community asks for the participation.
- Establish memorandums of understanding (MOUs), which formalize the activities.
- Encourage productive collaborative relationships.
- Funding agencies should be active partners in the process. Ethically responsible for making sure project is operating to achieve goals and community benefits. Ideally also an advocate for community voice to balance power relationship.
- Develop appropriate funding structures which link research and subsequent intervention.

Summary of Breakout Session on Partnership Building

HAAF is only one model of how partnerships can be established successfully. This section synthesizes the discussion on partnership building and its value to schools of public health, state and local health departments, and public and private funding agencies. Challenges that must be overcome are also detailed.

Meeting participants identified additional projects that had successfully established collaborative partnerships between communities and researchers. The first, "Lead Busters" is an intervention project in New Orleans where community residents are employed and trained to make home visits to conduct interventions. In a similar project in Chicago, community members hired a researcher to work with them in performing the investigation. In addition, residents were hired and educated to help conduct research on asthma in the community. Finally, the Community Action Against Asthma (CAAA) project in Detroit demonstrates the effectiveness of community residents working together with scientists. In collaboration with researchers, residents help conduct asthma interventions by setting-up home air monitoring equipment and administering in-house

questionnaires. In this example, the leadership and participation of residents from within the affected community proved important.

The group considered the following two common themes as leading to the success of the projects and partnerships:

(1) Employment of community residents to participate in research efforts was seen as crucial to the success. By hiring residents, they are imbued with a sense of equality and empowerment. It demonstrates the researchers' appreciation for and value/respect of community participation.
(2) Community leadership plays an instrumental role in positive programmatic outcomes. In the three examples cited as successful models, all possessed some form of community leadership. Meeting participants expressed that better science was achieved when the community hired the researcher. Other commonalties included:

- Value/respect
- Trust
- Common language
- Information transfer (community ↔ researcher)
- Flexibility by all partners
- Working towards win-win
- Patience
- Co-authorship with community

Challenges and Approaches

Participants identified several challenges facing partnership building and offered ideas for approaches to overcome them. Funding was seen to present a challenge in three respects: consistency, focus, and priorities. When researchers and communities are assured of funding from one year to the next they are better able to work toward developing partnerships rather than searching out future resources. To begin addressing this challenge, institutions ought to consider developing long-term grant programs, such as the NIEHS Environmental Justice and Community-Based Prevention/Intervention Research programs.

Focus relates to the desire of funding institutions to pursue a specific health issue. To this end, funding is contingent upon research projects that address the chosen topic. The research focus presents an obstacle because it might not be relevant to the health concerns of a community, and it often does not factor in the multidisciplinary nature of many community health issues. As such, a greater emphasis needs to be placed on multidisciplinary research rather than overly focused research. Such an approach will engender a holistic view of the health problems facing communities.

Research priorities for many institutions are based in the laboratory. This fact typically means that community-based research efforts do not receive the same attention or resources as laboratory-based research. Consequently, it is difficult for investigators to

establish meaningful partnerships with communities. This challenge is particularly difficult for junior researchers, because they must exhibit their productivity to be considered for tenure. In this context, often the expectations for community-based research are greater than expectations for basic research. Investigators believe they have to justify their activities by demonstrating positive public health outcomes more so than for laboratory research. Schools of Public Health and Government agencies can begin addressing this challenge by developing incentives for their researchers to pursue more community-based research efforts. For example, schools of public health could develop new tenure guidelines that would include incentives for junior researchers to pursue community-based research.

Some challenges may be classified as institutional. Such as organizations that possess bureaucratic systems that do not encourage partnerships, or organizations that lack diversity at upper levels of leadership. If the institution does not promote partnership building it is unlikely that effective relationships can be developed between researchers and communities.

At times the best-intentioned researcher may sometimes present a challenge to developing a partnership. It takes a special person to be a community-researcher. Someone who possesses cultural sensitivity and understanding of the community served. At times the appearance of the researcher makes a difference in the level of trust between them and community members. Most importantly, if the investigator does not desire to study those issues of greatest concern to the community, it will be difficult for them to nurture an effective partnership.

Sense of empowerment presents a challenge to partnership building. If the community does not believe that it is truly a partner in the research process, the relationship suffers. In addition to sustainable funding, there is a crucial need for people to sustain community-based research projects. Therefore, as mentioned earlier, successful projects will hire community residents to work on the project. Other approaches for engendering a sense of equality include co-authoring journal articles with community members and funding community-based organizations and having them sub-contract with universities. Co-authorship accomplishes two outcomes. First, it demonstrates equality in the partnership, and second, it serves to disseminate information out to the community in a timely manner. When community-based organizations receive grants from funding institutions, they possess a sense of control about research directions, rather than feeling obligated to do what the researcher states.

Divergent expectations between communities and researchers sometimes present a challenge to a healthy partnership. From the scientists' point of view, results cannot be released until ample testing of data has been performed. The community, on the other hand, may not want to wait for the complete scientific assessment to be completed, especially if there exists enough proof to implement an intervention. In the same context, the community often needs to see progress for them to understand the benefit of the research performed in their neighborhood. Thus, it is crucial to establish attainable, intermediate goals so that residents benefit throughout the research process and do not

have to wait for the conclusion of the project. Researchers may sometimes have to intervene when results indicate it is reasonable to do so. That is, combine the intervention with the assessment of pathways so that communities benefit from the research sooner rather than later.

Benefits

Partnership building provides schools of public health and funding institutions with the opportunity to participate actively in creating networks of community relationships through which future support, research and interventions can be channeled and integrated. Community-partnered research creates a sustainable, institutionalized relationship for bringing resources and expertise together through a community-driven model for solving problems, which, in turn, influences health status at the local level. Trusting partnerships between investigators and communities will benefit schools of public health and funding institutions in the long run because research outcomes will be more reflective of community health concerns. In addition, by working with communities, recruitment and retention of residents to participate in the investigation will be greater, thereby assuring more valid results. Financially, it will likely be more favorable because, although it takes time to establish trusting partnerships, in the end, the results will be useful and positive health outcomes will be visible.

For state and local public health departments, as mentioned by a state health official at the meeting, such partnerships will help them advance their mission. In addition, successful partnerships will assist them in developing health care programs that are appropriate to the community's needs and understanding.

Summary

When Community buys into the research project, researchers and funding institutions have a better chance of receiving quality data. It also broadens the scope of allowing community to understand the research. Successful knowledge allows community residents to declare ownership of the intervention, thereby leading to sustainable solutions. By involving community members in the research process, the investigator is better able to test the accuracy of the initial research hypothesis in a shorter timeframe. In addition, community participation increases the community's understanding of disease risks.

Successful Process in Community-Based Participatory Research
Thomas Arcury
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There are numerous examples of successful community-based participatory research (CBPR) projects. These projects have accomplished their research objectives and shown research productivity by maintaining a positive working relationship between community and scientific collaborators. While there are successful projects, there is not a single "model" for success. Rather, the process of CBPR entails several components, stages or elements that must be considered if we are to understand the features of successful process. These components include (1) the formation and ongoing maintenance of community relationships; (2) developing a focus and defining research problems; (3) understanding the ideological background and political nature of CBPR; and (4) documenting and communicating CBPR results. Problems in the CBPR process and gaps in our understanding of the CBPR process must also be addressed. Finally, we need to understand the features of CBPR process that are important for the institutionalization of this research paradigm within schools of public health and public health departments.

Formation and Maintenance of Community-Scientific Institution Relations

CBPR requires a working relationship between a community or community-based organization and at least one scientific institution. The scientific institution is usually a college or university, but may also be a nonprofit research corporation or hospital. Formation of a relationship may occur when a community group searches for technical assistance or when a researcher comes upon data that indicate potential health risks to a particular community. How community group or researcher initiate contact with each other will often determine the trajectory of the relational process. The formation and maintenance of relationships between communities and scientific organizations involves understanding community infrastructure, and building inter-organizational as well as interpersonal relationships.

Understanding the community infrastructure: Successful projects take the time to explore or map the structure and resources that exist in the community. Such an exploration discloses the different groups in the community, community leaders, and the resources and skills available in the community. It also delineates how other communities share social space with a specific community. Understanding community structure is an ongoing process as communities are dynamic and change over the life of a collaboration. Academic organizations are also dynamic social units (e.g., deans leave, presidents change, department chairs resign). Individual investigators and community organizations must continue to be aware of this part of the structure with which they must deal.

It is important that the collaborators measure the community's current characteristics -- demographic, social and political. Accepting old information on face value can lead to mistakes and misunderstandings. In some instances, community members have requested that researchers assist them in developing more accurate portraits of community characteristics. For example, in North Carolina, farmworkers have changed over 1990's from the majority being native African Americans, to large numbers being Haitians and other Carribean Islanders, to the majority being Mexicans. The composition of the Mexican worker population is changing to a higher proportion of Indigenous Peoples. The 1990 population census, and estimates based on this census indicate that there are few Latinos in North Carolina, while the actual population now numbers in 100,000s.

An unexplored (or unreflected upon) element in the development of relationships for CBPR projects is that of the community's social ecology. How does rurality or urbanity affect relationships between community members and scientists in CBPR projects? In some situations, rurality may ease the CBPR relationship where the staff of formal service organizations (county health departments and social service departments, county administrators) are members of effected communities and share common histories with the members of community-based organizations. A shared common history may not be present for the staff and officials of formal and governmental organization and community groups in metropolitan areas. Metropolitan formal organizations that serve local communities draw their staff from a much larger pool. A shared history can also be detrimental to CBPR relationships. In some rural areas, those who administer and staff formal and governmental organizations have different backgrounds from the members of groups experiencing environmental injustices or health disparities. For example, often those who provide services in rural counties are related to (i.e., are the spouses, siblings and children of) the employers of farmworkers, the operators of intensive livestock operations, and operators of the strip mines.

The experiences of successful CBPR projects show that even when a significant effort is made to map a community, there will be unanticipated or not fully appreciated elements of the community. This lack of community knowledge or understanding can result in difficulties for individuals, organizations and collaborations. While these occurrences are often learning experiences, to those who experience them they are akin to the learning experience for the child who puts a finger in a wall socket – it is unclear if the new knowledge is worth the pain.

Building and Continuing Relationships: Building person-to-person relationships is extremely important for conducting successful CBPR projects. These relationships entail individual scientific investigators working with and developing the trust of community members and community organizations. Building these collegial relationships between community members and scientists takes time. The time invested to build mutual understanding is essential if a CBPR project is to flourish, because the investment in person-to-person relationships is translated into the flexibility and trust necessary for those stressful aspects of collaboration such as building project agenda and preparing grant applications.

It is also important to establish organization-to-organization relationships between academic and community organizations that extend beyond the person-to-person relationships. If the success of community-academic partnership is based solely on the positive relationship of an individual from an academic organization with the members of a community, then this relationship can be easily disrupted. Community organizations need to have a sense that academic institutions are reliable partners; that the scientific organizations are not ready to withdraw when political pressure is applied. There are several mechanisms that increase academic institution reliability. First, efforts should be made to educate the university's upper level administrators about the CBPR project and the health issues that it addresses. If administrative leaders are educated about the full scope of a CBPR project, they will be able to respond to external questions and pressure in an informed manner. For example, University of Iowa faculty members investigating the community and economic consequences of intensive hog production facilities educated the university president about their research program. When representatives of the hog industry tried to pressure the president, she was able to respond appropriately and continue university support of the research.

Involving students in projects is another mechanism for increasing academic organization reliability in CBPR projects. The primary mission of universities is training students. A cadre of students who have had positive experiences in a CBPR program is a foundation for support within a university.

Finally, scientists involved in CBPR projects should seek colleagues to involve in these collaborations. Increasing the number of faculty members who participate in CBPR projects has several benefits. First, there are a greater number of potential investigators to work on new project ideas as they develop through university-community interaction. Second, there is a group of advocates if university administrators threaten to remove support for a specific project. Finally, it allows individual scientists to move from a university without precipitating the collapse of a CBPR collaboration. Scientists involved in CBPR projects need to be aware of colleagues who have important research skills and who already have the ideology that will make them amenable to working in CBPR.

There are obstacles to building inter-organizational relationships between community and academic organizations. Many academic institutions have checkered histories in their relationships to local communities, and some have an acknowledged racist history in their dealing with minority populations. The dominant research paradigm within academic institutions continues to be intellectually elitist, often idealizing "pure" research and denigrating "applied" research. Therefore, the occupational and professional promotion of those who engage in CBPR can be jeopardized. While this jeopardy varies by discipline, those in the senior ranks of the professorate have substantial power over promotion no matter the discipline of the CBPR researcher. Finally, the current realities of academic employment severely limit the time academics have to build community relationships. In particular, junior faculty members need support in these efforts. As community members often have full-time jobs, the time

for community relationship building is often in the evenings and on weekends. The academic researcher who is involved in evening and weekend CBPR activities is often investing family time and is not given release time from other professional duties.

Developing a Research Focus and Defining Research Problems

How a research focus is selected and how research problems are defined are important aspects of success in the CBPR process. The development and continuity of relations between community members and university scientists improves how research problems are defined and projects are focused. The chances for success are greater if the research focus and problem reflect real issues for community members. For example, childhood asthma is real to a community with many sick children. Genetic differences in the role of allergy susceptibility for asthma attacks may be of greater research interest to scientists than is research on ways to improve indoor air quality. However, community members can implement changes based on indoor air quality research, and therefore see the results of their efforts in reduced hospitalizations. They cannot do anything about their children's genes. For scientists to pursue "less theoretically interesting" but more effective problems is facilitated by a firm relationship with community members. (The converse is also true. When there is a firm relationship between academic scientists and community members, if the scientists ask for community support for projects that have a less direct effect on improving health in the community there is a greater likelihood of receiving this community support.)

Greater success is also related to how research questions are raised in a CBPR project. Research questions initiated by community members are automatically of interest to that community. For example, community members will be more willing to support and participate in research on the effects of diesel exhaust fumes on lung disease among community residents when they perceive it as a community health issue, and less willing to collaborate with an academic scientist who simply wants to specify the fraction of air pollution made of diesel fumes.

Specific problems that have tangible results are more amenable to success in CBPR projects. A CBPR project can successfully remove lead, or learn ways to reduce the amount of lead to which children are exposed. Delineating the causes and implementing the procedures or interventions to eliminate all of the factors resulting in health disparities are much more difficult undertakings that may require a radical restructuring of the society. However, for CBPR projects to be successful their results must also be used to change public policies such as the unequal provision of essential services, unjust siting of toxics-emitting or noxious facilities, and selective enforcement of existing laws and regulations.

Understanding the Ideological Background and Political Nature of CBPR

A successful CBPR process is dependent on participants acknowledging the roles of ideology, politics and policy. Participation in a CBPR project by community members and scientists requires that they share an ideology about the importance of community

participation in society and in problem solving. The science that is conducted as part of a CBPR project must meet the same standards as that of any research project. However, collaborating on a CBPR project is a statement by community members and academics that mutual respect and work is democratic and enhances the benefits of research for local communities.

CBPR is a political process and a political statement. Acknowledging this simple fact will frighten some members of the academic community, particularly those who still operate under the illusion that science is value-free and that politics are seperate from research. However, all research is value-based. We should all be conscious of the influences of the political process on how governments allocate research funding, and that "pure" scientists are eager to apply for that funding when it is available.

In the process of CBPR we must address political realities. In all CBPR projects we are working on issues that affect societal elites – politicians, industries – with political power. Ignoring political and legal pressure is detrimental to CBPR projects. The entire domain of SLAPP (Strategic Lawsuits Against Public Participation) suits has been one legalistic response of elites to extinguish CBPR projects.

CBPR must deal with advocacy and policy. Community groups involved in CBPR are advocates for their communities. For the process of CBPR research to succeed, participants need to provide a constructive format to translate scientific results and advocacy into policy at the local, state, and national levels. The willingness of academic researchers to engage in advocacy and policy enhances credibility in the community and builds trust. The CBPR researcher should educate his or her institution about the issues being addressed.

Documentation, Dissemination and Communication of CBPR Results

Making research results accessible to communities and community members is fundamental to successful CBPR process. Results need to be published in many forms to ensure that the entire partnership benefits from reporting project results.

Results published for the community must be disseminated in appropriate venues (local newspapers, newsletters, circulars) and in appropriate languages for community members. Efforts must be placed on methods of dissemination and communication that meet the special needs of community members. In communities with a history of scarce educational resources and limited educational attainment, the communication of CBPR results needs to make use of media other than print. For example, direct oral presentations to groups of community members, local radio and television broadcasts (e.g., using local access channels), and providing videotapes through community organizations are all ways to disseminate study results to those with limited literacy. Among some immigrant communities, particularly those from Mexico and Central America, *photonovella* and comic book formats are culturally appropriate media for communicating study results. Community dissemination can be a full-time job, and project resources must be allocated for this purpose.

It is also important to disseminate CBPR project results in professional journals. Publication in peer-reviewed journals makes the results of CBPR projects more powerful influences for policy change. Publication of CBPR results in refereed journals not only records what was found, but also validates results among other scientists. Seeing the results of CBPR projects in professional journals will improve the evaluation of CBPR among professional colleagues, and among university leaders.

Disseminating CBPR results is not an activity to be left to the end of the project. It must be an ongoing activity of successful CBPR projects. The active dissemination of CBPR results is an important mechanism for providing a progress report to community members. It provides feedback to community participants, and acknowledges their time and efforts. Reporting results in progress can be a ticklish issue for the scientific aspects of a CBPR project. Preliminary results are often incorrect. Releasing results while still collecting data or evaluating interventions can "contaminate" or influence the project results.

Finally, dissemination and communication of CBPR results are important avenues for influencing policy. Solid, defensible scientific results are more difficult for entrenched political powers to ignore than are the "undocumented" opinions of community residents.

Gaps and Problems

In addition to problems already discussed that can damage process in CBPR projects, there are several additional gaps and problems that need to be considered. The first of these is researchers over promising what science can deliver. A single project, no matter how well designed and executed, can seldom result in a cure for long-term problems experienced by a community. Developing culturally appropriate health education materials and processes is important for improving general health in a community, but health education cannot alone cure social injustice or health disparities.

From the other perspective, community members should not blame scientists for not finding what the community wants them to find. Community advocacy groups often say that community members already know the answers, they are only waiting for scientists to prove them right. Unfortunately, sometimes community members are wrong. It is better to learn from projects that do not prove community members' beliefs and look for other causes, than it is to blame researchers for lacking skills or sincerity.

Too often in CBPR projects the collaborators do not address the real end-game, policy. More attention must be paid in the development and implementation of CBPR projects to producing and disseminating results in a manner that can directly effect policy.

Finally, in CBPR projects there is a tension between process and product. Much effort is invested in the process of CBPR, in building relationships and ensuring

participation. On occasion, projects fail because no resources remain for actually completing the research after the investment in the process.

Institutionalization of this Research Paradigm

The ultimate success of CBPR process depends on the institutionalization of this paradigm within schools of public health and state and local public health departments. However, both of these institutions must be convinced that CBPR is beneficial to their meeting their primary missions – educating public health professionals and improving the public health. CBPR must be seen by these institutions as a process that better enables them to these ends. Improved efficiency in data acquisition and intervention are motivation for exploring CBPR by both schools of public health and state and local health departments. Relationships built between a school or department and a community during one project will provide the basis of future projects and cooperation during emergencies. The increase in cultural competence and in simple humanity gained in institutions through participation in CBPR projects will also reduce the likelihood of breaches in medical ethics and mistakes that damage community health.

Evaluation

**Evaluation as a Strategy for Documenting the
Strengths of Community-Based Participatory Research**
Linda Silka
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Schools of public health, departments of public health, and funding agencies are showing increasing interest in the successes of community-based participatory research (CBPR) projects. As such, evaluations assist researchers demonstrate their public health outcomes, in addition to the processes by which effective community-based partnerships achieve their effects. This summary addresses the following four questions raised during the evaluation breakout session:

1. What are these effects of community-based partnerships?
2. How do CBPR partnerships achieve these effects?
3. What kinds of evaluations are most helpful in enabling us to assess these effects?
4. How might funders assist schools of public health and departments of health in setting the conditions for effective CBPR partnerships?

What are the effects of CBPR: The Findings Emerging from Partnerships

Evaluations of community-based participatory research point to a variety of important achievements emerging from these partnership approaches:
- New research questions that would not have emerged except through close collaboration
- Greater usage of research findings by community groups and individuals who are most at-risk for compromised environmental health
- Maintenance over long periods of time of ongoing research and application collaborations
- More effective recruitment of minority youth to education and training in environmental health careers
- Greater involvement of communities in designing and carrying out research protocols so that the findings speak to the concerns of the community as well as the interests of the researchers
- Better sampling methods for hard-to-locate communities because the methods are based on the depth of community understanding of how to reach people and elicit their interest
- Emphasis on reaching multiple audiences (academics, communities) with research findings so that steps can be taken to implement changes based on high quality research
- Shifts in the ways in which departments of public health engage in education and outreach with their local communities
- Redirecting of the training of environmental health scientists so that collaborative approaches to carrying out research are more fully understood

As is suggested above, CBPR is replete with new and innovative elements (practices, interventions, approaches to decision making, partnership arrangements, ways of incorporating health practices into community institutions, strategies for searching out research questions). During the conference, participants pointed to multiple ways in which they are using evaluations to build a repository of lessons about CBPR and its successes that can be made available to communities, researchers, and others. These evaluations:

- Demonstrate the benefits of operationalizing translational research
- Identify general products or outcomes that are more likely to occur under CBPR than under other approaches
- Build a body of knowledge that can be generalized to other settings and communities
- Place information about the successes of community-based research approach in the hands of multiple users
- Trace process as well as outcome, partnership building as well as health outcomes
- Document immediate and longer-term outcomes that emerge from CBPR
- Refine evaluation tools that can capture complex partnership developmental issues over time
- Show which practices are needed if CBPR is to be sustainable across time and across new partnership arrangements
- Identify workable strategies for community-researcher partnerships to address challenging problems of sharing power
- Provide models that assist communities in building new partnerships with researchers
- Assist critics in better understanding the strengths and benefits of CBPR

Participants also called attention to the important role that evaluation is now playing as an empowerment tool. Effective CBPR evaluations are motivational as well as diagnostic. They energize participants and direct attention to what is working and what may be in need of some refinement. Evaluations provide information that documents effective practices but also focus on motivating partnerships to improve practices through identifying and overcoming barriers.

How do these partnerships achieve their effects?

Much of the focus on evaluation has been on pinpointing how these partnerships achieve their effects. They achieve their effects through clear, well-documented partnership processes that share certain characteristics but which also vary in distinctive ways that are responsive to local conditions. The examples of the Detroit-based *Michigan Center for the Environmental and Children's Health* as well as *Healthy African American Families* in Los Angeles reflect these partnership processes. These partnerships produce research that benefits many groups throughout the country, but do so in ways that are responsive to local needs. Evaluations of successful partnerships such as these have documented that they:

- Build ground rules and decision-making criteria that specify conditions under which the partnership will operate

- Move beyond a limited advisory board approach to a broader set of ongoing working relationships
- Define partnership, equal voices, and other processes that will be central to the collaboration
- Attend to the temporal cycle of research and intervention and involve all partners in decision making at each critical juncture
- Recognize that there will be significant up front partnership development time but that will then result in long term, flexible research and intervention collaborations
- Focus on capacity building that includes all members of the partnership
- Develop sustainable rather than single study or investigation relationships
- Recognize that ownership of the research findings does not reside only with the researchers
- Use multiple, ongoing methods to share and communicate research results

Even the process of deciding on the evaluation design is important to the partnership. Successful partnerships make this process participatory. Discussion focused on the importance of not undercutting the partnership process through the approach taken to evaluation. Evaluations of CBPR are successful to the extent that they employ methods that attend to the partnership as the audience rather than to individual researchers. It was noted that CBPR often moves along by carefully establishing community-university research partnerships, yet this collaboration is sometimes undone at the point of the evaluation's introduction when there is a sudden reversion back to the researchers or funders as the primary audiences. The informational needs of the community partners are eclipsed. Successful evaluation strategies have been found to be those that are culturally- and partnership-appropriate. Evaluators are now paying close attention to how a particular CBPR partnership communicate s and are identifying ways in which capacity for evaluation can be built within partnerships by using recurrent reporting practices, tools, and community metaphors.

Successful partnerships are not all alike. Participants at the conference pointed to the importance of attending to the factors that make a partnership work under local conditions. CBPR programs are shaped by context. An important caveat was made about not generalizing until local conditions are well understood. Too general a focus can lead to a failure to understand how partnerships are created and sustained under particular conditions. Within the discussion it was noted that it is sometimes assumed that it is possible to replicate practices that were successful in one place. Experienced participants in partnerships pointed out that care must be taken to allow for building a focus on context into the evaluation approaches. We can learn from each others' programs and partnerships but it is important to recognize the extent to which these are not "plug-in" programs.

What kinds of evaluations are most helpful in enabling us to assess these effects: Common features of successful evaluation models

Converging models for evaluating partnerships are now appearing, including those from NIEHS EJ and CBPIR programs, CDC REACH2010, HUD Community Outreach

Partnership Centers, CSAP Community Partnerships, Aspen Institute "Comprehensive Community Initiatives" Roundtable, and the Community Tool Box/Healthy Communities Initiatives. All of these models integrate the evaluation of process and product, avoid the "black box" problem of identifying impacts but not input, and do not simply mimic pretest/posttest random assignment design. They emphasize the tracking of complex research partnering over time. These models quantify process. In other words, they identify quantitative proxies for qualitative events, use logic models to identify key process variables, and often use cumulative graphs to chart temporal changes. These evaluations focus on partnership developmental issues. That is, they focus on generalizable models of partnership building, emphasize feedback cycles for program improvements, and are responsive to the cultures of key stakeholders. These models can assess problem solving, innovation, impact, sustainability, economics of effort, strength and equality of partnership, and change in research/community practices. Successes captured by these models include: emergence of new research questions, a clearer understanding of applications, shorter time to usage of findings, and convergence of perspectives.   All of these models focus on a partnership approach in which all of the partners are invested in identifying the strengths of the partnership and programs and are focused on identifying ways that successful CBPR can be achieved.

How funders might assist in setting the conditions for effective CBPR partnerships

Finally, conference participants also raised questions about the uses of evaluation— questions that have direct importance to the decisions that funders might make about the evaluation requirements that they build into their "requests for proposals."

In this regard, participants pointed to the importance of sorting out who will use the evaluation (e.g. the community, researchers, or funders), and toward what ends (e.g. program documentation, program outcome assessment, program improvements, improving local practices, or generalizing to other programs). Participants raised questions about the kinds of evaluation designs and data collection particular users will find credible. These points were repeatedly framed in terms of the question, "Who is the *client* for the evaluation?" It was noted that sometimes there are, in effect, hidden clients or users--those who might adopt what was begun as a demonstration program (clients such as state departments of public health). These "absent" or future clients sometimes are not included in initial evaluation discussions, yet without their involvement it remains difficult to envision what they might want to know about the workings of these programs. It was also noted that the partners or clients for the evaluation sometimes change over time. Some groups such as schools of public health might not have been interested in a particular CBPR in its initial stages. Only later do they become interested in adopting or developing similar programs and need specific information about process and outcome. We need to be attentive to the kinds of evaluation information they find credible and we may also want to work with these "absent" partners to assist them in learning about which evaluation practices have been found to be appropriate for CBPR.

In calling for more community-based research partnerships, conference participants also pointed to several next steps that could be taken in promoting evaluation guidelines and

best practices that would prepare new partnerships for success. Participants suggested that funders (or perhaps groups of current grantees) might develop a guide to "best practices" for evaluating CBPR. This guide would summarize current successes and describe multiple models that reflect different kinds of partnerships and health problems currently addressed in CBPR. Evaluation tools used by partnerships that are appropriate to CBPR partnerships could be included. Such a guide would enable partnerships to make informed decisions about how evaluations can be carried out in a participatory fashion even in the face of limited resources. Such a guide would also provide models, information, and ideas to foundations and other federal agencies that are attempting to increase use of CBPR. In designing RFAs, funders could then draw on such a guide and encourage evaluation approaches that are aptly suited to capturing the complex characteristics of the CBPR approach. An RFA could summarize what will be considered acceptable evaluation approaches and could suggest evaluation tools that partnerships might use. Criteria should be included that are appropriate to the direction of the research. Participants also noted that we might look for opportunities during the review process itself to prepare reviewers for assessing whether the evaluation components employ practices that are consistent with the partnership approach.

Attention was also drawn to the need to develop strategies for building evaluation capacity within all parties to CBPR partnerships. In other words, if evaluations are to be truly participatory, then effort needs to be directed at developing practices that will prepare all parties to contribute to this process. The evaluation should not focus just on what is of interest to the funder or academic partners, but should also be designed to gather information that will enable to the community partners to answer community questions. The process by which the information is gathered, summarized, and disseminated should be consistent with the partnership approach.

Concerns were raised about the costs of carrying out high quality evaluations if they are to provide detailed process and outcome information. Various suggestions were made to reduce costs. Perhaps the focus of evaluations could be prioritized within specific projects. Rather than focusing on all elements of a partnership, a few components that have been found to be especially challenging to implement could be emphasized. These targets of intensive evaluation would then change over time as more knowledge is gained about the workings of CBPR. Costs could also be contained by integrating the evaluation data collection into the research components or by using archival materials or administrative data sets where available. The University of Michigan has identified and implemented strategies using this approach. Representatives of partnerships described having embedded evaluation within the educational components of the partnership, again as a way to integrate evaluation and also reduce costs. Yet another alternative suggested was to look at ways to aggregate information across various partnerships or projects. This suggestion came with the warning that one needs to make certain that aggregation is not carried out in a way that is inattentive to the needs or focus of particular partnerships.

Final Comments

Community-based participatory research has reached maturity. Evaluations of successful partnerships now provide a body of evidence of the conditions under which CBPR will achieve gains in directing resources toward environmental health risks of greatest concern to communities. Effective partnerships have emerged in settings around the country and are not limited to particular geographic locations. In some partnerships the researchers and community members live and work in the same community. In others, the partners are separated by thousands of miles. Detailed evaluation information is increasingly becoming available that speaks to successful arrangements under a variety of conditions that bring underserved communities, health care providers, and environmental researchers together in sustained ways. The guidelines for practice articulated by participants throughout the NIEHS Conference on *Successful Models of Community-Based Participatory Research* and summarized in this report point to opportunities to increase CBPR in initiatives carried out by departments of health and schools of public health.

Research and Intervention

Successful models combining intervention and basic research in the context of community-based participatory research

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Definition of "success".

For community-based participatory research projects combining intervention and basic research, success can be defined by many different criteria. Some of these criteria include: the successful undertaking of the basic research component of the project; successful outcomes of the intervention research component of the project, increased capacity building due to the project, successful community-researcher partnership aspect of the project; sustainability of the intervention component (if successful and deemed worthy of sustaining); sustainability of the partnership; and translation of the research. One way to evaluate the success of a community-based participatory research project that combines intervention and basic research is to consider how well both the intervention and the basic research components are able to meet their specific aims (as articulated in the original grant proposal), and are able to do so in a way that is found to be respectful, beneficial and participatory to the community partners involved in the project.

One recognized challenge in identifying examples of successful community-based participatory research projects which have combined both basic research and intervention research is the limited national dissemination of the work beyond academic journals. As one participant noted, "We don't publicize what we do". Given the amount of time it takes to implement and evaluate intervention research and then undergo peer review and publish the results, a delay of four to five years may result before the project is described in the literature. One partial solution to this problem could be to use a strategy recently adopted by the CDC funded Prevention Research Centers. The Prevention Research Centers now post descriptions of their projects on their individual web page. The issue still remains that scientists are often reluctant to release scientific findings before they are peer-reviewed, but use of electronic media can be one solution for the need to disseminate community-relevant information prior to publication of scientific findings.

Examples of Successful models.

Admittedly, the combining of intervention research, basic research, and community-based participatory research can be challenging. While many good examples exist of projects that successfully demonstrate one or another of these types of research, there are fewer examples of projects combining all three of these types of research. Nevertheless, several good examples come to mind. The Highlander Center in Tennessee has been involved in community-based participatory intervention research for many years and is

most notable for establishing and maintaining an infrastructure to continue the partnership aspect of this type of research long after the initial funded project has finished.

The Centers for Disease Control and Prevention (CDC) funded Urban Research Centers include examples of projects that have successfully combined intervention research with basic research in the context of community-based participatory research. For example, the Detroit Urban Research Center has established a community-based participatory partnership that is currently involved in 7 affiliated research projects, all of which focus upon areas of concern identified by the community partners. In the East Side Village Health Worker Partnership in Detroit, an Urban Research Center (URC) affiliated project, researchers are both implementing a lay health advisor program to improve women's and children's health as well as exploring, through longitudinal data, the relationship of social determinants (e.g., stress, social support, community capacity) to women's self-reported health status.

The National Institutes for Environmental Health and Sciences (NIEHS) community initiatives also include examples of successful community-based participatory research projects combining intervention and basic research. The NIEHS funded Oregon project "Reducing Pesticide Exposures in Families" is an example of a project that includes migrant farmworker community representatives, analytical chemists, epidemiologists, exposure assessment scientists, investigators skilled in qualitative research methods, and neurobehavioral scientists. The blend of each of these areas of expertise allows for the generation of information to the community (e.g. workshops, training videos) and scientific information on the pesticide exposures of farmworkers and their families and the effects of exposures on human health. The community benefits for the increased knowledge of the nature and extent of pesticide exposures in their work and home environments while the basic and applied scientist gain an increased sensitivity of community priorities and the need for culturally appropriate research methods and communication.

The Lead Awareness: North Philly Style project focus involves the implementation and evaluation of community-based strategies addressing childhood lead poisoning. The targeted population is an economically disadvantaged, underserved urban African-American population in North Central Philadelphia, who are at risk because of lead in their environment. In order to achieve culturally appropriate approaches applicable to underserved populations, the selected community-based strategies have been developed with community residents in an alliance with agencies having a demonstrated history of grass-roots activism in this community. The aims are: (1) To test community-developed, community-based prevention/intervention strategies that will increase knowledge regarding the environmental health risk of childhood lead poisoning; and (2) To test community-based prevention/intervention strategies that will increase hazard, exposure and outcome surveillance for lead as an environmental agent.

***Common features/threads of models combining intervention and basic research in the
context of community-based participatory research***

Some common features of models include:

*Importance of a strong partnership and the building of an infrastructure to sustain that
partnership*. Successful models of CBPR combining intervention and a basic research
have the common feature of a strong partnership. In some cases, this partnership was
formed to respond to the RFA. For example, the NIEHS-funded Oregon farmworker
project brought together scientists from a research center focused on work and
environmental exposures and health, and a long standing community agency, the Oregon
Child Development Coalition, which had an infrastructure that had a history of partnering
with other agencies to obtain federal funding. While the players in the project
represented a new mix, the process of collaboration and resource sharing was familiar to
both.

In other cases, the partnership has been established at least a few years before the current
intervention/basic research project is funded, thus allowing time for partners to develop
the relationships and trust level needed to successfully develop and apply for a project
combining intervention and basic research. This existing partnership is most crucial in
projects which contain basic research which might be considered invasive or not of
immediate value to community members and participants. Related to the presence of an
already existing partnership is the existence of some type of infrastructure to sustain the
partnership through the various project cycles. For example, the Detroit URC was able to
more easily apply for the NIEHS/EPA Centers for Excellence in Children' s Health RFA
because they had already been in existence for 3 years prior to the RFP announcement.
During this time, the URC had been able to identify priority areas for future projects and
one of those priority areas was children's environmental health. Also, the URC had been
able to establish a level of trust which more easily allowed the members of the
partnership to discuss openly their concerns about combining basic research with
intervention research in the context of the application to NIEHS/EPA. In addition,
through funding provided by CDC, the URC has been able to establish an administrative
infrastructure that is not dependent on funding from any one project.

The challenge of combining research and intervention. For projects that combine
intervention and basic research, a constant challenge is the tension between the "research
aspect" and the "intervention aspect" in the eyes of community and academic partners.
For example, the need to delay the beginning of the intervention due to data collection for
the basic research aspects of the project can be a source of frustration for community
partners who feel the community is receiving no direct benefit from the research until the
intervention activities begin. Secondly, a well-designed intervention study involves
extensive planning for the baseline and post- intervention data collection that will
determine the success of the intervention. This methodical approach to planning the
intervention can be viewed as too prolonged to community members who recognized the
need in the community for the intervention to occur in a timely manner. Successfully
navigating this challenge is greatly facilitated if the partnership has established a level of

trust that allows honest and open discussion of all members concerns. Open discussion of the timelines of the project and the projected outcomes that will be of benefit to each of the collaborators is of utmost importance. One of the factors that can facilitate the establishment of a level of trust is the length of time the partnership has been established and in operation.

The need to clarify goals to all involved. A common element of the successful models of CBPR which combine intervention and basic research is identification of and agreement upon the goals and expected outcomes of the project at the beginning of the project. This process of goal identification should involve all partners so that the researchers understand the community partners expectations of the benefits and outcomes of the research and the community partners understand the researchers desired outcomes, expected benefits. During this process of goal clarification, potential challenges to the successful completion of the project can be identified. For example, for purposes of sound intervention research, the researchers may suggest a control group design. However, the community partners may be concerned that in a traditional control group design, all participants will not necessarily receive the intervention. By identifying this issue up front, the partnership can work to find a solution acceptable to all members of the partnership, such as a delayed intervention design.

Value-addedness of Combining Basic Research and Intervention Research. The integration of basic research with intervention research in the context of community-based participatory research can produce a synergistic effect for the overall research as well as individual benefits for the basic research and the intervention research. For example, the intervention component can use data collected through the basic research component to guide intervention activities as well as to evaluate the effect of the intervention. In addition, if the basic research component involves human participants, study participants are better recruited and retained through the opportunity afforded for involvement in intervention activities. Together the two components may share costs of personnel and data collection, which allows for resource sharing. Also, by combining the two components under one steering committee or advisory board, the project is able to protect the time of community partners by not asking them to participate on two separate steering committees.

Value of Community-Based Participatory Research to Project Combining Basic Research and Intervention Research

Value of Community in Framing Research. The input of community members in the project design, implementation and evaluation of combined CBPR Basic and Intervention Research greatly enriches the research process and overall outcome. Community members' contribution to framing the research questions, reviewing and revising questionnaires and publications, designing recruitment and retention strategies, identifying and hiring staff, and overall project design ensures that the research is of high quality and grounded in the experience of members of the particular community where the research is taking place. Involvement of community members also greatly increases the cultural appropriateness of interventions and outcomes that are being measured.

Researchers learn a "community context" versus a "laboratory context". The difficulties of implementing interventions and evaluating outcomes in a community are better appreciated.

Role of Community in Identifying/Guiding Ethical Dilemmas. The input of the community can be valuable in assisting researchers with ethical dilemmas related to the research activities. As one participant noted, community members can be most valuable in recognizing potential ethical problems that may not be visible to the researchers (such as research methods that could be perceived as coercive or as misleading to the community; risks that may be specific for certain cultural groups). In addition, community members can assist the researchers in finding solutions to possible ethical dilemmas that are identified such as translation of informed consent forms into a meaningful context for non-English speaking research participants.

Role of Community as "Consumers" of the Potential Products of the Research. By involving community members in the planning, implementation and evaluation of the initial intervention and basic research, researchers can ensure the acceptability of the intervention to potential consumers. Community members are the future consumers of the intervention that is being tested. Their input in refining the intervention and evaluating not only its effectiveness but also its acceptability to future "consumers" will enhance the quality of the research findings.

Potential Role of Community in Policy Change. Community members can be effective agents for policy change and can undertake activities, such as lobbying, that agency and university staff may not be able to undertake. Through involvement in all aspects of the research, community members can become better informed of the research results and implications and can use that knowledge towards policy change activities.

Capacity-Building Benefits of CBPR. The approach of community-based participatory research emphasizes capacity building for all partnership members. Through the acquisition of new skills and understanding, the capacity of all partners can be increased. This increased capacity can result in positive long-term effects such as social change and civic involvement. Though researchers are still struggling with how best to document and measure these long-term effects, there is growing evidence of the importance of effects such as civic involvement on the health of communities.

Major Issues/Gaps to Be Addressed

Translation of basic research and sustainability of intervention research. Given the increasing interest in translation of basic research into practice and sustainability of "model" interventions, CBPR projects face the combined challenge of both translation and intervention sustainability. "Translation" can be thought of in two ways: translation of findings of basic research into information that the community can understand, and translation of findings of basic research into interventions that directly target the health of individuals. One recommendation for funding agencies is to require all basic research projects to include translation requirements. For example, basic research studies of

biomarkers for exposures that occur in communities or health effects from exposures need to be explained in a meaningful manner to community members who may think only in terms of "contaminated or clean", "well or sick". Inadequate translation of the research methods and the results of the research may be perceived to be unethical to the community participants. In addition, these basic research studies for biomarkers should include explanation of how this research can, and if possible, will be translated into practice for the community involved.

Another recommendation for funding agencies is to require projects with intervention components to address how the intervention will be sustained past the initial funding period. A successful approach to ensure translation and sustainability is the use of funding for "translational projects". Two examples of this type of funding are the Marshfield Clinic, Wisconsin and the state of Iowa "translational grants", both of which provided funding to communities to replicate successful intervention programs. Participants also noted that the USDA extension service, while not as involved in community-based participatory research, is an excellent example of an organization that translates basic research into practice through the development and provision of services to community members. The extension service is also an example of an organization that has acquired a continuous level of funding to be able to sustain its work of service to the community through the years.

Underfunding of Intervention Research/Applied Research. A major challenge for partnerships attempting to undertake intervention research is the current funding levels for this type of research. Many types of research projects face the similar challenge of attempting to accomplish their specific aims with less funding than maybe desired. For intervention projects within a CBPR framework, this issue is particularly challenging since funding is required not only for the intervention activities but also for the community involvement and the extensive evaluation components to properly assess the effectiveness of these intervention strategies.

Lack of Agency Collaboration. Another gap that needs to be addressed is lack of agency communication and collaboration around the support of community-based participatory research projects. While some government agencies, such as NIEHS, EPA and CDC, have begun to support CBPR efforts, other agencies have not been as active. In addition, participants noted that there needs to be more communication and collaboration between governmental "research" funding agencies (such as NIH) and governmental "service" funding agencies (such as HRSA) around issues of community-based participatory research. These types of collaborations could result in findings from NIH funded community intervention projects being used to leverage funding for the integration of successful interventions into an established framework for funding community services and community programs. The successful CBPR projects then serve as "demonstration projects" of what works in the community and this information is then used to fund similar programs in established service providers and agencies.

Infrastructure for Sustainability. As noted above, the existence of an infrastructure for sustaining a Community-Based Participatory Research partnership through the various

project cycles is crucial to the long-term success of any CBPR partnership. One identified gap in the support of CBPR is the lack of funds to support and sustain the establishment of such an infrastructure independent of the undertaking of a specific research project. Often, funding sources for partnerships are tied to a specific research project. Given the amount of time and resources which must be devoted to establishing a working relationship among the partnership members and the level of trust needed to undertake a combined basic research and intervention research approach, funding tied to a specific project is not always appropriate to allow the adequate development of the partnership.

Relevance of Projects Which Combine Basic Research With Intervention Research in the Context of Community Based Participatory Research

Benefits of CBPR for schools of public health include the opportunity for interdisciplinary research that combining basic and intervention research can provide. For example, the Community Action Against Asthma project, through the combination of the basic research and intervention research components, has a research team that includes community partners, epidemiologists, environmental health scientists, pediatric pulmonologists, social scientists, and occupational health physicians. The CAAA project is not only serving as an incubator for other inter-disciplinary proposals at the SPH but it has also served as a teaching case study for how the different disciplines within public health can work together to address current health problems.

The CBPR project in Oregon provides an opportunity for interdisciplinary interaction and also meets a crucial mission of the research institution to provide outreach and community service to communities and workers of Oregon. Because of its multifaceted nature, the CBPR project has formed a springboard for obtaining additional funding from agencies that have not been as proactive for community-based projects in the past as has been NIEHS.

For funders, state and local health departments, and schools of public health, the relevance of combining basic research with intervention research in the context of community-based participatory research can be found in the increased possibility of enhancing the relevance and quality of the research. As one participant noted, "if the focus of much of our research and practice efforts today is on health disparities, I can't imagine research not being community-based participatory research.

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The following is a summary of the viewpoints expressed in the Health Care Delivery and Services breakout session.

Community Contributions

Community participation can enhance access to and quality of health care services. While the community is often described as "vulnerable" or "at risk", it also has numerous strengths. Several mechanisms exist through which the community makes special contributions:

1) The community knows the social situation. For example, the community would know that it may be very difficult for an underserved patient to have a 9:00 am clinic appointment if he or she needs to take three buses to get to the clinic. The community supplies social support, serves as an advocate, and identifies other resources. It is unit that also understands the political system. Community workers know, for example, the family issues pertinent to prenatal care, or the challenges that researchers may face drawing blood in the community. The community can also help with home health care visits.

2) The community serves as a network for intervention. It is a conduit through which officials can spread accurate information to the population, such as when a gonorrhea and syphilis outbreak occurred in Los Angeles and it was necessary to inform the community for public health reasons. And information can also flow from the community to public health officials. For example, some public health officials in Los Angeles learned about a Hepatitis C outbreak from the community. In addition, the community draws people into health care, because community members can develop trusting relationships with outreach workers. The community can also serve as a coalition for broader social and political issues. Preexisting community-based partnerships with academia can be built upon so that future investigators do not have to recreate the wheel.

3) There are also short-term gains from community-based participatory research. These include service and quality improvement in the immediate target population. By adopting an inclusive community perspective, there can be more impact. For example, in New Mexico the State Department of Public Health convened all laboratories to help develop standards. Involvement of the broad community led to more buy-in. The community can also help nurture cost-effective care by targeting effective care to where it is most needed.

4) The community is creative and has a can-do attitude. It plays an important role in shaking up the entrenched interests. The community will question. For example, regarding health disparities, the community can help where the present system clearly has not worked.

5) Community organizations can help identify the needs and resources of neighborhoods, as well as decrease possible conflict up front by gaining the support of key community members and by avoiding bureaucratic infighting. Without seeking the help of the community, researchers and government officials are lone rangers who will not go far. An example of identification of community needs occurred in Los Angeles when residents noted that trucks would recycle at 3:00 am causing dangerous noise and lead levels. The community can also help identify priorities and tradeoffs. An example would be in the Southwest where issues of land and water preservation had to be balanced against increases in taxes.
6) There are links between public health, political power, and social struggles, as exemplified by the role of the Congressional Black Caucus in public health.

Challenges

1) Challenges include the relatively scant flow of money to community-based research efforts. A major concern is that cuts in medical reimbursement have adversely affected public health efforts in the community. In the past, it was easier for community health agencies to get funding for reimbursable services, and then cost shift some of those resources to unreimbursed community health activities. As for-profit agencies enter a market and drive the community health organizations from the reimbursable fields, this diminishes the chance for creative health organizations to fund nonreimbursed activities such as community health. This environment reflects the personal health versus public health dichotomy. Reimbursement tends to go towards individual health, and not public health. In fact, many public health services are not reimbursable, and public health providers have limited resources. Insurers in the government have often not been supportive. There is a need to link public health in the community with reimbursement.
2) Increasingly there are two tiers of organizations. To grossly generalize, there are community health centers, which are committed to the community, and many other types of health providers who are not sufficiently committed to the community.
3) Similarly, communities have sometimes had a strained relationship with the ivory tower. Sometimes there is reluctance to give information to "big brother." However, there is also a willingness to work towards the greater good and health of the community.
4) There is a need to bolster the capabilities of a number of partners. In the community, this includes bolstering research and intervention capability. There is a need to work on the local practitioner level. Community health centers require additional resources for release time and skill development in areas such as research. Research investigators need to develop more team and people skills.
5) A major challenge is the sustainability of interventions. Researchers are often needed to begin creative interventions, but frequently there is a lack of money to sustain the effort. There are examples of NIH, HRSA, and managed care programs working together up front. NIH supplies the model and the others become the implementers. The end users need to be in on the initial study design so they can have buy-in. Thus, when the study is completed, they are more likely to agree that the results are adequate for change to occur. This is in contrast to some study approaches in which regardless of the results, health providers or purchasers may not buy-in because the study only included outcomes that were not relevant or important to the end user.

6) The role of some Public Health Departments has been problematic. They sometimes view that primary care is out of their line of responsibility.

7) Another problem is that funding for public health is dependent upon the volatile winds on Capital Hill. The politicians set funding priorities and thus funding can be variable.

8) Change in the community can be difficult. An example is the HRSA "Models That Work" program that had variable success, with differences in community dynamics being very important.

9) Currently, there is chaos in the health care system, and there is a need to empower the community to deal with this chaos as well as to deal with physicians. This involves patient empowerment programs and political empowerment within communities.

10) The mission of academic medical centers is not necessarily aligned with that of public health. There are many vested interests in the health system, and academic medical centers sometimes have private money conflicts of interests where they are more beholden to private funders as opposed to the community. Of course, simplistic generalizations should be avoided.

11) Time is required for partnership building and planning. There is a need to create learning tools and capacity.

12) An important issue is cultural competence.   This includes appreciating within-groups diversity. Also language needs to be culturally competent.

13) Key issues in community-based research include implementation, sustainability, and linkage to partners with resources. Intervention research should eventually lead to diffusion of efforts.

14) There is a need for community-based primary care. This includes pilot training programs for academic, provider, and community, and linkage with sustaining funders.

15) Key questions include whether the system or the physician should be the partner. Often physicians are overburdened, and thus the system may be a more appropriate partner.

These are the diverse viewpoints that were discussed during the breakout session on health care delivery and services.

Social Capital and Policy: Summary Statement
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With the recognized relationship between deindustrialization, the marginalization of minority populations in the inner-city, the growing gap in income between the rich and the poor in this country, and inequities in health related to race, poverty, substandard housing, lack of employment opportunities, and an increasing perception of hopelessness and powerlessness among marginalized populations, public health researchers are increasingly interested in studying the influence of the social environment on health disparities. In an era with unprecedented technological advances as well as our increased understanding of the pathophysiology of disease, we have had comparatively little impact on increasing health disparities - a paradox which remains poorly understood. Evolving evidence has brought new attention to the hypothesis that the health of individuals is affected not only by their personal characteristics, but also by social processes and characteristics of the social situations in which they live ([1],[2]).

Central to this paradigm is the concept of social capital which is broadly viewed as those features of social organization external to the individual such as mutual trust, respect, and reciprocity, as well as secondary civic and political organizations, which foster and facilitate collective action among community members to address social issues and health problems at the neighborhood, community, and societal levels ([3]). These insights have emerged in parallel with a resurgent interest in a partnership approach to research and the practice of public health involving the communities we are interested in studying. Community-based participatory research (CBPR), which focuses on physical as well as social environmental inequities through active involvement of community members, organizational representatives, civic institutions, neighborhood health centers, and researchers at all stages of both research and intervention processes, offers an invaluable tool for community empowerment which may have longstanding impact on building social capital, influencing policy and, in turn, impacting public health ([4],[5]). This section will examine more in-depth the concept of social capital, describe a particular CBPR project that addresses social capital, and summarizes the discussions from the social capital breakout session.

Community Organization and Health

Community-level variables are receiving increased attention for their critical role in determining health inequalities between racial/ethnic and socioeconomic groups. Numerous studies have documented that the quality of the social environment significantly influences health ([6]), for example, the effects of income inequality on mortality ([7],[8],[9]), the links between residential segregation and black infant mortality ([10]), and the impact of neighborhood deprivation on coronary risk factors([11]), low birth weight ([12]), homicide ([13]), morbidity ([14])as well as all-cause mortality ([15],[16]). A recent study, using U.S. data aggregated at the state level, reported strong cross-sectional correlations

between indicators of social capital and mortality. Civic trust, perceptions of reciprocity, and associational membership were all strikingly correlated with lower mortality rates [(r) = -0.79, -0.71, and -0.49, respectively], even after adjustment for state median income and poverty rates ([3]). While many of the studies on community effects focus on "pathological" features of the social environment, there are many communities that, though low on many socioeconomic indicators, are able to thrive despite relatively adverse circumstances. These *resilient* communities indicate that there are other factors that mediate the effects of living in low SES neighborhoods. One potential mediating feature of community life that has generated considerable attention is the concept of "social capital." Social capital has been defined as those features of social organization—such as the extent of interpersonal trust between citizens, norm of reciprocity, and the vibrancy of civic associations—that facilitate cooperation for mutual benefit ([17]). It is proposed that income and race disparities greatly affect public health through reduced access to material resources and opportunity; erosion of social cohesion, resulting in divergent interests and reduced public support for redistributive remedies; and direct psychosocial effects including stress, hostility, and distrust ([3]). Social capital, and related constructs, have been linked to: economic development ([18]); investment in public goods such as education ([19]); and crime ([20]). More recently, public health researchers have turned to the notion of social capital to explain heterogeneities in health status across socioeconomic and geographic boundaries ([21],[22]).

Social capital is strongly correlated with violent crime rates, which impacts community resilience by further undermining social cohesion ([23],[24]). Research suggests that crime is most prevalent in societies that permit large disparities in the material standards of living of its citizens ([25]). Thus, crime and violence (or the lack of it) can be used as indicators of collective well-being, social relations, or social cohesion within a community and society.

Violent victimization is a major cause of childhood morbidity in urban America. One national study indicated 6.2 million youth aged 10-16 years experience some form of completed assault or abuse per year; one of eight (2.8 million) experience an injury as a result; and one per one hundred (almost 250,000) require medical attention ([26]). Rates of witnessing serious and lethal violence among inner-city youth are also high ([27],[28],[29]). A prevalence study in a pediatric primary care clinic at Boston City Hospital found that 10% of children had witnessed a knifing or shooting before the age of 6; 18% had witnessed shoving, kicking, or punching; and 47% reported hearing gunshots in their neighborhood ([27]).

Historically, research on the health effects of social violence has typically centered on direct exposure of individuals to violent acts ([30],[31],[32]). More recently, investigators have focused on large population studies to explore the effect of living in a violent environment, with a chronic pervasive atmosphere of fear and the perceived threat of violence, on health outcomes ([33],[34],[35]). It has been widely speculated that the conditions known to be associated with violence exposure may be related to the experienced stress ([36],[37]). A growing body of research explores potential adverse psychological consequences on children growing up in chronically violent neighborhoods and homes

(^{38},^{39}). What are notably missing, however, are studies that examine possible adverse implications growing up in a violent environment may have on physical health, and specifically chronic disease expression. Chronic violence exposure may be a pervasive environmental stressor imposed on already vulnerable populations (^{40}) resulting in greater psychological, behavioral, and physical morbidity.

Could Secular Trends in Social Inequalities in Health?

During the 1970s, income inequality in the United States began to rise with a sharp rise in the 1980s (^{41},^{42}). The top 5% of US households increased their share of the nation's aggregate household income from 16% to 21% between 1974 and 1994; the top 20% of households increased their share from 44% to 49%, while that of the bottom 20% decreased from 4.3% to 3.7 (^{43}). Over the same time period, there has been a rise in socioeconomic inequalities in health in industrialized nations. For example, in the US, studies have shown widening disparities in mortality by educational level (^{44}) and income level (^{45}), since the 1960s, particularly among blacks (^{46}). Crude statistics, (arrest records and murder rates) document an increase in violence in the US since the 1970s (^{47},^{48}). Thus, trends in the social environmental factors coincide temporally with rising socioeconomic health disparities and are changing in the right direction to account for the increase underscoring the need to study such social inequalities in relation to health.

Maternal Child Lung Study

In the Maternal Child Lung Study (MCL), an ongoing population-based longitudinal study of childhood asthma, we have begun examining the role of social stressors including community violence on asthma morbidity. The study site is the East Boston Neighborhood Health Center (EBNHC), a community health clinic which provides primary care to several inner-city Boston communities. This study was initially conceived and funded as a longitudinal investigation of the effects of maternal smoking during pregnancy and environmental tobacco smoke (ETS) exposure after birth on the development of lung function and the occurrence of respiratory symptoms in young children.

In a study nested in the MCL Study, we have ascertained exposure to violence (ETV) level through personal interview questionnaire. To date, data are available on ETV for 416 families based on a parental-report interview. The violence questionnaire used in the MCL Study is a modified version of the My ETV instrument (^{49}) which obtains information on both violence in the home and in the community. Preliminary analyses suggest a link between violence exposure in the home and asthma/wheeze syndromes in this cohort. These data suggest that exposure to violence, at home and in the community, is associated with the occurrence of asthma/wheeze syndromes and prescription BD use in these urban children. Future studies which examine social determinants (e.g., social capital, social cohesion, violence exposure) as risk factors for childhood asthma analogous to individual characteristics and physical environmental exposures (e.g., allergens, tobacco smoke, air pollution) may further our understanding of the increased asthma burden on populations of children living in poverty in urban areas. Such research

may also point to unique interventions to decrease morbidity associated with chronic illness such as asthma. For example, it may be that we need to attend to such problems as high crime rates and violence in the communities in which people live before we can get them to attend to medication compliance and other positive health behaviors which will foster well being.

<u>1. Other successful models in examining the role of social determinants (i.e., social cohesion, social capital) and building social capital through CBPR.</u>

In 1992, the W.K. Kellogg Foundation funded a nationwide Community-based Public Health Initiative (CBPHI) aimed to promote long-term change in institutions of public health research and public health practice. The aim is to get away form models focusing on community deficits and research which does not give back to the community to models that empower communities by building on local assets and professional-community partnerships.

Examples of research which will directly benefit the participants include the Michigan Center for the Environment and Children's Health in Detroit, Michigan and the Neighborhood Asthma Coalition (NAC) in St. Louis, Missouri. The Michigan Center for the Environment and Children's Health is a multi-level project working to improve the health of children on the eastside and across southwest Detroit. As part of the Center, the Community Action Against Asthma (CAAA) research program has been developed through partnerships between community-based organizations, health agencies and universities which aim to study and ameliorate environmental risk factors for childhood asthma. The design and implementation of this project has been guided through the establishment of a Steering Committee comprised of key representatives from all partner organizations including civic and community health systems and organizations (e.g., Detroit Health Department, Detroiters Working for Environmental Justice, Friends of Parkside, the Henry Ford Health System, etc.) and the University of Michigan Schools of Public Health and Medicine. The collaborative Steering Committee has, through a process of consensus, been responsible for all major decisions regarding study design as well as numerous more specific decisions concerning, for example, recruitment strategies, wording of instruments, and hiring of community-based personnel. For example, the study hires and trains staff from the community to serve as interviewers, air monitors, environmental checklist administrators, household dust collectors, and community environmental specialists which perform home visits in the community for the purpose of environmental exposure assessment.

The Neighborhood Asthma Coalition (NAC) was developed as a collaboration between Washington University researchers and the Grace Hill Neighborhood Services, a social service settlement house active in disadvantaged neighborhoods of St. Louis, Mo. The aim of the program was to develop and emphasize neighbor-to-neighbor support and encouragement of asthma management. It was developed through Grace Hill's Wellness Initiative which includes neighbor involvement in governance through neighborhood based Wellness Councils. The NAC included promotional campaigns to increase awareness of the project, asthma management courses based on the American Lung

Association's *Open Airways* through schools and other neighborhood settings, involvement of neighborhood residents in planning programs, training neighborhood residents to implement asthma management classes, recruiting neighborhood residents to assist in NAC activities, and recruiting neighborhood residents to act as Change Asthma with Social Support (CASS) workers. CASS workers provided basic education and support to parents and children in asthmatic families. These investigators have been able to show that parents in the NAC neighborhoods have positive health promotion attitude changes toward their child's asthma (e.g., increased indorsement of such attitudes as 'Parents can do a lot to help children take their medicine and avoid things that cause asthma to act up') compared to parents of asthmatic children in control neighborhoods. Parents of children from NAC neighborhoods also reported greater improvement in appropriate medication use and discouraging smoking around their children. There was also evidence that greater levels of program participation and contacts with CASS workers in the NAC neighborhoods were associated with greater reduction in acute care for asthma.

Another example discussed was the CDC Prevention Research Center for Environmental Disease supported Louisiana Childhood Lead Prevention Program. The goal of the Louisiana Childhood Lead prevention Program is to develop and implement a comprehensive childhood lead poisoning prevention program for the State of Louisiana. This initiative has included the establishment of critical community partners with community representatives' involvement in survey design and administration. This included employment of community residents for the implementation of nutritional education and household cleaning and control interventions focused on lead reduction. Use of community members in this way increases trust in the research study on the part of the participants.

2. Common threads/features of the models?

Participants underscored the need to start with asking the community what is important to them, then link with them to see what is available (assets) and if something not available then develop this at the start. The fundamental aim of CBPR is committed to conducting research that will ultimately benefit the participants either through direct intervention or by using the results to inform action for change or policy both within and beyond the community of interest.

3. What value does CBPR add to social capital and policy?

CBPR empowers community members who can in turn take both what they learn (knowledge, networking skills) and the resources that are developed (neighborhood or resident organizations who have learned to work collectively together to achieve a desired goal) to subsequently impact policy and to educate legislators and government officials to have long term impact on policy. Community organizations which are formed for one purpose can have lasting impact as they persist and provide available social capital resources to facilitate future collective action in response to other identified public health issues within that community. The process of communities coming together and

having success builds such social capital and enhances the capacity to address future issues. CBPR aims to link economic and social resources to facilitate community development.

CBPR begins to address the need to develop linkages with other organizations and institutions to address the complexities of problems as identifies or prioritized by the community. These problems may otherwise seem overwhelming when faced by either the community alone or the academic community. Building partnerships between communities, academic institutions, and various agencies can bring a broader perspective to the development of specific interventions (e.g., asthma and housing issues, HUD).

Many participants underscored the need and the benefit of involving youth and students in the community education process. For example, to encourage youth participation in the design processes for physical facilities in the community (e.g., schools, parks). Parallel to principles of CBPR, this will increase networking and cohesion between the youth community members involved and increase pride in the community. For example, developing projects at the Harvard School of Public Health are integrally linked with several minority training programs in existence already at the School of Public Health. The *Summer Program in Biostatistics* is an NIEHS funding short-term summer enrichment program designed to introduce mathematically talented students from underrepresented minority groups to careers in biostatistics and public health. Over 45 students have participated over the past 7 years. In 1998, the program expanded to include an IMSD grant (Initiative for Minority Student Development) from NIH. This program supports students for 10 week long summer internships and also supports predoctoral and postdoctoral students from underrepresented minority groups. The IMSD grant is joint with the Department of Health and Social Behavior at HSPH and has a scientific focus of *quantitative methods for community-based research.* Such efforts provide critical practical training opportunities for students and will, in the long run, institutionalize support for CBPR and focus on social determinants of health including social capital.

4. What are the major gaps or issues yet to be addressed?

Historically much of the research funds have gone towards deficit model studies. It was widely felt that we need to shift funding priorities to also support academic and community partnerships which would work together to identify community assets and priorities. This approach not only facilitates the building of sustainable partnerships, but ensures success of the research.

Historically funding is often categorical. This, in large part, prioritizes the issues or problems that are addressed in research. CBPR underscores the need to work with communities and community members to define and prioritize the issues. If we are responding to those problems identified by the communities, we will build mutual respect and trust which will be important in ensuring the success of the research endeavors. Too often in research attempts involving marginalized populations (minorities, low SES groups), study recruitment and retention are major hurdles. An identified obstacle to

studying marginalized communities is the lack of trust that may in part be contributing to the difficulty in recruitment and retention. This, in part, stems from prior experience with academic institutions which focus on a particular community for recruitment of subjects for the purpose of studying a particular categorical health outcome driven by the funding priorities, not the community. Residents of these marginalized communities complain that they have not traditionally been informed of the results of the research and consequently have not been able to benefit from the research. It has been the experience of several in the discussion group, that when the community concerns are addressed in the research, these factors improve as well.

We need to more broadly define environmental characteristics to include social determinants of health. Also, we need to develop research and intervention strategies across disease categories, linking knowledge that will allow us to address problems more comprehensively.

There needs to be more flexibility for community/researcher partnerships to define topics of funding/projects. That is, we need to be cognizant of whose priorities we are responding to.

We need to support research to strengthen the science base linking social constructs including income inequality and social capital to health disparities as well as for evaluating and implementing strategies to achieve social capital building. Improvement in methodologies and assessment measures of social capital should be a part of this effort.

University tenure and promotion is recognizably linked with the amount of funding gained by investigators. Increased funding of CBPR would raise awareness of the importance of this type of research within academic communities.

With regard to facilitating and operationalizing CBPR to build social capital, existing funding mechanisms are restrictive in many ways. Timeframes are restrictive. Grant cycles need to be expanded and lengthened. Funders need to make money available to help establish CBPR relationships. We need long-term funding to bring bout these types of changes and complex evaluations. Community building approaches are work intensive, require a great deal of time up front which may not be supported within academic departments. Also, current funding cycles are not conducive to such community building needs. Most researchers involved in CBPR at this meeting agreed that a minimum of a year (or more) was needed to establish collaborative working relationships with key representatives across the community and academic institutions needed to move the work forward. Adequate funding is not allocated to sustain the infrastructure needed to support continued research or implementation of desired interventions in the community once the grant cycle has expired. Consequently such research endeavors are expensive. It may be necessary to promote dual funding models to support an adequate budget in certain circumstances.

Use of the Research Program Project (P01) Grant mechanism creating centers of excellence to support the broad, integrated, interdisciplinary, community-based, multi-

project health services research needed to most effectively support CBPR in this capacity. Such facilities will bring together researchers focused on CBPR to share essential facilities, services, knowledge, and other resources in purchasing and developing data sources, developing new methodologies, performing analyses across supported projects and working with partners and communities to conduct research and translate that back into practice that will directly impact the community partners and their residents. The goal here is in developing sustainable and meaningful relationships with communities and community organizations. In order for the study of social capital to impact practices, policies and outcomes more effectively, research must establish linkages between CBPR partnerships and change agents including both the public and private sector, payers and policy makers, provider groups including Community Health Centers, clinics and practice networks, local and national organizations, community organizations such as religious and social groups, patient organizations such as those organized around diseases, and the media.

The particular importance of documenting the successes and failures of CBPR was underscored. This will facilitate communications across investigators and communities which may increase the effectiveness of new projects. The more we document in varied places including peer-reviewed journals, popular and local press, places where funding agencies get their news (e.g., *Philanthropy Newsletter*) to raise awareness of the importance of the work, the better. Including the funders as partners and participants in community efforts/meetings/planning may be a way to educate them on the importance of CBPR and influence future support.

We need to institutionalize CBPR. In the face of a rapidly changing health care system such community-based collaboration is arguably more important that ever. Medicine must move beyond only treating individuals and diseases and incorporate population-based prevention of disease and maintenance of health and well being, albeit this is difficult within the time constraints and cost containment pressures in the medical climate of today. There needs to be an ongoing collaboration between schools of medicine and public health in order to address the recognized social and economic issues in health care today.

5. Why should the social capital warrant attention from Schools of Public Health, state or local health agencies and funding agencies?

Populations that experience environmental inequities are also often characterized by high levels of poverty, hopelessness, lack of opportunity, and unemployment (i.e., diminished social and human capital). It is unlikely that the health problems of these disadvantaged populations can be improved unless these larger issues are also addressed. A robust understanding of the pathways (psychological, social, and biological) which link experiences within SES strata to pathogenic processes influencing poor health outcomes may explain social class disparities which, in large part, remain unexplained to date. Such research may be important to pinpoint where the disease might be most vulnerable to interventions that might diminish such social class effects. For example, it seems likely that both improvements in living conditions and life opportunities may be

necessary for getting disadvantaged populations to attend to more traditional health education interventions and make desirable behavioral changes. Social cohesion may influence the health behaviors of neighborhood residents by promoting more rapid diffusion of health information, or increasing the likelihood of adoption of healthy norms of behavior such as exercise, or exerting social control over adverse health behaviors, such as adolescent smoking and drinking. Another way in which neighborhood social capital may affect health is through increasing access to local services and amenities. Evidence suggests that socially cohesive neighborhoods are more successful at uniting to ensure the budget cuts do not affect local services, for example. The same kind of organizational processes could conceivably ensure access to services such as transportation, community health clinics, or recreational facilities, that may be relevant to health.

Emerging evidence underscores the need for policymakers to pay increased attention to economic forces which go beyond well-established determinants of health (i.e., access to quality health care) to impact the nation's public health. Arguably, the policy levers needed to reduce income inequality already exist (i.e., raising the minimum wage, increasing child care credits, and expanding the earned income tax credit) ([50]). The adverse consequences of inequality not only impact the poor as everyone suffers a deleterious costs of increased sickness and crime, as well as for the degradation of civic institutions and the social environment more broadly.

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Conclusions and Recommendations

Discussions led to the identification of several benefits of community-based participatory research (CBPR) in general, as well as for the target audience: schools of public health, state and local health departments, and funding agencies and institutions. Some challenges were also identified that must be addressed. This section will list overall and specific benefits, highlight the challenges, and offer some next steps.

Overall Benefits

- **Establish trust to enhance data quality and quantity.** Workshop participants agreed that true CBPR assists scientists. Building upon increased trust, three important benefits mentioned consistently were **increased quantity and quality of data collection, subsequent use and relevance of collected data, and information dissemination**. Participants emphasized that with active community participation from start to end of a research project, investigators would be able to demonstrate the rationale and benefit of the research to community residents. Consequently, the investigator would obtain increased community support for and participation in the research, thereby increasing the quantity and quality of data collection, subsequent use and relevance of collected data, and information dissemination.

- **Move beyond categorical approaches**. Traditional research is often conducted in scientific silos. Several researchers, all with different interests, may investigate one community. CBPR places equal emphasis on community participation. In the same context, CBPR **extends research and intervention beyond a specific project** to explore broader community interests**.** By so doing, there may be some overlap of research efforts that are brought together through CBPR.

- **Improved research definition and direction.** When investigators work with communities they can both develop a **clearer understanding of research questions**. Most participants highlighted the benefit for the researcher in this instance, drawing attention to the historical practice of arriving at a community with a research question conceived outside the community. By interacting with community representatives, **new research questions and hypotheses emerge**. In addition, with open dialogue it is easier for the investigator to **identify ethical dilemmas.**

- **Enhanced translation and sustainability.** With better comprehension of research questions and community support, often times there is a **shorter time to application of research findings.** In addition, CBPR facilitates the **translation of research into policy.** Such applications are more likely to have a longer-term impact when communities and scientists work together to institute them.

- **Knowledge benefits the community's health, education and economics.** As information is disseminated to community residents in effective and culturally-relevant manners, their abilities to address environmental health conditions is

strengthened. However, communities benefit from more than an increased knowledge base. CBPR projects often bring additional **resources and services to a community**, enabling residents to obtain the necessary capacity and training to improve individual employment and community economics. In that context, CBPR projects **build infrastructure and sustainability** by fostering skills of the community. The resulting improvement in community knowledge, economics, and control serves to enhance overall social capital and thereby serves as a significant positive influence on health status.

Benefits For Schools of Public Health

- CBPR brings together a wide variety of components, including research, education and service to the community. To this end, schools of public health can use CBPR as a means for **fulfilling their research, education, and service missions**.
- CBPR projects **increase student interest and participation** in this research methodology.
- The **interdisciplinary nature** of CBPR facilitates the interaction of programs that have historically worked within their own discipline.

Benefits for Health Departments

- CBPR is being used by health departments to **increase primary care, patient contact and engagement (self management).** By including community residents in the research process, it becomes easier to obtain their support and buy-in, as well as to develop messages that are culturally-relevant.
- CBPR **enhances behavioral change and prevention, while decreasing costs** to the health department.
- Due to its interdisciplinary nature, CBPR inevitably **increases partnerships** and helps health departments develop and strengthen **contacts as well as resources in community.**
- CBPR assists health departments in developing and implementing **effective practices through translation** of research findings into health care practice.

Benefits for Funding Agencies

- A benefit of CBPR projects is their **non-categorical** design.
- These projects are also **cost effective** because as researchers work collaboratively with community residents, their projects will be more efficient in addressing public heath concerns.
- The interdisciplinary nature of CBPR projects lends to **different perspectives** on particular topics, consequently funding agencies are likely to develop **new partnerships**.
- CBPR **increases the trust** community residents have in funding agencies. Support for CBPR demonstrates an agency's willingness to invest in the community.

Challenges

Participants identified several challenges to the continued success and enhancement of CBPR.

- **Initiation and maintenance of community-university partnerships**. Such collaborations are difficult to establish, time-consuming and costly. Some of the solutions offered were planning grants, long-term support, and up-front partnerships (researcher-researcher, researcher-service, or researcher-community). Planning grants would be used to establish a trusting partnership between communities and researchers. Commitment to long-term support would provide researchers and communities with a sense of security so that their attention could be directed toward research issues rather than in looking for continued support. It would also insure a continuous project without interruption.

- **Institutional commitment,** especially within the University system. A proposed solution for funding agencies to emphasize the importance of CBPR, which, in turn, should enhance the recognition and value of such work within academic institutions.

- **Training for researchers, providers, and community**. CBPR is still very new in the global context of research. Consequently, there exists a need for training of all participants.

- **Evaluation for individual sites as well as cross-sites**. Evaluation is critical for any program or project to evolve and improve. However, the method for conducting such an evaluation poses a challenge to researchers, in addition to funding agencies.

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