# **10 YEARS** Of Making A Difference

### COLLABORATION PARTNERSHIPS COMMUNITY



The real voyage of discovery consists not of seeking new landscapes but in having new eyes.

-Marcel Proust

**CBPR History Report** 

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### **EXECUTIVE SUMMARY**

When the Robert Wood Johnson Foundation (RWJF) introduced community research and leadership development training requirements as part of its 2005-2015 funding of the Clinical Scholars Program (CSP), the principles of community based participatory research (CBPR) were relatively unknown to physicians conducting health research. Since then, the RWJF CSP at Yale University has embraced this opportunity and co-developed a program with community partners that remains vibrant today. As of June 30, 2015, 33 CBPR projects had been completed by 57 scholars with 28 different community partners and cumulatively



have had a positive impact on over 2,600 people, with the hope of influencing many more through dissemination and subsequent action from the completed research. In addition, the program has trained 30 other researchers from the Yale Schools of Medicine, Nursing and Public Health. This report details our CBPR journey through June 2015 and our hopes going forward. **CBPR History Report** 

Implementing a Model for CBPR Training and Support of CBPR Projects with New Haven Community Partners One of our first tasks was to become familiar with the New Haven community to: 1) understand what community leaders considered the most pressing health and health-related priorities; 2) assess attitudes regarding Yale and scientific research; 3) identify potential common ground between the goals of the CSP training and the interests of the community and; 4) explore the interest and willingness of community leaders to work with the CSP in shaping community-partnered research.

Establishing a Steering Committee on Community Projects From a series of meeting with community leaders, a Steering Committee on Community Projects was formed to help guide the direction of the program's CBPR efforts and advise Yale Clinical Scholars on their CBPR projects. The Committee was composed of two types of members: 1) community leaders who had a broad view of New Haven health priorities and could partner with or connect scholars with potential partners for New Haven relevant projects; and 2) representatives from other programs of research at Yale focused on improving the health in New Haven. The Committee held its first meeting in March 2005 to develop a set of operating principles, help frame an orientation to New Haven for incoming scholars, review the CSP CBPR training curriculum, and recommend ways to approach CBPR projects. The Committee has met monthly since.

**CBPR Values** 

Consistent with established best practices, our CBPR values include: 1) the scholar and community partner(s) co-create the project and are equally involved in all phases of the research; 2) both the researcher and community partner(s) bring equally valuable expertise to the research; 3) building trust through the honest expression of respective partner needs is required; 4) power is shared in decision-making in all steps of the research process; 5) commitment to rigor in the research is maintained while keeping in mind the need for action; 6) community partners are fairly compensated for their roles in research activities; and 7) co-learning, capacity building, and increased competencies among all partners result from the projects. The Definition of Community for CBPR Projects For the purposes of Yale CSP CBPR projects, community was defined as New Haven or one of its neighborhoods, a specific community or patient population, community health care organizations, and/or a local governmental entity. The same principles of co-leading a research project from start to finish would apply regardless of the community of focus. However, because of our commitment to improve the health of New Haven, projects were required to directly benefit the people of New Haven. We agreed to allow some projects to go beyond New Haven as long as New Haven was included as a central part of the project.

Beginning in the fall of their first year, Scholars explored potential projects with New Haven community partners. Each scholar was expected to spend 4-6 hours/week or at least 15 percent of their time working on a CBPR project. Each project addressed an issue deemed important to the community that was also of interest to the scholar. Projects were expected to be completed within a 15-18 month period with the resources available and include plans for dissemination and sustainability.

### **Overview of CBPR Projects (July 2005-June 2015)**

Between 2005 and June 2015, 33 CBPR projects were completed by 57 Yale Clinical Scholars with 28 different community partners.

These projects ranged from improving access to care for the uninsured and underinsured to addressing health issues for specific populations, as well as requests from community partners to improve health care or programs in the community. Four projects involved assessing issues that had relevance for CBPR projects in general. All projects required a litmus test of being relevant to and supported by one or more community partners. A summary list and description of projects that have been completed over the past 10 years can be found in Appendix 6. A list of community partners can be found in Appendix 7.

For more information on specific projects, please contact Ann Greene, Yale CSP Community Research Liaison, at ann.greene@yale.edu.

Impact of CBPR Efforts

Steering Committee members, community research partners, and Yale RWJF Clinical Scholars were surveyed to elicit their perceptions of the impact of their CBPR experiences through the RWJF CSP. Several themes emerged from those surveys.

## The Future of Community-Academic Partnered Research at Yale School of Medicine

The future for community-academic research partnerships at Yale is bright and we are poised to take the next steps in our CBPR journey.

When the RWJF, in early 2014, announced it would be defunding the CSP in 2017, community partner representatives came together to share with the Foundation their concern regarding the disruption the defunding would create in terms of advancing CBPR efforts that had been benefiting our communities. At the same time, the announcement provided an opportunity for the medical school and the Yale CSP leadership to discuss the relevance and importance of community engagement in research.

The community partner advocacy with the RWJF resulted in Yale receiving a \$50,000 planning grant from the Foundation to develop a strategy for extending community-academic research partnerships. The Yale School of Medicine (YSM) and the Yale Center for Clinical Investigation (YCCI) have agreed to continue funding training and research support for community-partnered research. The Steering Committee on Community Projects has been working with the CSP CBPR faculty to discuss how best to expand community-partnered research with the resources that have been made available.

These goals have been established for the next steps in community-partnered research at YSM: 1. Continue to make a positive difference in health outcomes for New Haven residents

- 2. Create a permanent "home" for community-engaged research at Yale School of Medicine
- 3. Support bi-directional research collaborations
- 4. Advance and operationalize health data democracy across New Haven, where all citizens create, have access to, and are trained in the use of data to create action to improve lives in New Haven
- 5. Honor the CSP CBPR legacy



### **Observations**



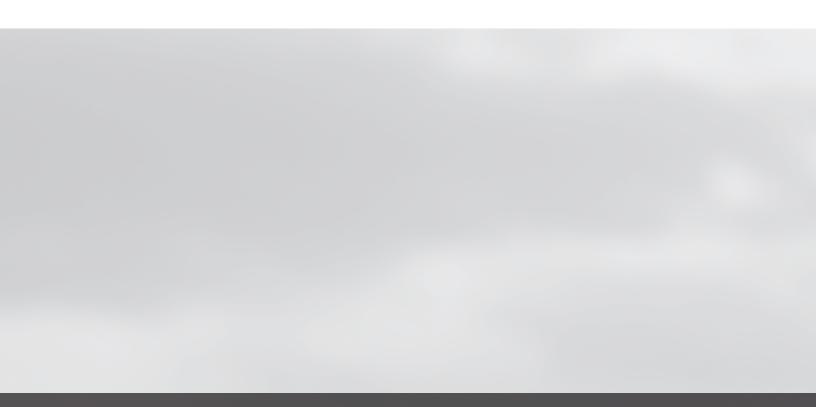
#### **Steering Committee Member and Community Partner**

CBPR offered a new model for community/ university research relationships that was balanced and not one-sided in the direction of just the university researcher's interests.

Community partners developed a new attitude about the value of research as a result of their experiences with CBPR. Community members were seen as research partners and not subjects.

Scholars are seen as a resource to the community willing to address issues of concern to the community, share their knowledge and skills, and work toward a greater good.

Through CBPR projects with RWJ CSP Scholars, the capacity of community partners to do research to advance their own work has increased, as has their ability to negotiate with other researchers who are trying to engage them. Scholar initiated CBPR projects have made very specific and visible contributions to New Haven. Some examples include helping to create Project Access-New Haven and the new medical respite program at Columbus House, completing the first inventory of primary care resources in the greater New Haven area, stimulating the development of neighborhood community resilience teams to address violence, and the publication produced with the Community Foundation of Greater New Haven of "A Guidebook to Successful Research Partnerships" for community-based organizations. **CBPR History Report** 

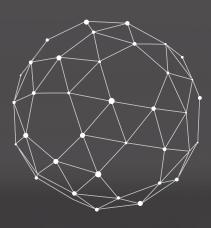


### Yale Clinical Scholar Alumni

Participating in CBPR projects has changed the way graduates of the CSP think about conducting relevant research and the importance of involving stakeholders in all phases of the research, including dissemination.

Many graduates of the CSP have shared how they have taken the knowledge and skills learned through CBPR to other activities in their current positions in health systems, policy settings, and government.

CBPR experiences through the CSP have provided new career opportunities including securing positions with and funding for communitypartnered research in their new settings.



### INTRODUCTION AND CONTEXT

Community Based Participatory Research (CBPR) was a relatively unknown approach for physicians conducting health research when the Robert Wood Johnson Foundation (RWJF) introduced community research and leadership development as new training requirements for its 2005-2015 funding of the Clinical Scholars Program (CSP).

While not initially explicit about CBPR in the December 2001 Request for Application (RFA), the focus of community research training quickly evolved toward CBPR as the desired approach at all four funded CSP sites. The new CBPR training initiative advanced the health research training innovations begun by the RWJF CSP in 19721. (See Appendix 1.)

In the 1990's, public health researchers suggested that CBPR would result in more relevant and actionable research for those studying health in communities.<sup>2</sup> CBPR embraces equal partnership and joint decisionmaking by those affected by health issues and the researcher in all phases of research, from design through implementation and dissemination of findings. CBPR recognizes the role the social environment plays in health and the unique insight, expertise, and local knowledge community partners can bring to the research that is of comparable value to the expertise of researchers in scientific methods. The long-range goal of CBPR is eliminating health inequities.<sup>3-6</sup>

Yale had been a RWJF CSP site since its first award in 1974 and wanted to retain this twoyear fellowship that had generated valuable research expertise and resources for YSM. Introducing CBPR as a new training element in the CSP for the 2005-2015 years posed challenges for Yale School of Medicine (YSM), the existing Yale CSP, and the relationship between YSM and the New Haven community. In 2001, CBPR was struggling to find its place and respectability in academic institutions nationally. The CBPR approach did not fit the model of health research in which the researcher is the expert and the community is only a source of data. Academic publishing in high impact medical journals, the primary currency for advancement in academic institutions, did not include manuscripts from CBPR projects.

Changing the culture of the Yale CSP, which was scholar-centric, and gaining acceptance for CBPR as a legitimate approach to research provided some serious challenges, as did gaining the trust of the New Haven community for this new research approach. Many of the historic town-gown issues had not been resolved. The New Haven community was distrustful of medical research from its longstanding history with African Americans research subjects.<sup>7,8</sup> New Haven was and still is a medium-sized urban community where Yale has a very large presence. Many researchers from Yale have done research involving New Haven residents and/or organizations serving them. These participants have described how they have rarely benefited from this research or even knew what happened as a result of their participation in the research.

Incorporating CBPR in a substantive and meaningful way for the benefit of both scholars and the community had to be addressed in the application. Fortunately, a few exceptions to this pattern existed. A small core of community health leaders agreed to meet with the leadership of the CSP to help put together the proposal that would result in Yale being selected to launch community research training emphasizing CBPR.

### Fast forward to 2015

By June 2015, the Yale RWJF CSP had trained 57 Yale Clinical Scholars in CBPR, completed 10 years of productive engagement of the New Haven community in fully partnered research, generated 33 projects with 28 community partners, and published 22 academic manuscripts as well as numerous other dissemination products from the research. The program also provided CBPR training

to 30 others on the Yale health campus from the Schools of Nursing, Public Health, and Medicine.

How did all of this progress transpire over the past 10 years? This report, Ten Years of Making a Difference, describes this journey and its impact.

### Why Produce this History?

We are sharing the program's CBPR experience to provide accountability to the stakeholders who supported these efforts and to provide guidance to those who would like to use a community-partnered research approach, as represented by CBPR, with community, patients, providers, and other stakeholders who influence health and healthcare.

### The Yale CSP CBPR Stakeholders

**Funders.** The Robert Wood Johnson Foundation, RWJF CSP National Program Office (NPO) and CSP National Advisory Committee (NAC), has provided financial and other types of support for Yale's CBPR training. At Yale, Medical School Dean Robert Alpern, MD continued Dean Kessler's financial commitments for Yale's CBPR training and scholar/community CBPR projects; and the Yale Center for Clinical Investigation (YCCI) has also provided financial support for CSP CBPR initiatives.

#### CSP Steering Committee on Community Projects.

Established in March 2005, the Steering Committee has been an active contributor to every CBPR project. Members also serve as valued advisors to the CBPR faculty and program leadership on our CBPR vision and structure. This document provides them with a record of their work with us. **CSP Community Research Partners.** In addition to the Steering Committee, individual community organizations have been essential research partners making this work real and useful. Since 2005, scholars have worked with 28 different community partners, several on multiple projects with different cohorts of scholars.

**Scholar Alumni.** Scholars have grown in their understanding of and appreciation for CBPR over the last 10 years. Many alumni have reported back on how they are using the skills developed through CBPR in their current careers.

**The Program Directors.** Our program directors, especially Harlan Krumholz and co-directors Elizabeth Bradley, Cary Gross, Leslie Curry, and Rani Hoff, have directed resources and provided visible support for this new research approach over the past 10 years.

**Future Academic and Community Researchers interested in CBPR.** This report will include some guidance for those considered doing CBPR or

#### How the Report was Developed

CBPR projects and their immediate impact have been systematically documented over the past 10 years. This documentation has provided much source material and includes reports to the Steering Committee, the program's Institutional Advisory Committee, the NPO, the Dean's office, and the YCCI. These materials reflect key milestones including the evolution of the Yale CSP CBPR curriculum, CBPR project guidelines, operating principles for the Steering Committee on Community Projects, and many dissemination products from CBPR projects. Historical correspondence from 2001 has been

#### How the Report is Organized

The report is divided into five parts.

Part 1 reviews the background of CBPR at the Yale CSP and the foundational elements put in place to implement CBPR training in the CSP. Part 1 also reviews the challenges the Yale CSP faced as their CBPR requirements unfolded.

Part 2 summarizes each CBPR project and their impact in the community, among scholar alumni, and others at Yale.

Part 3 offers guidance for those considering CBPR. While insights in conducting CBPR

#### The Authors of this Report

The primary authors are Georgina Lucas, MSW, former Yale RWJF CSP Deputy Director and Director for CBPR Training and Marjorie (Margi) Rosenthal, MD, MPH, Yale CSP Assistant Director and Director for CBPR training.

Margi joined the Yale RWJF CSP in July 2005 after completing the RWJF CSP at Yale. A pediatrician trained at YSM and Johns Hopkins, improving their partnered research, including patient centered outcomes research (PCOR).

reviewed to capture the NPO's rationale for incorporating CBPR into the training and Yale CSP's early efforts to do so.

In addition, CBPR stakeholders (Steering Committee, community partners, Yale CSP alumni, co-directors, and others at Yale) were surveyed to elicit the nature of their experiences with CBPR through the CSP. Several of these individuals were also interviewed to provide more in-depth perspectives. Selected experiences of these stakeholders are included in Part 2 of the report.

are referenced throughout the report, this section pulls some key lessons together for those seeking to use a CBPR approach for their research, whether looking to partner with local community members, patients, or other stakeholders.

Part 4 discusses the future direction of CBPR as part of the CSP CBPR legacy on the health campus. This section was written by the new CBPR leadership team.

Part 5 includes the Appendices referenced in the report

she earned her MPH at the University of North Carolina. In each of the cities in which these institutions reside, she was involved at a community level.

During the past 10 years, Georgina and Margi have both lived in New Haven with a personal commitment to a healthy New Haven.



### PART 1 Implementing Community-based Participatory Research (CBPR) Training at the Yale Clinical Scholars Program

On July 1, 2005 the Robert Wood Johnson Foundation Clinical Scholars Program (RWJF CSP) began incorporating community-based participatory research (CBPR) training into its two-year postdoctoral health research training program for physicians. The Yale School of Medicine (YSM) and three other medical school sites¬—the University of Michigan, the University of Pennsylvania, and UCLA—were selected as sites and required to implement this new research training approach. Creating the foundation for this component of the RWJF CSP began in December of 2001.

#### The 2001 Call to Incorporate CBPR into Scholar Training and the YSM Response

In December 2001, the RWJF circulated a call for applications to expand leadership training and introduce CBPR into the CSP at medical school sites in the country. In addition to maintaining training in biostatistics, clinical epidemiology, and health policy, selected sites would receive a 2-year planning grant to develop a CBPR training structure. Hosting institutions had to demonstrate their strengths in engaging individuals and organizations outside of their institutions.<sup>9</sup>

Harlan Krumholz, MD, SM, Harold H. Hines Jr. Professor of Medicine and Director of the Yale-New Haven Hospital Center for Outcomes Research and Evaluation (CORE) and the program's third program director, saw this as an opportunity to build upon the understanding of the context for research and the levers needed to translate research into health and healthcare improvements. Harlan previously had expanded the curriculum to include health policy and health policy leadership, honing scholars' skills in stakeholder collaboration and effective communication, while continuing the rigor of the research training for which Yale had become known.

Seeking ideas on how to incorporate meaningful CBPR training and create community

partnerships for CBPR, Harlan convened a meeting of health leaders in New Haven. These individuals helped the program's leadership think through the best approach to creating community partnerships for CBPR. These individuals included former New Haven Health Director, Bill Quinn, former director of the Community Health Division of Yale-New Haven Hospital, Jim Rawlings, former CEO of the then Hill Health Center, the late Cornell Scott, and retired Executive Director of Fair Haven Community Health Center, Katrina Clark.

Concurrent with engaging community health leaders, Harlan also began working with the leadership of the YSM to seek their support for this new direction. To demonstrate the YSM commitment, the then Dean of YSM, David Kessler, agreed to provide 10 years of financial support to hire staff/faculty to build, nurture, and coordinate the community research infrastructure and to provide 10 years of research funds to support community/scholar partnered research projects. Dean Kessler also agreed to chair an Institutional Advisory Committee (IAC), which would oversee the new iteration of the program. He, along with Harlan, invited leaders of clinical departments, the Deans of the Schools of Public Health and Nursing, and three leaders of community health institutions to join him. The IAC

has continued to support and guide the overall program within YSM. A listing of IAC members in Appendix 3.

The following excerpt from the application submitted by the Yale CSP represents the new program direction:

"The next generation of Yale CSP will address the nation's need for physician leaders who are capable of developing solutions to the problems that continue to undermine health and health care. Despite enormous technological advances in medicine and health care, these future leaders are inheriting a health care system plagued by many pressing problems including barriers to access, a disproportionate burden of illness imposed on vulnerable populations, misaligned incentives, fragmentation of health care services, and persistent concerns about the safety, effectiveness, efficiency, equity, and patient-centeredness of care. What are needed are not merely physicians who will characterize these and other deficiencies of the health care system, but individuals who will address and resolve them. Through coursework and practical experiences, the Yale CSP will prepare scholars to work effectively across disciplines, think creatively and rigorously about health care issues, generate ideas and test hypotheses, participate in policy development, work within communities, and lead organizational change." (Letter to the Foundation from then Dean Kessler, p.1.)

With community and YSM commitments, the quality of the application, and the positive experience from the site visit for the application review, Yale was awarded a two-year planning grant in July 2003 for the newest iteration of the RWJF Clinical Scholars Program commencing in July 2005.

#### Creating the Foundation for Yale/Community Research Partnerships

To develop research and training partnerships with New Haven-based organizations and community leaders, Harlan organized several activities during the planning grant period, including:

1. A Guide to Community-Based Research at Yale University and in the Greater New Haven Area, a compilation of community/university partnerships at the time, was developed by student research assistant Lauren Gold and disseminated.<sup>11</sup> Contained in this Guide was the Kellogg Foundation's definition of CBPR and tips for conducting CBPR. The Kellogg Foundation definition of CBPR closely reflects the approach the Yale CSP would take:

"Community-based participatory research is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community, has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities." (Guide, p.3) 2. Marta Moret, MPH, President of Urban Policy Strategies, was hired to begin building the preliminary training structure and curriculum for a pilot of the CBPR approach with the 2004-2006 cohort and to help recruit a director of community-based research training for the program.

3. The first CBPR curriculum was piloted in 2004 with community health instructors Marta Moret and Yale School of Public Health faculty Kari Hartwig, DPH, Jeannette Ickovics, PhD, and Jim Jekel, MD, MPH.

4. Georgina Lucas, MSW was hired as Director of Community-Based Research Training in September 2004 to further develop the training and infrastructure for supporting RWJF Clinical Scholars in carrying out CBPR projects in the New Haven community. She contributed a systems change perspective to scholar training rooted in collaborative approaches to improve health and mental health. Georgina came to the CSP with leadership experience in community organization, program and policy development, bridge building between sectors, and translating research into action. Her charge, in addition to building a strong CBPR training program, was to build mutually beneficial relationships between the scholars program and the New Haven community to support and guide meaningful CBPR projects.

5. In June 2005, Marjorie (Margi) Rosenthal, MD, MPH, Associate Research Scientist, was hired as the Assistant Program Director and Director of the program's CBPR training efforts after completing the RWJF CSP at Yale. Margi provided research methodological mentorship for CBPR projects. Her domestic and global experiences working with marginalized communities and her perspectives as a physician researcher and scholar added valuable guidance to the program.

### Implementing a Model for CBPR Training and Support of CBPR Projects Early Conversations

One of our first tasks was to get to know the New Haven community. We wanted to: 1) understand what community leaders considered the most pressing health and health-related priorities; 2) assess attitudes toward Yale and toward research; 3) identify common ground between the goals of the CSP training and interests of the community and; 4) explore if the leaders we met with would be willing to work with the CSP in shaping a new way to systematically conduct community partnered research.

Initial conversations were held with those with whom Harlan Krumholz had already established relationships. These individuals guided us to other community leaders including Amos Smith, originally with the Community Foundation of Greater New Haven and now CEO of the Community Action Agency of New Haven, Barbara Tinney, Executive Director of the New Haven Family Alliance (NHFA), and others at Yale engaged in the New Haven community including Margaret Grey, Dean, Yale School of Nursing, Jeannette Ickovics and Kari Hartwig from the Yale School of Public Health, Leif Mitchell of the Center for Interdisciplinary Research on Aids (CIRA), Mary Tinetti and Joan McGloin from the YSM Program on Aging, and Dr. David Katz and Beth Comerford from the Yale-Griffin Prevention Research Center.

### Established a Steering Committee on Community Projects

From these meetings, a Steering Committee on Community Projects (SC) was formed to help shape the future direction of the program's CBPR efforts. The Committee was composed of two types of members: 1) community leaders who had a broad view of New Haven health priorities and could partner with or connect scholars with potential partners for New Haven relevant projects; and 2) representatives from other Yale programs of research focused on improving the health in New Haven. The Committee held its first meeting in March 2005 to develop a set of operating principles, help frame an orientation to New Haven for incoming scholars, review the CSP CBPR training curriculum, and recommend ways to approach CBPR projects. The Committee has met regularly since. Current and past members of the Committee are listed in Appendix 2 along with the operating principles the committee developed.

Two questions we and others forming community advisory committees are regularly asked are: 1) Who can represent the community? and 2) Do you think your committee adequately represents the community?

No one individual can ever represent the community. Our goal was to ask individuals to serve who had a general understanding of health issues facing New Haven, were respected in the community, and had connections to constituencies at both the neighborhood and city-wide levels. Our hope was that, depending on the specific scholar project, individuals could be recommended as potential research partners by the SC for the project.

### **Finalized CBPR Training and Project Goals**

Through our early experiences with CBPR projects and the guidance of the Steering Committee, the following goals were established for CBPR efforts:

### **Goals for Scholars**

- Help scholars understand health and potential interventions from community and consumer perspectives
- Have scholars make a definable contribution to the health of New Haven while in fellowship
- Provide opportunities for scholars to develop skills working with and co-leading diverse teams in addressing health issues and applying rigorous quantitative and/ or qualitative methods learned in the classroom
- Gain experience in translating research into action through strategic dissemination and

### **CBPR Training Framework**

Our vision for the training necessary to achieve our goals included several elements:

CBPR Values. The following values underlying the CBPR approach would be honored: 1) Scholar and community partner(s) would cocreate the project and be equally involved in all phases of the research; 2) both the researcher and community bring equally valuable expertise to a project; 3) trust is built through the honest expression of partner needs; 4) power is shared in decision-making for all steps of the research process; 5) commitment to rigor in the research is maintained while keeping in mind the need for action; 6) community partners are fairly compensated for their roles in research activities; and 7) co-learning, capacity building, and increased competencies among all partners result from the projects.

sustainability efforts within the time of the fellowship

 Apply CBPR principles, processes, and skills developed through their CBPR projects while in fellowship into their careers regardless of their practice setting

### **Goals for Community Partners**

- Develop new knowledge, insights, and products to use with their stakeholders
- Provide added credibility to research efforts they wanted to employ to influence their stakeholders
- Develop new skills in conducting and implementing research they could use in their organizations to advance their own organizational missions
- Strengthen their ability to evaluate proposed partnered research opportunities that other researchers might present to them

**Education.** Through didactic content, scholars would be exposed to the principles, practices, and ethics associated with CBPR and learn how to use research methods taught in other classes to address local health issues. During the first summer, new scholars also receive an orientation to New Haven and meet a number of health leaders at the organization and neighborhood levels. A summary of the curriculum is contained in Appendix 4.

**CBPR Project.** Beginning in the fall of their first year, scholars explore potential projects and New Haven community partnerships. Each scholar was expected to spend 4-6 hours/ week or at least 15% of their time working on a CBPR project of ~15-18 months duration on an issue deemed important. Each community project would have a consumer-knowledgeable community partner or consortium of community partners engaged in all aspects of the research project. Origins of projects could come from the community, from the scholar with the SC helping to link them with potential community partners who shared interest in the health issue being considered, or from building on previous scholar projects. Scholars could work as a single researcher, in dyads, in small groups, or within an entire cohort. It was expected that would be completed within the period of the fellowship, including preliminary dissemination, and be accomplished with the resources available. A copy of the project proposal format Scholars needed to complete is contained in Appendix 5.

**Relationships**. Scholars would experience productive research relationships by successfully working with others to identify health issues, explore solutions, and implement research to improve the health of the community—from neighborhood and community-based organizations to local, and in some instances state, policy-makers. Scholars would be expected to build on existing CSP relationships as well as establish new relationships that would facilitate their projects and the work of future scholars. Momentum

#### Challenges

Incorporating CBPR into CSP training presented both internal and external challenges. We expect that these issues were not unique to Yale and share these experiences to provide guidance for others considering partnered research.

#### **Misperceptions of CBPR**

In our view, there were several misperceptions of CBPR when it was introduced to the 2005-2007 cohort. Some scholars interpreted the project requirement as a community service they would provide while in fellowship. Others saw themselves as consultants to the community, experts who would help the community address health issues. Many scholars and faculty saw CBPR as a "method" of research rather than an approach or belief about how health research should be conducted using established research methods. Some thought CBPR was interchangeable with qualitative research. This new paradigm of full partnership in coleading, executing, and managing all phases of the research (whether using quantitative or qualitative methods) was foreign to the scholars

and continuity of relationships from one cohort to another would be provided by the Steering Committee on Community Projects and by CBPR faculty.

**Community Products**. Each community project undertaken would result in a tangible community product for use by the community partner upon the completion of the project. The desired product(s) would be defined by the community partner and could include a program evaluation, grant application, research report, policy brief, or communication materials, among others.

Academic Product. Scholars also would be expected to produce an academic manuscript to advance knowledge on the issue studied, the methodology used, or how CBPR can be applied to generate new knowledge on a community health issue. Community partners would be invited participate as co-authors on all manuscripts generated from projects.

and the core CSP faculty, as well as counter cultural in the program and Yale School of Medicine.

While program leadership at all four sites and the National Program Office embraced the idea of CBPR, few had experience with this research approach. As each site began to roll out their respective models for CBPR, the intellectual, programmatic, and practical challenges of CBPR quickly presented themselves. These challenges became the topic of consultant visits and special sessions at the annual National Meeting.

### How Community was Defined for Yale CSP CBPR Projects

For the purposes of Yale CSP CBPR projects, community was broadly defined as New Haven or one of its neighborhoods, a specific community or patient population, community health care organizations, and/or a local governmental entity. The same principles of co-leading a research project from start to finish would apply regardless of the community of focus. However, because of the commitment we made to help improve the health of New Haven, projects were required to directly benefit the people of New Haven. We agreed to allow some projects extend beyond New Haven as long as New Haven was included as a central part of the project.

Early on we had hoped each cohort would work as an entire group on a health issue with subsequent cohorts building on the work of the previous cohort. In theory that was an idea that made sense and was supported by the SC; however, after two years, we discovered that unless there was mutual passion on the part of the community and scholar partners to work on a specific health issue, it was difficult for a project to gain traction and make the project meaningful for both.

#### How CBPR Projects Aligned with the Yale CSP Fellowship Training and Career Development

Historically, the majority of scholars pursued careers in academic settings where publishing original research in high impact peer reviewed medical journals and securing NIH grants represented paths to a successful career. As we began to implement CBPR requirements, both scholars and core CSP faculty were concerned with balancing time needed for CBPR projects and other CSP research commitments. Concerns were also expressed about how to balance research rigor with relationship building and the emphasis on action. Some scholars felt that the role of the researcher was to generate findings but not necessarily translate the research into action, and that engaging in advocacy compromised the objectivity of the research.

All of these concerns were expressed in questioning the CBPR requirement. This was compounded by some initial confusing messages from both the NPO and Yale CSP on the extent of the requirement. In the early years, scholars saw CBPR as separate from the core curriculum. The strongest evidence for this view was the lack of inclusion of CBPR project progress in monthly research progress reports and their exclusion in Research and Progress meetings and site visit reviews of scholar research.

Our goals were to make CBPR projects careerrelevant to scholars, to embed CBPR values into the program culture, and to integrate CBPR projects into the overall program goals, regardless of decisions at other sites. We also wanted to attract scholar applicants committed to action-oriented research. All of this was particularly important because scholars were not our only stakeholder group; the New Haven community, through our Steering Committee and prospective community partners, was an equally important stakeholder group.

With increased understanding of CBPR and its connection to translating research into action and with the initial success of projects, the value of CBPR was increasingly embraced and became central to the Yale CSP training for scholars, faculty, and the community. As indicated by the testimony cited in the previous section of this report, we have made much progress toward relevance of CBPR for the scholars and community. Our progress has also been tracked by the NPO through its annual site visit where the site visit team meets with scholars, faculty, the Steering Committee, and community partners. At the May 2009 site visit, the team reported that, "The program has made impressive progress with its integration with the community as evidenced by the scholars, their projects and the testimony of community representatives."12

#### **External Challenges**

Concurrent with the internal challenges we encountered, external challenges had to be addressed. Initial challenges stemmed from previous experiences the community had with researchers. Other challenges emerged as our community partners actually began CBPR projects.

### Building Trust between the Program, Scholars, and Community

The biggest external challenge we faced was building trust among the community members of the Steering Committee and initial community partners on projects. Many in the New Haven community expressed skepticism about how the community would benefit from any partnerships. A common theme we heard when meeting with community leaders described how previous research did not benefit the community. Researchers would come into the community and request access to clients, patients, and/or their records; community organizations wanted to be helpful and would be accommodating. After a while, they realized the community never heard back from the researcher about the results of the research. Many in the community still carried with them stories of past exploitation of researchers from national studies like Tuskegee or the Henrietta Lacks experience.7,8

Those who had engaged in relationships with researchers around program interventions became frustrated when those relationships ended as funding ended. With this in mind, sustainability of our CBPR efforts needed to be demonstrated as part of trust building. Sustainability strategies now are a part of conversations in the beginning phases of all CBPR projects. Scholars and community partners put in steps during the dissemination phase to build the foundation for sustainability. We, as CBPR faculty, play a role between scholar cohorts to encourage new cohorts to take on the next steps in the work of previous cohorts.

### Community Partner Time, Compensation, and Capacity Required for CBPR

In addition to CSP faculty and scholars, community partners were also concerned about the amount of time CBPR would take. All were surprised at how much time co-constructed research takes, including time for related training in aspects of the research. Even when community based organizations recognized the value of the research for their organizations, they still had to consider what they would be giving up from their main mission to partner in the research.

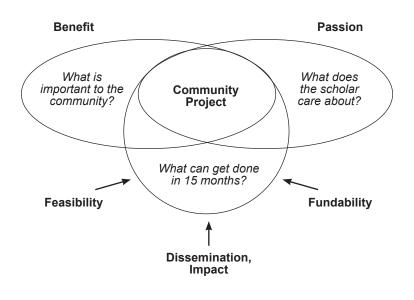
Early on, members of the Steering Committee on Community Projects pointed out that community partners should be compensated appropriately when the research required the time of organizational staff, much like an academic research colleague would be compensated for their time and effort (including training time) if asked to join a project. The funds provided by the Dean's office to support CSP community partnerships provided us with the resources necessary to carry out meaningful CBPR projects.

**Finding CBPR Projects that were Meaningful to the Community Partner and the Clinical Scholars** Mutually meaningful projects were developed over time through experience, the assistance of the Steering Committee, the refinement of project requirements, and the role of brokering by CBPR faculty. At the core was finding a project that was of importance to the community partner, that a scholar felt passionate about, and could be completed within a 15-18 months period with the resources available. The final elements of projects also needed to include plans for dissemination and sustainability.

Openness from each partner to learn from the other was foundational to successful CBPR projects.

**CBPR History Report** 

### Focus of CBPR Projects



The brokering role we played and CBPR faculty/ staff continue to play is critically important to the success of CBPR projects, particularly in the beginning stages of a project. The broker role facilitates conversations about the needs of scholars and community partners, ensuring that the focus is on research and not community service, helping both partners keep time frames and scope of projects on track, and running interference for either the community partner or the scholar as problems arise. We have often been the interpreters with feet in both academic and community worlds and can build the necessary bridges between them. The 2013 site visit report also describes what we believe were positive CBPR experiences between the New Haven community and the Yale CSP. "The engagement of the Steering Committee (and community partners) was palpable, and has increased steadily over the past several years. The turnout of community members was most impressive, as were their compliments for the scholars and the program. The emerging realization amongst the community partners of the value of evidence-based approaches was particularly encouraging."<sup>13</sup> Subsequent reports have repeated these themes.



### PART 2 CBPR Projects: Overview and Impact (July 2005–June 2015)

The CBPR component of the Yale Clinical Scholars Program was designed to make meaningful contributions to the city of New Haven through community partnered projects addressing health issues deemed important by the community. These projects are summarized below as well as the impact of CBPR experiences for Steering Committee members, community partners, clinical scholar alumni and others.

### **Completed CBPR Projects**

As previously mentioned, 33 CBPR projects have been completed by 57 Yale clinical scholars with 28 different community partners in various configurations of scholar teams. It is estimated that over 2,600 hundred people were cumulatively affected by these projects through the duration of the projects; it is our hope that many individuals and organizations continue to be positively impacted as a result of dissemination and action resulting from the projects.

Projects developed primarily in response to priorities identified by the community. Scholars have also presented preliminary research ideas to the program's Steering Committee on Community Projects. When that was the case, the Steering Committee guided scholars in finding community partners who shared common interests. Scholars also have built on the work of previous scholars, allowing a deepening understanding of a particular issue and further deepening community relationships. CBPR projects have ranged from improving access to care for the uninsured and underinsured to addressing health issues for specific populations with health being broadly defined. Community partners have also been interested in quality improvements in their programs. There have been four projects that cut across many issues and have helped inform how CBPR projects can be carried out. All projects have required a litmus test of being relevant to and supported by one or more community partners. Below is a summary list of projects that have been completed over the past 10 years. Detailed descriptions of these projects and a list of community partners can be found in Appendices 6 and 7. Two issues of high priority to the community have received emphasis in CBPR: 1) improving access to care, and 2) violence prevention. Many of the issues addressed through CBPR projects, particularly access to care, were consistent with issues identified in the first round of visits to key organizations by the first cohort of Scholars in the summer of 2005. See Appendix 6 for more detail on the projects listed below.

### **Projects**

## Improving Access to Healthcare

- · Helping to Create Project Access New Haven
- Evaluating Project Access New Haven Medicaid Emergency Medicine Initiative
- Creating Medical Respite Care for Homeless Individuals
- Assessing the Landscape of Primary Care for New Haven (PC4NH) Medicaid Beneficiaries

## Addressing Health Issues for Specific Populations

- Understanding the Root Causes of Youth Gun Violence
   Through Photovoice
- Understanding Gender Differences in the Experience of Youth Violence
- Creating YouthHaven to Train Youth in Research, Community Organizing, and Leadership
- Creating Tools to Support Neighborhood Responses to Chronic Gun Violence
- Creating Community Resilience Strategies at the Neighborhood Level as a Violence Prevention Strategy
- · Expanding Physical Activity in New Haven Public Schools
- Creating Tools for Healthier Pregnant Women and New Mothers
- Increasing Pregnancy Prevention Understanding among 8th and 9th Graders
- Reviewing Motorcycle Mortality from the Lack of Helmet Use
- Improving Health Interventions for Refugees
- Preventing Pertussis (Whooping Cough) through Vaccination Cocooning for Caregivers of Newborns
- Improving Access to Healthy Foods in the West River Neighborhood
- Improving the Health and Mental Health of the New Haven
   Police Department
- Review of the Efforts of the Mayor's Teen Pregnancy Prevention Council 2007-2012
- Increasing Partner Notification of HIV/AIDS for Men Who Have Sex with Men (MSM)
- Exploring the Role of Electronic Media in Increasing STD/ HIV Screening Behaviors for Adolescent
- Increasing Breast Feeding through a Text Messaging Support Program
- Using LARC (Long Acting Reversible Contraception) Methods to Prevent Unintended Pregnancies
- Understanding Cultural Attitudes and Barriers to Organ Donations among Local Indigenous People

### Quality Improvement in Healthcare/Community Programs

- Evaluation of the New Haven Family Alliance's Street Outreach Workers Program (SOWP) to Prevent Violence
- Assessing the Implementation of the National Diabetes Prevention Program at a Local Federally Qualified Community Health Center
- Integrating Weight Reduction and Diabetes
   Prevention Projects in Fair Haven
- Improving Transitions of Care for Homeless
   Individuals
- Understanding Parent's Perceptions Toward Coordinating Pediatric Primary Care and Mental Health Services in a Single Location
- Improving Patient Centeredness at the Yale New Haven Hospital (YNHH) Adult Primary Care Center (PCC)

### Community-wide Projects Informing Future CBPR Projects

- Assessing Community Leaders' Perceptions of the Social Determinants of Health in New Haven
- Dissemination Practices in CBPR
- Conducting a Health Impact Assessment (HIA) for the Downtown Crossing Project
- Understanding Experiences in Community/ University Research



### Increased Awareness and Competence in CBPR Beyond the Yale CSP

Concurrent with training scholars in CBPR, the CSP leadership has also raised awareness of CBPR within the university and community and advanced the science, principles, and practices of CBPR.

- In the fall of 2005, the program collaborated with the School of Public Health and the Prevention Research Center to present a series on community-based research projects. See Appendix 8.
- In late fall of 2005, the CSP was asked to help prepare the community engagement section of the School of Medicine's application for the NIH Clinical and Translational Science Award (CTSA). We partnered with the Steering Committee in conceptualizing an ideal community/ university research partnership model and shared that with those drafting the application.
- In September 2006, the CBPR faculty brought Sarena Seifer, MD, Executive Director of the Campus Community Partnerships for Health to New Haven, Carol Horowitz, MD, MPH, CBPR and policy researcher from Mount Sinai, NYC, and Ann-Gel Palermo, MPH Chair, Harlem Community and Academic Partnership to New Haven to New Haven to present the CBPR approach at a community forum for both academics and community members, consult with scholars, our Steering Committee on Community Projects and meet with the leadership of the Yale Center for Clinical Investigation on their community engagement strategies.
- In 2007, the RWJF Clinical Scholars Programs at Michigan and Yale collaborated to support a CD-ROM self-study guide developed by Barbara Israel, PhD, MPH, one of the earliest pioneers in CBPR.
- In 2009, Margi Rosenthal collaborated with our counterparts at the other CSP sites in publishing an article in Academic Medicine

on teaching the principles of CBPR to physicians in a fellowship program.<sup>14</sup>

- In 2009, the Dean's office and the leadership of the Yale Center for Clinical Investigation (YCCI) approached the scholars program to explore if our CBPR course could be extended to other post-doctoral fellows and junior faculty interested in expanding their approaches to research. Beginning in July 2010, through a joint effort with YCCI, the scholars program began offering its CBPR training to others on the Yale health campus. In the first year, 5 individuals took the course with the RWJF Clinical Scholars. To date, 30 postdoctoral fellows and junior faculty from the Schools of Medicine, Nursing, and Public Health have been trained in CBPR. This year 11 individuals are participating in the course.
- We served as reviewers for a special 2009 CBPR issue of the American Journal of Preventive Medicine.
- Margi Rosenthal and Barbara Tinney, Executive Director of the New Haven Family Alliance, submitted a successful grant application, as co-investigators, to the NIH to create YouthHaven, a program to train high school students in research, leadership, and community advocacy to engage other youth in New Haven to address violence.
- In June 2014, Making Research Work for Your Community: A Guidebook to Successful Research Partnerships was jointly produced and disseminated by the Community Foundation for Greater New Haven and the Yale CSP. See Appendix 10.
- In June 2014 and April 2015, CBPR faculty led two training workshops for communitybased organizations on CBPR including how to effectively partner with academic researchers.

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- From 2006-2014, Georgina has served on the Community Advisory Committee of the Yale Prevention Research Center and the Yale School of Public Health's Community Alliance for Research and Engagement Steering Committee and from 2013-2015 served on the Community Engagement Core of the Yale Center for Clinical Investigation.
- In 2014, Margi Rosenthal led a communityacademic partnership in publishing an article on how community capacity building

#### Impact from CBPR Efforts

What kind of impact have the CSP CBPR efforts had on the Steering Committee, community partners, scholars who have come through the program, and others at Yale? What follows is a summary of the ways in which we believe the CSP CBPR efforts have had an impact.

External Acknowledgments of the Impact of Yale RWJF Clinical Scholars Program CBPR Efforts

- Harlan Krumholz has shared with the Steering Committee on Community Projects the influence Yale CBPR projects have had on his thinking and his contributions to the Patient Centered Outcomes Research Institute (PCORI), which was created through the Affordable Care Act.
- Many of the scholar and faculty efforts have been recognized in professional circles with 22 articles in peer-reviewed journals. A listing of those articles is contained in Appendix 12, including major presentations at professional meetings and other forums such as the Institute of Medicine. Two scholars had their CBPR projects nominated for the Lipkin Award, an

can sustain the effects of multiple, two-year CBPR projects. See Appendix 14.

Both Georgina Lucas and Margi Rosenthal have coached and mentored several faculty members seeking to better understand CBPR and how it may inform their research and training of others; they also have provided orientation sessions to New Haven for medical residents in the adult and primary care centers at the York and Saint Rafael campuses of Yale New Haven Hospital.

award for scholarship for medical residents and fellows from the Society of General Internal Medicine. Scholar alumna, Rachel Skeete was a finalist for her participatory evaluation of the NHFA Street Outreach Program, and Ryan Greysen won the award for his research on transition care for the homeless.

- In April 2011, Georgina Lucas was the recipient of an Elm-Ivy Award jointly conferred by then President of Yale University Richard Levin and then Mayor John DeStefano for improving relations between the University and the city.
- In June 2011, Yale Medicine featured the scholars program and their CBPR efforts in their spring/summer issue. In the article, entitled, "Scholars Work toward Healthy Communities," Des Runyan, CSP National Program Director, was asked to comment on Yale's CBPR work. He commented, "The Yale program is doing exceptional work in the community... Yale had a reputation for a town/gown split, so it's remarkable how strong the ties are now, how invested people have become."

#### **Stakeholder Experiences**

As part of assembling this report, several groups of individuals who have been involved with the program's CBPR efforts were surveyed, including Steering Committee members, community partners, scholar alumni, and others at Yale. To preserve confidentiality, most survey responses were anonymous. A few of those surveyed were also interviewed. To see the range of settings in which scholar alumni are currently working and applying CBPR skills (and with their permission), their names are included in the quotes shared. Below is a summary of the themes that emerged with a few illustrative quotes. A full listing of all quotes by stakeholder group is in Appendix 13.

### **Community Members' Comments**

Several themes emerged in the comments from Steering Committee and community members:

### CBPR offered a new model for community/university research relationships that was balanced and not one-sided in the direction of just the university researcher's needs.

The Yale RWJF Clinical Scholars Program shifted the paradigm of how the community and university could do research together. Community partners learned that CBPR provided a different and more balanced approach to community-based research rather than the previous one-sided research done by university investigators... As far as Yale goes, CBPR is still in its embryonic stage. Yale University needs to find ways to institutionalize this approach beyond the scholars program. —Steering Committee member and community partner

### A new attitude about the value of research to the community occurred as a result of participating in CBPR projects.

The scholars and the scholars program have changed and improved the perception of research among community groups/organizations in the New Haven area. There is more trust, willingness to participate in research efforts, because the scholars have embraced the CBPR model and developed true partnerships with community entities. The projects have had a positive impact - e.g., creating new programs, building organizational capacity, etc.

-Steering Committee member

The impact has been dramatically positive. Scholars have changed the reputation of 'research' in New Haven and specifically at Yale and created a climate where research is viewed as an asset to the community. The scholars have been patient and methodical with building trust, carrying through on commitments, and building community capacity. There is sincerity to their work that is very special. –Steering Committee member

### The scholars are seen as a resource to the community, willing to address issues of concern to the community, to share their knowledge and skill, and work toward the greater good (not just their careers).

When there is a need for research in the city, the Clinical Scholars come immediately to mind as a potential resource.

-Community leader and community project partner

Scholars have spent a lot of years and time learning their craft, it was just amazing that they are so willing to share their knowledge to help improve the lives of community people outside of their medical community. They are a great resource and they are really sacrificing for the greater good. This is a tremendous community building effort for communities anywhere in the country. —Steering Committee member and community project partner



### Through CBPR projects with scholars, the capacity of community partners to do research for their own purposes has increased.

Because of the science-centered emphasis, community partners developed their capacity for using research for their own benefit as well.

-Steering Committee member and community partner.

The scholars have hugely improved health research and capacity building in New Haven. I think that some CBO's have 'stepped up their game' in terms of serious research and programmatic and policy initiatives based on that. In a subtle manner, I also think the interaction between CBO's, neighborhood associations and the Scholars Program have contributed to a sense of social parity, and increased the prestige of the CBO's and associations. —Steering Committee member

For more on capacity building across several projects from the partner's perspective please see a recently published article by Yale CBPR faculty, scholar alumni and their community partners (15). The full article can be found in Appendix 14.

### Scholar CBPR projects have resulted in very specific contributions to New Haven.

The scholars made a deep and extensive contribution to the formation, direction and development of PA-NH... They helped PA-NH appreciate and incorporate research and evaluation into the program model and embrace a larger systems-focus in our work.

-One of the founding members of Project Access-New Haven (PA-NH)

The scholars involvement made a world of difference. This program (PA-NH) saves lives and without the scholars, this new organization would not have happened. The scholars really cared and gave the time and resources to this project. This project also demonstrated that anything is possible. —Community partner and Board member of PA-NH.

We had two scholars whose research included the issues of homelessness and healthcare. The first scholar identified critical issues for people who are homeless as they access or don't access healthcare. His work started us thinking about how Columbus House should respond to the medical needs of this very vulnerable population. The next scholar worked closely with us to make the case for Medical Respite, which is now operating within Columbus House. This scholar did intensive research, supported our advocacy efforts to secure funding and contributed to the program's design and continues to act as an advisor to the program. Respite has become an important addition to the services we provide.

### -Community partner

The nature of the work our Healthcare Kitchen Cabinet is to ensure that the voice of the people impacted by an issue are heard and their recommendations are used in making of public policy. There is a lot of skepticism among people that are poor that their opinions don't matter. It was very encouraging to our program participants to be solicited for their input. It gave the group encouragement to continue the advocacy work they are doing. The PC4NH project report generated as a result of the scholars interviewing 89 medical practices in the New Haven area is helping shape the ongoing work of the Healthcare Kitchen Cabinet.

-Community partner

### Yale Clinical Scholar Alumni

The scholars alumni themes include:

#### The CBPR experience changed the way graduates think about and approach research

My solid training in CBPR as a Clinical Scholar has had a last impacting on how I think about developing a research question and team and taught me the value of engaging stakeholders throughout the research process. In addition, it has informed how I think about research dissemination, which I have learned most effectively begins with the inception of project, may take various forms, and has the potential for direct impact on health outcomes. —Jennifer Edelman, Assistant Professor, General Internal Medicine, Yale School of Medicine

The RWJ CBPR training has influenced the entire way I perform research today. Whenever possible, I try to include stakeholder input into the research question, with stakeholders including adolescents, healthcare providers, policy makers and parents. The CBPR training instilled the importance of conducting research that has tangible value for the population, and to be careful not to offer research supported services that have no plan for sustainability. Our CBPR training also helped me understand the importance of relationship building and trust in moving forward any professional initiative- whether it be research-related, clinical, administrative or educational. —Deepa Camenga, MD, MHS, instructor, Pediatrics (Adolescent Medicine) Yale School of Medicine

I've found that engaging my operational partners and obtaining their input is invaluable in the design of my studies. I know this early investment is instrumental to our results being useful in identifying important operational and policy solutions. I continue to use many of the skills I learned during our CBPR experience. From the more core CBPR skills (i.e. community engagement, understanding and respecting power dynamics, recognizing individual strengths) to the more minute (agenda setting, running a meeting, creating budgets) - I use these skills on a daily basis and know my projects are the better for it!

 Anita Vashi, MD, MPH, MHS, Physician-investigator, Center for Innovation to Implementation, Palo Alto VA Healthcare System

### Scholar alumni have taken the knowledge and skills learned through CBPR to other activities in their current positions in health systems, policy work, and government.

I am actively applying the CBPR skills very vigorously in my current efforts to create practice and culture change at my hospital. Briefly, I am partnering with a wide range of clinicians and administrators outside my division (nurses, pharmacists, physical therapists, etc.) to create a program to improve outcomes for vulnerable, older adults admitted to my hospital... I think another key lesson that CBPR taught me was patience and persistence." —Ryan Greysen, Assistant Professor, University of California San Francisco

"Although I am no longer involved in research and don't have much direct contact with community, I would say a valuable lesson is the idea that individuals directly involved in the work or directly affected by the problem can hold critical insights on the nature of the solution. It has been important to keep that in mind when designing or implementing public health programs and policies. For example, many of our chronic disease programs operate in consultation with multi-sector advisory coalitions or partnerships.

-Mehul Dalal, Director of Chronic Disease Management, Connecticut State Department of Health

#### CBPR experiences through the CSP have provided new career opportunities

My CBPR project opened so many doors for me. I got a K award at the University of Colorado, to evaluate these types of projects; I am on two CMMI (Centers for Medicaid and Medicare Innovations) evaluation teams for programs that are similar in nature; and now I am writing an R01, given the preliminary positive results. Although I have only been a faculty member for one year the University of Colorado, my community partner organization here nominated me for the Colorado Coalition for the Underserved Physician of the Year Award and I was just awarded the Herbert Nickens Fellowship through the AAMC (American Association of Medical Colleges).

-Roberta Capp, Assistant Professor, Emergency Medicine, University of Colorado

As a Clinical Scholar, working on a CBPR project served to deepen my interest in collaborating with community-based organizations as part of my research career. During my very first year as research faculty, I applied for and received a competitive community-based pilot grant from my institution's Center for AIDS Research. My exposure to CBPR during CSP provided me with the skills and confidence to identify an appropriate community partner with whom I worked closely to develop a rigorous research proposal that could provide formative data to ultimately improve the health of my community partner's clients.

-Oni Blackstock, Assistant Professor, General Internal Medicine, Albert Einstein School of Medicine

### **Other University Stakeholders**

To assess the value of the CBPR course provided by the Yale RWJF Clinical Scholars Program to those from the health campus, participants were asked to share their experiences. Here's what some of those participants had to say:

*"As a result of the course, I've applied for funding using a collaborative approach to breast cancer research and patient-centered engagement that I wouldn't have considered before."* 

"I didn't know how relevant the course would be in the beginning but it ended up being really valuable."

"I was hoping to get an introduction to CBPR and exposure to community organizations in the New Haven area for potential future collaborative projects. The class has exceeded my expectations."

"We now know there are mentors and resources to help with CBPR."

### From YCCI Community Engagement Core Director

The emphasis on CBPR and community engagement in Yale research has enhanced understanding and helped it gain credibility as legitimate work especially in the medical school. I hope that the work will be even stronger due to the support of YCCI and the presence of more faculty who participated in the training.

-Margaret Grey, DrPH, RN, FAAN, Dean, Annie Goodrich Professor, Yale University School of Nursing, and T3 Translational Core Director, YCCI

As these selected quotes, illustrate, CBPR training and the related projects have had a positive impact in the community and within the university.



### PART 3 Suggested Guidance for Those Considering CBPR

Since we began our introduction and incorporation of CBPR into CSP training and engaging the New Haven community in partnered health research, CBPR has increasingly appeared on the radar of health campuses at major research universities and funding agencies. For example, NIH began funding community engagement under the Clinical and Translation Science Awards initiative and the creation of the Patient Centered Outcomes Research Institute. The Agency for Healthcare Research and Quality (AHRQ) and the Institute of Medicine (IOM) expressed value in community and patient partnered research through reports it has issued and recent funding opportunities. The purpose of what follows is to offers suggestions, based on our experiences, to academic researchers and potential community partners who are considering CBPR-like approaches to research.

### For Academic Researchers

There is a great deal of literature on how academic researchers can successfully carry out CBPR projects in addition to what we have shared in this report. A quick summary of general principles follows. For more in-depth discussions see the resources listed in Appendix 1.

- CBPR is different from recruiting subjects for research, surveying community members, or engaging community participants in focus groups or interviews to solicit community input. It is about co-creating and implementing research together.
- CBPR is not a method but a philosophy about how to approach and engage the community in the conduct of research in the community. It uses established quantitative and/or qualitative research methods.
- CBPR takes time, is iterative, and requires compromise while maintaining research integrity.

- Authenticity in developing community relationships is achieved by building relationships with potential community partners before funding opportunities are present, holding meetings in the community rather than at the University, and giving enough time for early conversations for relationships to build and deepen during the research to maximize the value of the partnership for both partners.
- Engaging in transparent conversations so each partner can express what they need and the time frame for meeting those needs at the beginning of a project.
- Building in funding to support the contributions of community partners and for those activities important to maintaining community involvement (transportation for meetings, childcare, food, community meeting space).

We have found two other activities very important to successful CBPR projects:

### Tapping into University Established Community Liaisons

At Yale, several community liaison (broker) positions have been developed to facilitate the connection between community and scholars. For instance at Yale, there are liaisons within the CSP, CARE (Community Alliance for Research and Engagement), CIRA (Center for Interdisciplinary Research on AIDS), and (YCCI) Yale Center for Clinical Investigation. While these individuals are familiar with the community, can make connections and begin the relationship process, each researcher must take the time to deepen the relationship to maximize the research relationship for both parties.

#### Need to Explain CBPR to Ancillary Research Support Structures

The commitment to CBPR goes beyond the university and community partner research team. It can involve the Institutional Review Board (IRB), which may not be familiar with CBPR, the business office, which may have to make adjustments in policies and procedures for reimbursing community partners, and for program or departmental leadership who may need some orientation to the challenges and benefits of CBPR.

#### For Community Partners

We do not want to be presumptuous in speaking from the community perspective but instead reference two documents written by community members from their experiences. One is an article on the benefits of partnering in research. It can be found in Appendix 11. The other, A Guidebook to Successful Research Partnerships, was jointly produced by the Community Foundation for Greater New Haven and the Yale Clinical Scholars Program and written by Natasha Ray, Consortium Coordinator for New Haven Healthy Start and her academic partner and CSP alumna, Karen Wang. The Steering Committee also provided considerable input. The Guidebook can be found in Appendix 10.

#### Responding to a Request from a Researcher

Here are some considerations the Guidebook suggests:

- 1. What will be the nature of the research relationship?
- 2. How much say will the community organization have regarding input on the research questions, methodology, analysis, writing up findings, and participating in dissemination?

- 3. What does the CBO want to get out of the relationship?
- 4. How will the CBO's work be impacted and do they have the time and capacity to fully participate and if not, on what basis are they willing to participate?
- 5. What funds will be available to compensate CBO staff for any specific research activities?
- 6. What contributions can the CBO make to the effort?
- 7. Who will own and have access to the data?

### Seeking Assistance from Researchers to take on a CBPR Project of Interest in the Community

This is a more challenging venture. The Yale health campus is not organized yet to maintain a clearinghouse of potential investigators for interested community-based organizations to tap into. Word of mouth through the CSP Community Research Liaison or through other Yale community liaison positions or those in the community who have worked with university researchers are starting points. Resolving this gap is an aspiration of future efforts at Yale. **CBPR History Report** 

#### Solidifying the CBPR Relationships

Regardless of the source of the partnership, it's important to find a mechanism for confirming all aspects of the research partnership including the research structure, expectations and goals of each partner, timelines, tasks, roles, decisionmaking processes, budget, communication preferences, milestones, recalibrations, dissemination, and sustainability strategies. Some partnerships use a Memorandum of Understanding (MOU) or other written forms of documenting agreements. Going through respective expectations for each of the prospective partners in a formal way allows needs to be expressed which will contribute to a clearer understanding of the relationship and project, avoid misunderstandings, and advance trust.

This section concludes our experiences over the last 10 years of CBPR projects. It has been a challenge itself to capture and communicate the very rich experiences we have had working with scholars and their community over the past 10 years. We look forward to what the next 10 years will yield



# PART 4 The Future of Community-Academic Research Partnerships at the Yale School of Medicine

The future for community-academic research partnerships at Yale is bright. The past decade of achievement in this realm through the RWJF Clinical Scholars Program at Yale School of Medicine has been documented in this report. We are poised to take the next leg of our CBPR journey.

When the RWJF, in early 2014, announced it would be defunding the CSP in 2017, community partner representatives at all four CSP sites came together to share with the Foundation their concern regarding the disruption the defunding would create in terms of advancing CBPR efforts that had been benefiting the local communities. At the same time the announcement provided an opportunity for the leadership of the medical school and Yale CSP to discuss the relevance and importance of community engagement in research, particularly in light of the financial support for CBPR faculty and projects that has been funded through the Dean's Office and the Yale Center for Clinical Investigation (YCCI) for the past 10 years.

Concurrent with the Foundation announcement was the call for renewal of the Clinical and Translation Science Awards (CTSA), which is at the heart of training and health research support at YSM through YCCI. Community engaged research has been an important core of YCCI. At the national level, community engaged research has received increased recognition as a central factor in translating research into practice and improved health. Like the CSP, CTSA national leadership defines community broadly to include members, patients, community advocacy organizations, and other stakeholders who can influence improvements in health and health care, including providers and policy makers.

#### The Future of Community-Academic Partnered Research at Yale School of Medicine

The community partner advocacy with the RWJF resulted in the Yale site receiving a \$50,000 planning grant from the Foundation to develop a strategy for extending community-academic research partnerships. YSM and YCCI have agreed to continue funding training and research support for community partnered/community engaged research. The Steering Committee on Community Projects has been working with the CSP CBPR faculty to discuss how best to extend the CBPR legacy with the resources that have been made available.

These four core values are guiding our conversations regarding future planning: 1) equitable engagement of communities and academic researchers, 2) respect for and recognition of varied expertise and experience, 3) transparency along the research process from budget to design to dissemination, and 4) commitment to build research capacity across diverse stakeholders, community members, and academicians.

After almost one year of planning conversations, several priorities have begun to emerge. Although still formative in nature, these action-oriented priorities provide a starting map for the future direction of CBPR/community engagement over the next 3–5 years. Initial exploratory work

regarding the feasibility of the described activities is supported by the CBPR legacy-planning grant from the RWJF. Our goals include:

#### 1. Continue to make a positive difference in health outcomes for New Haven residents

Ten years ago, partnerships were formed and coalesced with this singular priority in mind. Looking ahead, everyone reiterates what "brought them to the table" and this is the plumb line by which to judge whether proposed activities are mission-aligned. Although the many partners who have been engaged over the years are now experts in the process of community engagement, the primary emphasis of all involved remains on supporting research initiatives with clear and immediate relevance to practices and policies that impact the health of New Haven residents.

# 2. Create a permanent home for community-engaged research at Yale School of Medicine and in the community

Formalizing a centralized resource to facilitate authentic partnership across the community engaged research spectrum is an imperative. The rationale for this planned transition from community engaged research as a flagship element in the CSP to an institutionalized infrastructure is multipronged. First, this shift communicates the relevance and importance of community engaged research within Yale and to New Haven community members. Second, this institutional hub can facilitate broader and deeper community-academic research partnerships initiated by either community or academic researchers. Third, an organized research resource can establish standard community engaged research policies, protocols, and procedures. Lastly, a semiautonomous center for community engaged research activities can provide training, link with other institutions and organizations, build models for sustainability, and serve as a platform to launch community-university research partnership innovations.

Concurrently, a Data and Democracy subcommittee of the RWJF CSP Steering Committee on Community Projects has been formed to explore how to continue to build the capacity of the community to do research for their own purposes. In addition this group will explore developing a mid to long range plan to develop a community-academic entity based in the community that would be a repository for community-academic research data as well as a training site for developing research, dissemination, and advocacy skills.

### 3. Support bi-directional research collaborations

The commitment remains strong to support future scholars in the newly formed National Clinician Scholars Program who have an interest in community/stakeholder engaged research. The emergence of other related training programs, such as the Patient-Centered Outcomes Research Faculty Fellowship Program, is welcomed and the commitment to support future fellows is also steadfast. In addition to facilitating community linkages for Yale-affiliated investigators, there is substantial interest in providing avenues for community-based organizations and community members to be linked with academic partners to pursue research collaboration. Processes that help determine project prioritization and appropriately allocate limited resources would also support the success of projects whether initiated by academics or by community.

#### 4. Advance and operationalize health data democracy across New Haven

Enthusiasm is high to build upon the foundation of research previously conducted in New Haven, including both CBPR and non-CBPR projects, by building and sustaining a physical location solely dedicated to the reciprocal transfer of health research data between academic researchers and community members in greater New Haven. With a focus on increasing data literacy across diverse stakeholders, the framework in development furthers work on meaningful dissemination and on broadening the base of individuals with the capacity to identify research priority areas and questions. Synergistic with current initiatives such as Data Haven, there is significant interest in the parallel development of an innovative platform for data visualization and of a local and accessible repository for historical, current, and future quantitative health research data collected by local researchers and community organizations.

### 5. Honor the CSP CBPR Legacy

Much work and continued conversation needs to occur to move from planning to action, but the Steering Committee on Community Projects and the leadership of YCCI is prepared build on the work of the CSP over the past 10 years and take community partnered research to new levels.

# ACKNOWLEDGMENTS

The CSP CBPR efforts would never have been possible without the vision and leadership of Harlan Krumholz who was able to create an environment in which an emerging CBPR model could be co-developed with community involvement. In early 2002, Harlan brought together four New Haven community leaders to discuss what the new iteration of the Clinical Scholars Program could accomplish and to help draft the 2002 RWJF CSP renewal application. We would like to share our appreciation for those community leaders, the late Cornell (Scottie) Scott, founding CEO of the Hill Health Center (now the Cornell Scott-Hill Health Center), Katrina Clark, retired Executive Director of the Fair Haven Community Health Center, William Quinn, former Director of the New Haven Health Department, and James Rawlings, former Vice President for Community Health at Yale-New Haven Hospital. They welcomed us as we tried operationalized the ideas they developed for the renewal application.

We want to thank the Yale School of Medicine Dean's Office for the financial and organizational support of the Yale CSP CBPR vision that contributed to the selection of Yale as a site in 2002 and to current Dean Robert Alpern for continuing this support along with the Yale Center for Clinical Investigation (YCCI).

We would also like to thank Marta Moret, MPH from Urban Policy Strategies and her colleagues Jim Jekel, MD, MPH and Kari Hartwig, DrPH, then with the Yale School of Public Health, for helping to develop, coordinate, and teach the preliminary community research curriculum in 2004. They provided an important foundation for our subsequent work.

There are others who helped move our CBPR efforts along and became critical members of the Steering Committee. They include Barbara Tinney, Natasha Ray, Maurice Williams, Sandra Trevino, Jean Larson, Mark Abraham, Amos Smith, Stacy Spell, Lois Sadler, Joanne McGloin, Sandy Bulmer, Anne Camp, Lou Brady, and Steve Updegrove. We are grateful their contributions to the program and scholars.

We also want to thank our community partners over the last ten years. Thank you for trusting us and for providing your expertise to the scholars' 33 projects. We share our accomplishments with you because without you there would be no accomplishments or demonstration of the value of CBPR.

We want to thank Des Runyan, NPO Director and Kristin Siebenaler, NPO Deputy Director for their support and encouragement in our CBPR efforts and the members of the NAC, particularly the NAC chair, Richard Krugman, who made annual site visits and met with community members of the Steering Community. Their enthusiasm reinforced our sense we were going in the right direction.

We would also like to thank Leslie Curry, Marcella Nunez-Smith and Arian Schulze for their careful reading of the drafts of this report and their incredibly helpful suggestions for improving it. We also want to thank Arian Schulze for her creative cover design. Thanks go to Kendall Getek, the Yale CSP Program Coordinator for reading, editing, facilitating the production of this report along with Yale CSP Senior Administrative Assistant, Laura Williams.

Finally, thanks to the CSP alumni who have come through this training and shared their experiences while here and subsequently in their careers. Their application of CBPR principles in their post CSP careers is affirming.

The Yale CSP CBPR experience has not only been transformative for the scholars and community partners, it has been transformative for us as well. Thank you.

Georgina Lucas

Margi Rosenthal





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### Yale RWJF Clinical Scholars Program Steering Committee on Community Projects

#### **Operating Principles (established 2005)**

Mission of the Committee: Guide the RWJ Clinical Scholars and Program faculty in their community engagement efforts to make short and long term contributions to the health of New Haven residents.

#### **Responsibilities of Committee**

- 1. Provide overall guidance to the Program to assure adherence to principles of community involvement
- 2. Serve as a bridge between the community and the Program, serving as an ambassador for the Program and Scholars
- 3. Participate in a community-orientation program for new scholars
- 4. Provide advice to Scholars and others in the development of community projects
- 5. Help identify potential community mentors who can work with scholars and their research mentors on community research projects
- 6. Bring to the attention of the Committee potential funding opportunities that may advance improving the health of New Haven avoiding competition for funds where possible
- 7. Participate in "Research in Progress" meetings regarding community research projects community projects are presented if possible

#### Attendance

Committee members will be expected to attend 3/4 of the meetings each year to maintain membership.

#### Current Members of the Committee (June 2015)

Mark Abraham, Executive Director, DataHaven

Lou Brady, MBA, Chief Operations Officer, Cornell Scott Hill Health Center

**Sandra Bulmer**, PhD, Professor, Public Health, Southern Connecticut State University

**Anne Camp**, MD, Clinician, Fair Haven Community Health Center

**Beth Comerford**, MS, Deputy Director, Yale-Griffin Prevention Research Center Patricia DeWitt, MS MPH, Director of Ambulatory Services, Department of Community Health, Yale New Haven Hospital

Ann Greene, Community Research Liaison, Yale RWJF Clinical Scholars Program

Margaret Grey, DrPH, RN, FAAN, Dean & Annie Goodrich Professor, Yale University School of Nursing & T3 Translational Core Director, Yale Center for Clinical Investigation (YCCI) **Marcia Hunt**, PhD, Deputy Director, Northeast Program Evaluation Center, VA

**Clair Kaplan,** MSN, APRN, MH, MT (ASCP), Director of Clinical Research, Planned Parenthood of Southern New England

Karen King, Director, Yale University President's Public Service Fellowship & Community Affairs Associate, Yale Office of New Haven & State Affairs

**Joanne McGloin**, M.Div., MBA, MS Associate Director, Yale Program on Aging **CBPR History Report** 

**Susan Nappi**, MPH, Director of Evaluation, United Way of Greater New Haven

Marcella Nunez Smith, MD, MHS, Deputy Director for Health Equity Research & Workforce Development, Associate Professor of Medicine & Public Health & Co-Director for Community Research, Yale Clinical Scholars Program (Co-Chair of the Committee)

**Natasha Ray**, Consortia Coordinator, New Haven Healthy Start Program, Community Foundation of Greater New Haven

Martha Okafor, PhD, Director, New Haven Community Services Administration

Marjorie Rosenthal, MD, MPH, Assistant Director, Yale Clinical Scholars Program & Associ-

#### **Past Members**

**Chisara Asomugha**, MD, MSPH, MHS, Centers for Medicare & Medicaid, US Health & Human Services, former Director of the Community Services Administration, City of New Haven

**Sharon Bradford**, MSW, Southern Connecticut State University, School of Social Work

**Amy Carroll-Scott**, PhD, MPH, Drexel University School of Public Health, formerly at Yale School of Public Health

Althea Marshall Brooks, MS, M.Div., former Director of the Community Services Administration, City of New Haven

**Maria Damiani**, MS, Director of Maternal & Child Health, New Haven Health Department ate Research Scientist, Department of Pediatrics, Co-Director for Community Research, Yale Clinical Scholars Program

Michael Rowe, PhD, Co-Director, Program for Recovery & Community Health; Principal Investigator, CMHC Citizenship Project, Associate Professor of Psychiatry

**Alycia Santilli,** MSW, Director of Community Initiatives, CARE, Yale School of Public Health

Jerry Smart, Community Health Worker, Transitions Clinic

**Amos Smith**, MSW, Chief Executive Officer, Community Action Agency of Greater New Haven

**Stacy Spell**, President, West River Neighborhood Services Corporation

**Diana Edmonds**, formerly Coordinator, Adopt-a-Doc Program, Yale New Haven Hospital Pediatric Primary Care Program

**Brian Forsythe**, MD, Pediatrician, Yale School of Medicine

**Mario Garcia**, MD, MS, former Director, New Haven Health Department

**Kari Hartwig**, DrPH, Director of Whole Village Program, formerly at the Yale School of Public Health

Jeannette Ickovics, PhD, Yale School of Public Health

Jean Larson, MBA, former Community Outreach & Education Coordinator, Yale Human Protection Program (Yale IRB) **Barbara Tinney**, MSW, Executive Director, New Haven Family Alliance (Committee Co-chair)

**Sandra Trevino**, MSW, Executive Director, Junta for Progressive Action

**Stephen Updegrove**, MD, Pediatrician & Medical Advisory to the New Haven Schools

**Pina Violano,** MSPH, RN-BC, CCRN, PhD, Injury Prevention Coordinator, Trauma Department, Yale New Haven Hospital

**Emily Wang**, MD, MSc, Assistant Professor, Yale Department of Medicine, Co-Director for Community Research, Yale Clinical Scholars Program

Maurice Williams, Community Liaison Coordinator, Yale Center for Clinical Investigation

**Georgina Lucas**, MSW, former Deputy Director, Yale RWJF Clinical Scholars Program

Leif Mitchell, Senior Community Liaison, Gilead Services, former Community Research Core, Center for Interdisciplinary Research on AIDS

James Rawlings, former Director of Community Health. Currently, President of NAACP, New Haven Chapter & Urban Intertribal Council

Lois Sadler, PhD, PNP-BC, FAAN, Professor, Yale School of Nursing

### Yale RWJF Clinical Scholars Program Institutional Advisory Committee

#### **Dr. Robert Alpern**

Ensign Professor of Medicine (Nephrology), Dean, Yale School of Medicine

#### Dr. Thomas Balcezak

Chief Medical Officer, Yale-New Haven Hospital

#### **Dr. Paul Cleary**

Anna M. R. Lauder Professor of Public Health (Health Policy); Professor of Sociology; Dean, Yale School of Public Health; Director, Center for Interdisciplinary Research on AIDS (CIRA)

#### Dr. Gary Desir

Professor of Medicine (Nephrology) and of Forestry and Environmental Studies and Interim Chair, Department of Medicine

#### Dr. Gail D'Onofrio

Professor of Emergency Medicine; Chair, Department of Emergency Medicine

#### Dr. Linda Godleski

Professor of Psychiatry and Associate Chief of Staff for Education, VA Connecticut Healthcare System

**Dr. Margaret Grey** Annie Goodrich Professor and

Dean Yale School of Nursing

#### Dr. Forrester (Woody) Lee

Professor of Medicine (Cardiology); Assistant Dean for Multicultural Affairs

#### Dr. Suzanne Lagarde

Chief Executive Officer, Fair Haven Community Health Center

#### Dr. George Lister

Jean McLean Wallace Professor of Pediatrics and Professor of Cellular and Molecular Physiology; Chair, Department of Pediatrics

#### Dr. Linda Mayes

Arnold Gesell Professor in the Child Study Center and Professor of Epidemiology (Chronic Diseases), of Pediatrics and of Psychology; Chair, Directorial Team Anna Freud Centre at London; Special Advisor, Dean

#### Dr. Patrick O'Connor

Professor of Medicine (General Medicine) and Residential College Associate Fellow in Faculty of Arts and Sciences; Section Chief, General Medicine

#### Dr. Hugh Taylor

Anita O'Keeffe Young Professor of Obstetrics, Gynecology, and Reproductive Sciences and Professor of Molecular, Cellular, and Developmental Biology; Chief of Obstetrics and Gynecology, Yale-New Haven Hospital

#### **Michael Taylor**

Chief Executive Officer, Cornell Scott Hill Health Center

#### Dr. Mary Tinetti

Gladys Phillips Crofoot Professor of Medicine (Geriatrics) and Professor of Epidemiology (Chronic Diseases) and of Investigative Medicine; Section Chief, Geriatrics

#### Dr. Robert Udelsman

William H. Carmalt Professor of Surgery; Chair, Department of Surgery; Surgeon-in-Chief, Yale-New Haven Hospital; Clinical Program Leader, Endocrine Cancers Program, Smilow Cancer Hospital; Chairman of the Board, Yale Medical Group

## Yale RWJF Clinical Scholars Program CBPR Training Curriculum

#### Classroom Didactics (some sessions co-taught with community partners)

- CBPR basics: in terms of principles, values, ethics, processes and rationale
- Social determinants of health/population health
- The challenge of identity (race, ethnicity, gender, etc.) in doing CBPR
- Finding and developing relationships with community partners
- Using quantitative and qualitative methods in CBPR
- Defining working relationships in CBPR projects/developing a Memorandum of Understanding (MOU)
- Project management and CBPR budgets
- Strategies for communication, dissemination and sustainability
- Case studies

#### Summer/Early Fall Orientation to New Haven

- Bus tour of New Haven
- Neighborhood walking tours with neighborhood leaders
- Meetings with the leadership of City Hall, the New Haven Health Department, the Federally Qualified Health Centers, and Yale-New Haven Hospital
- Meeting with members of the Steering Committee on Community Project

#### **Community Project Design (Practicum Experience)**

Community has been defined by the Yale CSP as New Haven centric and included New Haven consumers of health care and their advocates, providers of healthcare, community-based organizations, and/or local and state government representatives—policy, administrative, and elected. Whenever larger systems were partnering, Scholars and those institutional partners would seek ways to also have the community's/patients' voice represented. Any projects that extended beyond New Haven were required to have a primary New Haven partner with a New Haven specific benefit.

### 2013-2015 Yale Community Project Proposal Requirements

Proposals for 2014-2016 Cohort Community Project Proposals are due on December 19, 2014. Your CBPR mentor is available to meet with you any time prior to the 19th to discuss your proposal ideas. Kendall Getek can help you build your preliminary budget and any reforecasts for CBPR leadership approval.

The following provides an outline of what's to be included in the proposal. Proposals should not exceed 5 pages. You and your community partner(s) should plan on presenting your project to the RWJF Steering Committee in January, February, or March 2015 at the latest and quarterly thereafter. Please indicate what month you are willing to present your project. Please share your proposal with your community partner(s).

#### Name of the Project:

#### **Brief Description of the Project:**

#### Community Partner(s):

#### Project Team:

#### Primary Mentor(s):

- 1. Why is this project needed?
- 2. Who in the community says this is an important issue to address?
- 3. What information gap will it address?
- 4. What do you and your community partner (s) anticipate will be done with the findings?
- 5. What kind of systems or policy change might this project lead to?
- 6. Who are the stakeholders and how will they benefit from the project?
  - Community partner(s)
  - Larger community
  - Scholar(s)
  - The RWJF Clinical Scholars Program
  - Others
- 7. Who else in New Haven is working on this issue? Have you met with them?
- 8. How will what you are considering complement work being done?
- 9. What is the primary research question?
- 10. Results of literature search in informing the research question:
- 11. Methodological approach and rationale for approach:
- 12. What metrics could you use to measure impact?
- 13. Roles of partners in the project:
- 14. Identity—How will the identity of the Scholars affect and be affected by the partnership and the project?
- 15. Timeline, project tasks and key milestones (including dissemination and plans for sustainability)
- 16. Anticipated community and scholarly products

**CBPR History Report** 

**Budget:** Using template provided on last page please put together a budget covering the following items. Please use template for Year 1, Year 2 and a total and make sure what you are sending fits on one printed page.

#### Reports to Community Research Faculty and the Steering Committee

#### First Meeting with Steering Committee (September of First Year):

- Share who you are-specialty, where you came from generally/professionally
- What attracted you to the Scholars Program as your next career step? Experiences working with communities/urban populations
- Ideas of areas you might like to explore for a potential community research project

#### **October of First Year**

Meet with CBPR faculty and staff to discuss possible ideas, potential partners, and next steps.

CBPR faculty/staff are available to meet with you and your potential community partners to explore ideas for projects

#### Mid-December of First Year

Submit initial proposals to CBPR faculty for review, discussion and finalization. The proposal should have the buy-in from your community partner.

#### Presenting Initial Project Ideas to Steering Committee (January-February of First Year)

- Bring community partner to meeting and talk about emerging project
- How you became interested in this project
- Who your community partner is and how you are working together
- What you hope to accomplish
- Questions for the Steering Committee to help shape your project

#### Project Updates (Fall of Second Year)

- Bring community partner
- Quick reminder about project
- Status of project
- Any challenges the project is experiencing
- Questions for the Steering Committee to address challenges

#### January of Second Year

Draft of dissemination plan which includes strategies for community dissemination and direction of scholarly product (focus and possible journals/venues) to CBPR faculty. This should be developed in concert with your community partner and project team.

#### February of Second Year

Draft of scholarly product to CBPR faculty. This should have input from your community partner (and other authors)

#### March of Second Year

Draft of community product jointly developed with your community partner with input from project team

#### April of Second Year

Finalize all products and begin dissemination, modify dissemination plan as mutually agreed upon by project team

#### Final Wrap Up to Steering Committee (May or June of Second Year)

- What was the project and why important to New Haven and/or your community partner?
- Who has been your community partner(s)?
- What has been accomplished?
- What are the plans for disseminating the results in terms of community products and scholarly products (ideally have any community products available for distribution at the meeting we can work with you on production of these products)?
- Who now owns the data from the project and how may that data be used in the future?
- What are the plans for any continuance of the project or spin offs from the project?
- What systems change do you think this project has stimulated?
- What insights have you gained in doing a CBPR project, skills you feel you have developed and how you will use what you've learned in your future work?
- Also plan on sharing with the Committee what you will be doing following completion of the Program
- Respond to any final dissemination actions as suggested by the Steering Committee

## Yale RWJF Clinical Scholars Program Summary of CBPR Projects (July 2005-June 2015)

From 2005-2015, 33 CBPR projects have been completed by 57 Scholars with 28 community partners in various configurations of Scholar research teams.

Projects have come from 3 sources: 1) in response to community priorities identified by the community; 2) Scholars research ideas shared with the Steering Committee on Community Projects who guided Scholars in finding community partners who shared common interests; and 3) projects built on the work of previous Scholars.

CBPR projects have included improving access to care for the uninsured and underinsured, a consistently articulated community need since 2005. Other projects have addressed health issues related to specific populations within the community or improving health care or a community program. Four have had more of a community-wide approach to issues. All projects have required a litmus test of being relevant to and supported by one or more community partners.

Below is a summary of projects:

#### Improving Access to Healthcare

- 1. Helping to Create Project Access- New Haven. In December 2008, upon the suggestion of the New Haven Health Department, the leadership of the New Haven County Medical Association (NHCMA) approached the 2008-2010 cohort to explore Scholars interest in collecting data to support the creation of "Project Access- New Haven (PA-NH)" to provide access to specialty care for the uninsured. Five Scholars (internal medicine physicians Erica Spatz and Kate Goodrich, neurologist Michael Phipps, urologist Dan Makarov, and surgery resident Kate Viola) engaged the Fair Haven and Cornell Scott Hill Community Health Centers, Junta for Progressive Action and the Christian Community Action Agency to work with NHCMA to create Project Access New Haven (PA-NH). PA-NH introduced patient navigation into the New Haven community. A sixth Scholar, cardiologist, Oliver Wang (2009-2011) subsequently joined the research team which helped PA-NH secure funding, build research and evaluation into strengthening their model.
- 2. Evaluating the Project Access Medicaid Emergency Medicine Program. PA-NH expanded their services to include patient navigation for Medicaid patients using the emergency room at Yale New Haven Hospital. Emergency medicine physician Roberta Capp (2011-210) partnered with PA-NH to conduct an evaluation of the PA-NH expansion for frequent emergency room users who are on Medicaid. This included understanding patterns and reasons among high users of the emergency room who were not using their primary care providers and the role that patient navigators might play in changing these patterns. The study also informed a leadership team at Yale New Haven Hospital who were looking at ways to reduce inappropriate use of the emergency room.
- **3. Creating Medical Respite Care for Homeless Individuals.** Building on the work begun by a previous Scholar, internist Ryan Greysen (2009-2011) emergency medicine physician Kelly Doran (2011-2013) partnered with Columbus House Executive Director, Alison Cunningham to explore options for establishing a medical respite care program homeless individuals being discharged from the hospital yet needing continuing care. She conducted a comprehensive literature review of respite care best practices for the

homeless individuals. Her findings were translated into a public policy brief and cost analysis of respite care compared to readmissions to the hospital. The dissemination of this work along with a partnered advocacy strategy resulted in a partnership between Columbus House, Cornell Scott Hill Health Center and YNHH and to the establishment of 12 medical respite care beds at Columbus House funded by the State of Connecticut.

Assessing the Landscape of Primary Care for New Haven (PC4NH) for those on Medicaid. The 2012-2014 cohort, 4. which included family medicine physician Jennifer Voorhees, geriatric psychiatrist Ilse Wiechers, emergency medicine physician Arjun Venkatesh, and dermatologist Jason Lott, worked together with a consortium of community organizations and health providers assess to primary care in the New Haven area for those on Medicaid. The study originated from the Director of Health for New Haven who was interested in understanding how the passage of the Affordable Care Act would impact those on Medicaid seeking primary care in New Haven. The Scholars engaged over 200 stakeholders including patients, patient advocate organizations, providers and policy makers to identify issues related to access to care. An advisory team representative of the stakeholder groups guided the project. Through multiple meetings with patient and patient connector groups they developed a survey and interview instrument that would identify the characteristics that patients thought important in accessing and receiving primary care. They also completed an inventory of existing primary care providers in New Haven and contiguous communities applying the instrument developed with community input. Findings were widely disseminated to a range of stakeholder groups engaged in this project in 20 briefings and presentations in the spring of 2014 as distribution of a community report.

#### **Health Issues for Specific Populations**

- 1. Understanding the Root Causes of Violence Through Photovoice. Four Scholars -Internist Luke Hanson, emergency medicine physician, Mitesh Rao, adolescent psychiatrist Jill Baron, and pediatrician Chisara Asomugha (2007-2009) partnered with the New Haven Family Alliance (NHFA) to conduct a qualitative study using the Photovoice method to engage youth in identifying the root causes of gun violence and programming needed to decrease youth gun violence. Photo boards and related quotes by the youth were introduced during an opening of an exhibit at the main New Haven Public Library on Elm Street. This Photovoice exhibit and related report has been circulated in the schools and other local settings to stimulate discussion as well as at some national forums. This project was foundational to subsequent project addressing gun violence in New Haven.
- 2. Understanding the Gender Differences in the Experience of Youth Violence. Katherine Yun (2009-2011) conducted this CBPR project with NHFA building on the initial findings of the Photovoice Project. This project focused on the unique experiences of girls. Using qualitative research new insights were highlighted resulting in a training tool for providers who work with adolescent girls was developed from this project to help girls understand the negative impact of violence on creating healthy lives. NHFA also staff use this tool to conduct workshops in high schools to talk to adolescent girls about safe dating and safety in general.
- 3. Helping to Create YouthHaven. Emergency medicine physician Anita Vashi and internist/pediatrician Nurit Harari (2011-2013) worked with NHFA Executive Director Barbara Tinney to submit a successful grant application to train a group of New Haven youth in research, community organizing, leadership, and conflict resolution to engage other New Haven youth in identifying ways to prevent violence in the city. Twelve youth participated in this leadership and research training program. Through this training, they conducted research, wrote op-eds and added to the City-wide Plan on Violence Prevention. The youth met with the New Haven Chief of Police to share their research-derived goals for youth gun violence prevention in New Haven.
- 4. Creating Tools to Support Neighborhood Responses to Violence. Emergency medicine physician Anita Vashi and internist/pediatrician Nurit Harari (2011-2013) worked with a neighborhood representative subgroup of the New Haven Community Violence Prevention Group (NHCVPG); this subgroup became the Community Resilience Steering Committee. The group was formed to examine how a disaster

preparedness and response model could be applied to the community trauma caused by chronic gun violence. This group developed a community violence resource guide and toolkit and distributed it in two high violence neighborhoods in New Haven (Newhallville and West River). As part of this project, residents in those neighborhoods formed neighborhood community resilience teams to stimulate more activities to increase social connectedness.

- 5. Creating Community Resilience Strategies at the Neighborhood Level as a Response to Violence. Working with the Community Resilience Steering Committee and neighborhood based community resilience teams, two Scholars, internist Brita Roy and critical care pediatrician Carley Riley (2013-2015) trained neighborhood residents in research methods and survey administration to assess social cohesion and exposure to violence. Survey results were used to inform interventions to prevent violence. Their work will be completed by June 2015. The process and preliminary results were presented at the annual meeting of the American Public Health Association, the 2014 National Meeting of the RWJF Clinical Scholars Program meeting and at the Institute of Medicine.
- 6. Expanding physical activity in New Haven Public Schools. The first CBPR project conducted by Yale Clinical Scholars involved emergency medicine physician Jay Schuur, pediatrician Mike Leu, neurologist Omotola Hope and psychiatrist Kevin Hill (2005-2007) partnered with the New Haven Board of Education to conduct an evaluation of the pilot "Take Ten" physical activity intervention in six pilot elementary schools in New Haven. The evaluation data was used to obtain a \$400,000 grant from the Connecticut Health Foundation to expand the program. According to follow up studies, these types of physical activity programs improved performance and school climate in the New Haven schools.
- 7. Creating Tools for the Health of Pregnant Women and New Mothers. Pediatrician Peggy Chen (2007-2010), building on the findings of a previous Scholar project on the social determinants of health in New Haven partnered with the New Haven Healthy Start Consortium to develop health educational tools to assess and increase awareness of healthier eating options and stress reduction for pregnant women and new mothers. Participants were incented to try local farmer's markets and try foods helpful to a healthy pregnancy. Education materials were provided as part of the study. Patterns of use of farmers markets were tracked as well as behaviors and attitudes about food groups. This work was presented at a national CBPR conference and won first prize.
- 8. Increasing Pregnancy Prevention Understanding Among 8th and 9th Graders. Pediatrician Lara Johnson (2008-2010) partnered with the Mayor's Teen Pregnancy Prevention Council and New Haven Public Schools to conduct a quantitative assessment of New Haven students' (8th and 9th graders) perceptions and experiences regarding pregnancy prevention efforts. A report on the results of this study was disseminated in the school system and in the Council. This study was used to inform the implementation of contraception counseling in the school-based health clinics.
- **9. Reviewing Motorcycle Mortality and Lack of Helmet** Use. Emergency medicine physician Adam Landman and neurologist Michael Phipps (2008-2010) partnered with the New Haven Health Department and Connecticut State Department of Public Health to examine patterns of motorcycle fatalities related to the lack of helmet use. Results from the study were disseminated to the local and state groups. Materials providing guidance on helmet use were shared with the New Haven Health and Police Departments.
- **10. Improving Health Interventions for Refugees.** Pediatrician Katherine Yun (2009-2011) partnered with Integrated Refugee and Immigrant Services (IRIS) to assess the health needs of new refugees coming into New Haven and identify interventions to improve their health and health care delivery. The project included a quantitative analysis of medical records at the YNHH Refugee Clinic. Findings were produced in a community report entitled Foundations for Health: Health and Health Care for Refugees and several state and national policy briefs. The findings from this project are being used by IRIS to secure funding and inform policies on the health needs of refugees.
- **11. Preventing Pertussis (Whooping Cough) through Vaccination Cocooning for Caregivers of Newborns.** Pediatrician Deepa Camenga and internist Kelly Kyanko (2009-2011) partnered with the Hospital of Saint Raphael and the New Haven Healthy Start Consortium to pilot a vaccination-cocooning project to increase the Tdap vaccination rate for caregivers of new babies to prevent pertussis (whooping cough). During infant

well child visits, all caregivers of the infant were offered the pertussis vaccination. The national rate for caregiver vaccinations is 5 percent; this project resulted in a 75 percent vaccination rate.

- **12.** A Review of the Efforts of the Mayor's Teen Pregnancy Prevention Council 2007-2012. Obstetrics and gynecologist Eric Hodgson (2010-2012) conducted a comprehensive review of the accomplishments of the Council from 2007-2012 with recommendations for the future of the Council. The report, "Answering the Call to Action: Helping New Haven Teens Avoid Unintended Pregnancy- Five Year Progress Report" was shared with the Community Services Administration and former Mayor DeStephano on June 21, 2012.
- **13. Improving Access to Healthy Foods in the West River Neighborhood.** Internist Oni Blackstock and neurologist Jed Barash (2010-2012) partnered with the West River Neighborhood Services Corporation and the Community Alliance for Research and Engagement (CARE) to collaboratively design and conduct a survey of West River residents to assess their attitudes toward health eating and options for increased access to healthy foods in the West River neighborhood. One result was a mobile satellite of the Farmers Market piloted in the neighborhood. The City's Farmer Market now have many mobile farmer's markets in neighborhoods where they did not previously exist.
- 14. Improving the Health and Mental Health of the New Haven Police Department. Surgeon Justin Fox (2010-2012) partnered with former Chief of Police Limon and the Police Union to assess the health and mental health needs of the New Haven police force. The findings were presented to the leadership of both organizations and resulted in improved access to health facilities and employee assistance for mental health. The research was also presented at the Connecticut Association of Public Health annual meeting in 2012.
- **15.** Increasing Partner Notification of HIV/AIDS for Men who Have Sex with Men (MSM). Internist Jen Edelman (2009-2012) partnered with AIDS Project New Haven and the State Department of Health to conduct a qualitative study called Project Coach. The aim of the project was to gain the perspectives on the experiences and challenges with partner notification for those diagnosed with HIV among men who have sex with men (MSM). Participants in the study included MSM's and providers, including medical case managers and the State Department of Health's Disease Intervention Specialists who work with these individuals. The goal of this study was to identify strategies to increase partner notification. This study has resulted in the development of tools to be used by providers, training for providers and several consumer awareness pieces circulated at local, state and national levels.
- **16.** Increasing Breast Feeding through a Text Messaging Program. Internist/Pediatrician Nurit Harari (2011-2013) partnered with Yale New Haven Hospital (YNHH), Fair Haven Community Health Center (FHCHC), and their WIC programs to develop and assess a text messaging research pilot with peer lactation consultants to improve adherence to breast feeding immediately follow birth (LATCH -Lactation Advice Thru Texting Can Help). Both quantitative and qualitative methods were used. The research resulted in developing texting guidelines for lactation consultants in Connecticut, a breastfeeding texting curriculum/intervention and a USDA grant partnered with the Yale School of Public Health professor Rafael Perez-Escamilla.
- **17.** Using Long Acting Reversible Contraception (LARC) Methods to Prevent Unintended Pregnancies. Obstetrics and Gynecologist Charlene Collier (2011-2013) partnered with New Haven Healthy Start (NHHS) to conduct a mixed-methods project using surveys and in-depth interviews to understand the use of long-acting reversible contraceptive (LARC) methods among NHHS participants. The project included several components: 1) a baseline knowledge and capacity assessment survey with medical providers; 2) in-depth qualitative interviews with NHHS Care Coordinators; and 3) a survey of community members. The findings resulted in the development of tools care coordinators, social services, home visiting and medical providers are now using to raise awareness of the use of LARC methods and help NHHS participants and clients and patients throughout the city to make informed decisions around family planning.
- **18.** Exploring the Role of Electronic Media in Increasing STD/HIV Screening Behaviors for Adolescents. Obstetrics and gynecologist Heather Smith (2011-2013) partnered with the Fair Haven Community Health Center Adolescent Clinic and their patients to identify how social media might be used to increasing screening for STDs and HIV. FHCHC has taken some of the knowledge gained from this project into their practices with youth.

**CBPR History Report** 

**19. Understanding Cultural Attitudes and Barriers to Organ Donations Among Local Indigenous People.** Second year Scholar and surgical resident Tasce Bongiovanni (2013-2015) has been working with the Connecticut Native American Inter-Tribal Urban Council to assess cultural knowledge, beliefs and attitudes with regards to organ donation and transplantation in Indian Country. The survey development and surveying phases of this project were completed in 2014. Results were presented at the 2014 RWJF CSP National Meeting, The American Transplant Congress, to the Tribal Council, and at regional Pow Wows. A manuscript is in preparation as well as material for the lay press including, Indian Country. Next steps include looking at the upstream effects of End-Stage Renal Disease and knowledge in the Native community about diabetes. The issues of trust in the healthcare system will continue to be explored as well as health literacy in the Native community. The Council is interested in continuing this project, and will start a new survey of the community at regional Pow Wows in the summer of 2015.

#### Quality Improvement in Healthcare and/or Community Programs

- 1. A Participatory Evaluation of the NHFA Street Outreach Workers Program (SOWP). Concurrent with the above project, internist Rachel Skeete (2006-2009) and research assistant, Emily Bucholz conducted two evaluations of the SOWP. The first was a comprehensive qualitative participatory evaluation examining how the program was being implemented from the perspectives of the youth in the program, from the Street Outreach Workers and the administrators of the program; the second part of the project used quantitative methods to examine initial outcomes of youth referred to the program and identify what elements of the program proved to be most influential in preventing youth from engaging in violence.
- 2. Assessing the Implementation of the National Diabetes Prevention Program in a Local Federally Qualified Community Health Center. Internist Calie Santana (2006-2008) partnered with Fair Haven Community Health Center (FHCHC) to assess how the National Diabetes Prevention Program (DPP) was implemented in a community setting using a family systems approach versus the usual individual patient approach. This work contributed to a successful application for funding from the Donoghue Foundation with a Yale University diabetes researcher and continuance of this successful program in the Latino community.
- 3. Integrating Weight Reduction and Diabetes Prevention Projects in Fair Haven. Building on previous the Scholar work with the FHCHC DPP Internist Rosette Chakkalakal (2010-2012) partnered with FHCHC and the Yale School of Medicine's Bright Bodies Program to better coordinate and integrate these two programs at the John Martinez School. As a result a structure was developed to continually assess and improve this program where the focus of diabetes prevention is concurrently focused on the child and parent.
- 4. Improving Transitions of Care for Homeless Individuals. Internist Ryan Greysen (2009-2011), partnered with the Director of Programs at Columbus House to conduct a mixed methods study of the experiences of homeless individuals being discharged from hospitals to improve care during and after hospitalization. Ryan subsequently brought together YNHH and Columbus House to share the findings. This new collaboration resulted in changed policies at both Columbus House and YNHH to improve admission and discharge planning for homeless. This study also identified a major gap in care the need for medical respite care at homeless shelters.
- 5. Understanding Parents' Perceptions Toward Coordinating Pediatric Primary Care and Mental Health Services in a Single Location. Pediatrician Nicole Brown (2011-2013), partnered with the Clifford Beers Clinic to conduct a qualitative study of parents' perceptions developing of a coordinated/co-located pediatric primary care and mental health services delivery system. This research was conducted as part of a planning process the agency had undertaken to develop a holistic and comprehensive wellness center for delivery of care to child and families who have experienced severe or chronic trauma. This work was incorporated into Clifford Beers successful grant application of \$9.8 from the Centers for Medicare and Medicaid Innovations.
- 6. Improving Patient Centeredness at the Yale New Haven Hospital (YNHH) Adult Primary Care Center (PCC). Internist Ted Long and obstetrics and gynecologist Mark Silvestri (2013-2015) partnered with a project team at YNHH to determine how the PCC could become more patient-centered. Serving on the project team

were the leadership of the PCC, patients, a family member of a patient, community representatives, patient navigators and hospital representatives. The team surveyed PCC patients on their priorities for improving care, and established a Patient and Family Advisory Council to implement these improvements and guide patient-centeredness on an ongoing basis.

#### **Community-wide Projects Informing CBPR Projects**

- 1. Assessing Perceptions of the Social Determinants of Health in New Haven. A team of 7 Scholars (2006-2008) partnered with the New Haven Community Services Administration, the New Haven Health Department departments and the RWJF Steering Committee on Community Projects to assess what New Haven policy, community-based organization and neighborhood leaders perceived to be the social determinants of health in the city and how research might inform improvements. This mixed methods study provided their insights on addressing the social determinants of health. It also gave researchers guidance in engaging the community in health researcher. This study has been used for successful grant applications and promoting CBPR principles in studies of New Haven by academic researchers.
- 2. Dissemination Practices in CBPR. Pediatrician Peggy Chen (2007-2010) partnered with a community member to conduct a systematic literature review of dissemination practices in CBPR projects beyond manuscripts and the degree to which community partners were engaged in discussions around dissemination. Peggy's engaged the Campus Community Health Partnership (CCHP) network in various stages of her research including dissemination. Her study was also published in the American Journal of Preventive Medicine (citation).
- 3. Conducting a Health Impact Assessment (HIA). Internist Gregg Furie and pediatrician Clara Filice (2010-2012) partnered with the New Haven City Plan Department as well as the Departments of Economic Development, Transportation and Health, and DataHaven to conduct the city's first Health Impact Assessment (HIA) on Phase I of the Downtown Crossing redevelopment. The goal of the study was to inform planning to increase pedestrian and bicyclist safety when the construction was completed. As part of the project, the Scholars also hosted a two-day training on HIA's for a cross section of New Haven stakeholders including city administrators, elected officials, community-based organizations and public health researchers. The Scholars were invited to present their work to the annual meeting of the American Public Health Association.
- 4. Understanding Experiences in Community/University Research. Internist Karen Wang (2010-2012) and community partner, Natasha Ray, New Haven Health Start Consortium Coordinator became co-investigators in assessing the experiences of New Haven community-based community organizations (CBOs) working with University researchers and the experiences of University researchers in doing community-based research. Natasha interviewed CBO leaders and Karen, university researchers. In addition to better understanding the issues to mutually beneficial research, the goal of this project was to produce targeted guidelines for each sector to maximize the value of the relationship. The results of the study have been shared through several briefings and presentation within the medical school and before national audiences. A guidebook for CBO's has been published and widely distributed locally and nationally.

## Yale RWJF Clinical Scholars Program List of Community Partners 2005-2015

Since 2005, the Yale RWJF Clinical Scholars have partnered with 28 different community partners on 33 community projects. Several projects involved two or more partners.

AIDS Project New Haven 2010-2012

Clifford Beers Clinic 2011-2013

Columbus House 2009-2011, 2011

Connecticut Office of the National Kidney Foundation, 2013-2015

Connecticut State Department of Public Health 2008-2010, 2010-2012

Cornell Scott Hill Health Center, 2008-2010, 2012-2014

DataHaven, 2010-2102

Fair Haven Community Health Center 2006-2008, 2010-2013, 2011-2013, 2012-2014

Health Kitchen Cabinet, Christian Community Action, 2012-2014

Hospital of Saint Raphael (HSR) 2008, 2010, 2009-2011

Integrated Refugee and Immigrant Service (IRIS) 2009-2011

Junta for Progressive Action 2008-2010

Male Involvement Network, 2012-2014

New Haven Board of Education 2005-2007, 2007-2009

New Haven City Plan Department 2010-2012

New Haven Community Services Administration 2006-2008, 2010-2012

New Haven Community Violence Prevention Group 2011-2103 New Haven Health Department 2006-2008, 2008-2010, 2010-2012, 2012-2014

New Haven Family Alliance (NHFA), 2007-2009, 2009-2011, 2011-2013, 2013-2015

New Haven Healthy Start (NHHS): 2007-2010, 2009-2011, 2010-2012, 2011-2013, and 2012-2014

New Haven Police Department 2010-2012

New Haven Teen Pregnancy Prevention Council 2008-2010, 2010-2012

Newhallville Community Resilience Team 2011-2013, 2013-2015

Northeast Medical Group

Project Access-New Haven (PANH), 2008-2010, 2011-2013

Urban Inter-Tribal Council 2013-2015

West River Neighborhood Services Corporation 2010-2012, 2011-2013, 2013-2015

Yale New Haven Hospital (YNHH) 2008-2010, 2011-2013, 2012-2014, 2013-2015

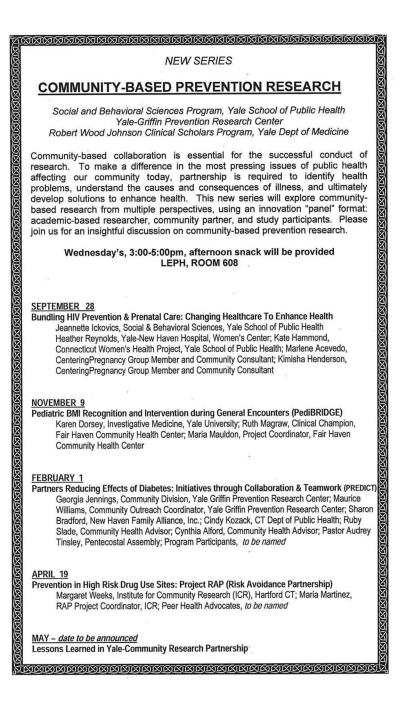
- o Yale New Haven Hospital Community Health, 2011-2013
- o Yale New Haven Hospital Trauma Department 2011-2013, 2013-2015
- o Yale New Haven Hospital Adult Primary Care Center 2013-2105

## Scholars' Community Site Visit Summary: Needs Raised (July/August 2005)

SITE	DATE	SITE ATTENDEES	CSP ATTENDEES	MAIN HEALTH ISSUE RAISED	
Dep of Public Health	7/18/05	Bill Quinn Maria Damiani Nancy Eatough Brian Karsif Darcey Cobbs Ken Rubano Kathy Carbone Paul Kowalski Pam Hansen Matthew Lopez	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas	<ul> <li>Asthma</li> <li>Diabetes/Obesity</li> <li>Infant Mortality (African Americans)</li> <li>Maternal/Fetal Health</li> <li>Inability to Access OB Records in Other Clinical Settings (ED)</li> <li>Lead</li> <li>STDs/Needle Exchange</li> <li>Perinatal &amp; Postpartum Depression</li> </ul>	
CT Health Policy Project	7/25/05	Ellen Andrews Carla Taymans	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas	<ul> <li>Access to Specialty Services</li> <li>Yale's Health access Grant</li> <li>Access for Uninsured</li> <li>Pediatric Dental Care</li> <li>Medication Costs for Elderly</li> <li>Coordination of Care</li> <li>Co-payments</li> </ul>	<ul> <li>Immigrants Need for Interpreters</li> <li>Immigrant Access to Service w/o Fear</li> </ul>
Agency of Aging	7/27/05	Neysa Stallman Guerino Kate McEvoy Beverly Kidder Julie Gelgaudo	Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas	<ul> <li>Access to Healthcare for Uninsured and Medicaid Patients</li> <li>Access to Specialty Care</li> <li>Navigating Healthcare Services When Needed</li> <li>Psychiatric Services for Medicaid Patients</li> </ul>	
Visiting Nurse Association	8/1/05	Joanne Walsh Ellen Reuben Pamela Grant Dianna DiAgostino	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas Margi Rosenthal	<ul> <li>Care Coordination (Info Sharing Among Multiple Specialists)</li> <li>Medication Costs (Especially non-Medicaid Patients)</li> <li>Communication Between Patients &amp; Clinicians</li> <li>Coordination of Services</li> <li>Transportation</li> </ul>	<ul> <li>Mental Health Care Access</li> <li>Depression &amp; Treatment</li> <li>Language Barriers</li> <li>Housing</li> <li>Prevention vs Treatment</li> </ul>
Errera Community Care Center	8/8/05	Lori Harkness Debbi Deegan Bob Rosencheck	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Margi Rosenthal	<ul> <li>Access to Mental Health Care</li> <li>Housing: Permanent &amp; Transitional</li> </ul>	

SITE	DATE	SITE ATTENDEES	CSP ATTENDEES	MAIN HEALTH ISSUE RAISED	
Community Foundation for Greater New Haven	8/15/05	Amos Smith Natasha Ray Christina Ciociola	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas Margi Rosenthal	<ul> <li>Transportation</li> <li>Mental Health &amp; Care Access</li> <li>Coordination of Care</li> <li>Depression Screening &amp; Treatment</li> <li>Diabetes/Obesity</li> <li>Undocumented Worker Health Status</li> <li>Long Term Care Quality (Elderly)</li> <li>Childcare</li> </ul>	<ul> <li>Infant Mortality (African Americans)</li> <li>Discrepancies in Infant Mortality Data</li> <li>Prenatal Care (Access)</li> <li>Lack of Health Services for Men</li> <li>Dental Care</li> <li>Alcohol/Drug Abuse</li> <li>Housing</li> </ul>
Fair Haven Community Health Center	8/16/05	Katrina Clark Laurie Bridger Jennifer Fournier Tracy Weber Tierney Vivian Acevedo-Rivas Clarice Begemann Dante Lewis	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas Margi Rosenthal	<ul> <li>Need for More Specialists</li> <li>Access to Mental Health Care</li> <li>Increased Services for Men</li> <li>Access to Care (Immigrant Populations)</li> <li>Language Barriers/Need for Interpreters</li> </ul>	Access to Dental Care (general/perinatal)
Clifford Beers Child Guidance Center	8/16/05	Pieter Joost Van Wattum Chet Brodnicki Pam Huebner Jody Rowell Kim Nelson Jen Merovick	Sakena Abedin Kevin Hill Mike Leu Georgina Lucas Margi Rosenthal	<ul> <li>Better Rates for Mental Health Coverage</li> <li>Spanish Speaking Clinicians</li> <li>Providers Do Not Take Back Responsibility for Mental Health Care &gt; Medication Clinic</li> </ul>	Insufficient School- Based Mental Health
Hill Health Center	8/17/05	Cornell Scott Steve Updegrove Staff	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas	<ul> <li>Access to Dental, Specialty, Mental Health Care</li> <li>Better Coordination With Yale Primary Care</li> </ul>	
New Haven Family Alliance	8/17/05	Barbara Tinney Bethany Kleine Blaney Bostic Shirley Ellis-West Sharon Bradford	Sakena Abedin Kevin Hill Tola Hope Lisa Leinau Mike Leu Jay Schuur Georgina Lucas	<ul> <li>Affordable Medication (Seniors)</li> <li>STD &amp; AIDS (Adolescence)</li> <li>Violence (Adolescence)</li> <li>Access Issues for Hearing Impaired</li> <li>Language Barriers</li> <li>Diabetes/Obesity</li> <li>Hypertension</li> </ul>	<ul> <li>Asthma</li> <li>Access to Mental Health Care</li> <li>Transportation</li> <li>Men's Health/Fear of Using Health Care</li> <li>Parenting Education</li> </ul>

### Flyer for Community-based Prevention Research Series



## Guidebook to Successful Research Partners from the Community Perspective

TI	e Community Foundation for Greater New Haven					
Imagine.	Inform. Invest. Inspire.					
	Working together to build a stronger community – now and forever.					
MAKING RESEARCH WORK FOR YOUR COMMUNITY:						
	Do you conduct surveys to learn more about your community?					
	Do you have participants fill out forms?					
	Do you perform evaluations to figure out the impact of your activities?					
	Do you have to report to your funders about outcomes?					
	Are you thinking about doing any of these activities?					
	Are you considering working with researchers or do you want to work more effectively with researchers?					
	A Guidebook to Successful Research Partnerships					

### Putting "Community" into Community-based Participatory Research Article

## **Participatory Research**

#### **A** Commentary

Roseanne Bilodeau, James Gilmore, MBA, Loretta Jones, MA, Gloria Palmisano, MA, Tinesha Banks, MPH, Barbara Tinney, MSW, Georgina I. Lucas, MSW

#### Introduction

Since July 2005, we have been working with the medical schools at the University of California at Los Angeles (UCLA), University of Michigan, University of Pennsylvania, and Yale University as they have sought to train Robert Wood Johnson Foundation (RWJF) Clinical Scholars in community-based research, specifically community-based participatory research (CBPR).

As the relationships in these mutual learning environments have been evolving, the respective communities are witnessing tangible benefits. However, in the design and implementation of these partnered projects, there have also been some challenges. The purpose of this commentary is to share perspectives on communityacademic research partnerships and offer ideas for strengthening relationships between university researchers and community health partners to increase the value to all stakeholders in the research: community partners, researchers, and the larger community. The projects listed below are only a part of that being done between the RWJF Clinical Scholars and their local communities.

With each class of Clinical Scholars, the number of community partners and projects grows; here is a sampling of the projects with which the collective authors have been involved:

- engaging the community in understanding and using state health data to track local health issues in Los Angeles;
- working with a coalition of community partners on a photojournal project to examine risk and resiliency factors related to men's health in Los Angeles;

 studying how hospital closures in Los Angeles are affecting senior citizens;
 understanding factors that lead ethnically diverse

- and example actors that read eminically diverse doctors to work in ethnically diverse communities;
   assessing health needs and potential interventions
- for the Asian population in Philadelphia; 6. conducting an economic analysis of a teenage preg-
- nancy prevention program in New Britain CT;
- 7. evaluating interventions for diabetes prevention and treatment through the Detroit REACH (Racial and Ethnic Approaches to Community Health) Partnership;
- 8. using photo-voice to better understand the influences on youth violence in New Haven CT; and
- 9. evaluating a Street Outreach Worker intervention to reduce youth violence in New Haven CT.

#### Benefits of Academic–Community-Based Research Partnerships

**Benefits to Community Partners** 

Exposure to unique clinical and research expertise. The Clinical Scholars have provided the opportunity to work with talented physician researchers, who bring clinical and research expertise to community organizations that otherwise may not be able to take on the kind of research projects needed to improve care, influence local and state policymakers, and secure funding for new programs or the expansion of existing services.

Enhancing the credibility of our work. The collaboration with Clinical Scholars and their respective universities provides additional integrity and credibility to our efforts to improve health and health care in these communities.

Building capacities for evidence-based practice. Related benefits include expanding the capacities of the organizations to think in a results-oriented fashion while building skills in research and scientific writing. The nature of CBPR requires that researchers be involved in all phases of the research, from identifying the research question to influencing the design, implementing the research, and analyzing and disseminating the findings. These additional skills add to our own abilities as

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From Greater New Britain Teen Pregnancy Prevention Program (Bilodeau), Pathways/Senderos, New Britain; New Haven Family Alliance (Tinney); Yale University School of Medicine (Lucas), Robert Wood Johnson Clinical Scholars Program, New Haven, Connecticut; Behavioral Health Services (Gilmore), Gardena; Healthy African American Families (Jones), Los Angeles, California; Community Health and Social Services Center, Inc. (Palmisano), Detroit, Michigan; Health Promotion Council of Southeastern Pennsylvania (Peterson), Philadelphia, Pennsylvania

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### Additional Stakeholder Quotes on the Impact of CBPR Training and Projects

#### Members of the Steering Committee on Community Projects

The work I have been privileged to do with the RWJ Scholars has helped to shape my career as a true Community Liaison! My experience of translating research to community residents has been enhanced by my involvement with the RWJ Scholars Program. This is an example of real quality relationships between academia and community we need to make communities healthy!

Serving on the Steering Committee has helped frame my understanding of health issues and expanded my knowledge around health access. The quality of the Scholars' work has not been superficial but deep and has informed my understanding on a number of health issues.

The CSP represents a valuable connection between the Yale and New Haven communities, which can lead to greater trust overall between the institution and residents, and therefore better health research.

The CSP has listened to the needs of the community and been responsive, and has directed work toward meeting those needs. The SC has helped me connect with other agencies and individuals committed to serving the needs of New Haven.

My role relating to the Steering Committee has offered me the opportunity to present a more expansive view of diversity than the traditional dominant European definitions of diversity.

The Program has brought much more attention and rigor to community engaged research, both from the university and community perspectives. It has raised the pro file of CBPR for both. When projects have carried from research to implementation, I believe they truly benefit New Haven and serve as national models. The CSP has tangibly, as anything to date, helped demonstrate the potential of CBPR to the community and the university.

The SC has kept me alert to possible collaborations with not only the RWJF Scholars but other academics as well- some of which have actually borne fruit.

Their efforts and support has helped the neighborhood take on projects that positively contributed to changes... We have benefited greatly from the resources provided through the work of the scholars. We have tackled issues that often prevail and appear to have no solutions but having knowledgeable people help us to develop problem solving avenues/methods moves us along.

The connections with professionals who share a vision for community engaged research has been inspiring and energizing.

The RWJF CSP has definitely taught (and reminded) researchers that New Haven and its residents and organizations should be seen as partners and not test subjects. This has helped the community feel respected.

The variety of projects and the diversity of partners made the research and capacity building tremendously impactful for the New Haven area. The scholars and the program have done a great deal in terms of both influencing health research and capacity building. It's clear that the collaborations/partnerships that have developed with community organizations have provided resources and expertise needed in order to conduct the work that was identified as an interest on behalf of the organization.

Community work in urban areas can be difficult. It is often difficult to get neighbors involved and volunteering to improve their community. The scholars were dedicated and patient with the communities they teamed up with. They stuck with the projects until they were up and running and able to sustain themselves.

Mentoring scholars and watching them grow during their time at Yale has been very enjoyable. I have also enjoyed watching community members come into the committee through projects and increase their capacity as research professionals.

The experience has influenced our work in terms about the way we think about our work, how we approach our work and this has lent itself to behavioral change among our organization's participants and community residents.

Being involved in the RWJCSP has personally excited, motivated and inspired me to go back to school to further my education so that I am able to participate in research on multiple levels.

YNHH participated in the "Texting Support for Breastfeeding Moms" project which supports WIC women who want to breastfeed their infants. This project provided valuable practical experience and assistance to these moms through texting to the peer counselors for breastfeeding information.

I hope the larger institution acknowledges, appreciates and nurtures the ground work that has been built by the RWJCSP with the New Haven community and sees that it is something that is beneficial to New Haven at large and is worth sustaining....I would hope that the valuable work can continue. It allows scholars to deal with real world issues working hand in hand with a community partner with practical problems that the community, public health practitioners and health care providers are dealing with on a day to day basis

Scholars have used some innovative methods to collect data that has been informative.

#### **Community Partners**

The scholars made a deep, and extensive contribution to the formation, direction and development of Project Access- New Haven. Their initial research identified the area of concentration of our efforts. They played a major role in generating the documentation and input to our records. And they generated research questions and projects that enabled us to maintain a high national profile. Their work generated grant support as well, and is still influencing our efforts.

The scholars' involvement helped PA-NH appreciate and incorporate research and evaluation into the program model and embrace a larger systems-focus in our work. In addition to providing services on a local level, we are always thinking about ways in which our model of care might be relevant to larger and broader populations.

The nature of the work our Healthcare Kitchen Cabinet is to ensure that the voice of the people impacted by an issue are heard and their recommendations are used in making of public policy. There is a lot of skepticism among people that are poor that their opinions don't matter. It was very encouraging to our program participants to be solicited for their input. It gave the group encouragement to continue the advocacy work they are doing. The PC4NH project report generated as a result of the scholars interviewing 89 medical practices in the New Haven area is helping shape the ongoing work of the Healthcare Kitchen Cabinet. **CBPR History Report** 

Every time the scholars were involved in a change process we moved to another level of clarity of intention, behavior and goal setting. We accomplished systems change in ways that we could not have without them.

Just as West River (through the neighborhood services corporation) began working with Clinical Scholars Jed Barash and Oni Blackstock, the largest supermarket in our neighborhood, Shaw's, was scheduled to close. We were already aware of issues of food access and the reality of food desserts in West River, which is why their proposed survey had currency; we knew we could use the data some day for our long-term revitalization efforts. But, faced with the imminent closure of Shaw's, collecting data to help make the economic case for another supermarket became urgent. Often, during team meetings, Stacy Spell and I acknowledged how useful the data collection was for us as neighborhood residents, because it kept us aware of the concerns and collective knowledge of our neighbors about this particular issue, and undoubtedly influenced what became our priorities as neighborhood activists. We also were convinced that this quantifiable information was an important tool for the case the Dwight/West River area needed to make to attract another supermarket. Since then, under the stewardship of Clinical Scholars Carley Riley and Brita Roy I've participated as a community resilience surveyor in Newhallville and West River. I've watched the transformation of activists, who because they are now armed with data, are learning how to talk about community issues at a whole new level. What CBPR does is 2-fold: it studies what is important to its subjects while building leadership capacity in its community partners.

#### Scholar Alumni/Current Scholars

My experience with community-based participatory research during my time as a scholar has transformed me, not only as a researcher but also as a human being. The relationships I now enjoy with community members are deeply meaningful to me, and the ability of our work to connect and affect real change has been powerful for me to see. Moving forward, I will approach research fundamentally differently. Through actively engaging core stakeholders from the very beginning to the very end of the research process, I anticipate my work to be more meaningful, more satisfying, and far more effective.

The RWJ CBPR training has influenced the entire way I perform research today. Whenever possible, I try to include stakeholder input into the research question, with stakeholders including adolescents, healthcare providers, policy makers and parents. The CBPR training instilled the importance of conducting research that has tangible value for the population, and to be careful not to offer research supported services that have no plan for sustainability. Our CBPR training also helped me understand the importance of relationship building and trust in moving forward any professional initiative-whether it be research-related, clinical, administrative or educational.

As a Clinical Scholar, working on a CBPR project with community partners in West River served to deepen my interest in collaborating with community-based organizations as part of my research career. During my very first year as research faculty, I applied for and received a competitive community-based pilot grant from my institution's Center for AIDS Research. My exposure to CBPR during CSP provided me with the skills and confidence to identify an appropriate community partner with whom I worked closely to develop a rigorous research proposal that could provide formative data to ultimately improve the health of my community partner's clients.

My CBPR training has deeply influenced the way that I do research. I try to focus on work that addresses priorities that have been identified by refugee communities. Fairness, equity, and mutual benefit are important not only when thinking about the impact of the work but also in how the work is conducted. CBPR is challenging. It takes time and commitment. Knowing that it is valued by Yale and by the RWJ Foundation has helped me to stay the course.

As you know I came into the RWJ thinking that I would be a large database researcher and through my CBPR project I found how connected I am given my background with vulnerable populations and how passionate I am about the issues related to health care access barriers for those who have Medic-aid insurance.

Being aware of and learning to invite key stakeholders to the table from the beginning (formation of intervention, brainstorming) has led to the success of several projects in my current job already. This is an important step that needs to be addressed systematically. I presented our CBPR work alongside one of our partners at the IBCLC conference this year in Phoenix. We equally shared in the preparation and presentation of our work. Inviting partners to be part of a team to analyze data was essential to extracting meaningful nuances that would not have been possible without their input. This was evident in the qualitative analysis of text messages sent by WIC moms in one of my projects. Successful partnerships throughout the intervention were key in pointing out issues that arose. For example, when there were technical issues with the texting platform, our peer counselors would notify us immediately. Without their investment and care in the projects, these issues may have gone undetected for days to weeks at a time.

The Yale CBPR experience has most certainly shaped the way I conduct my research. CBPR principles hold true regardless of the nature of the project - all research should be collaborative. In my current work, I knew to engage stakeholders early on and worked with them to define my research question and aims. I've found that engaging my operational partners and obtaining their input is invaluable in the design of my studies. I know this early investment is instrumental to our results being useful in identifying important operational and policy solutions. Health services research is evolving to include increasingly integrated and innovative approaches. CBPR as a research paradigm offers the potential to generate better-informed hypotheses, develop more effective interventions, and enhance the translation of the research results into practice. I continue to use many of the skills I learned during our CBPR experience. From the more traditional skills (i.e. community engagement, understanding and respecting power dynamics, recognizing individual strengths) to the more minute (agenda setting, running a meeting, creating budgets) - I use these skills on a daily basis and know my projects are the better for it!

The lessons in collaboration and coalition building that were inherent in the community-based research curriculum transcend any specific approach or even career focus. The skill to sincerely consider goals and priorities of diverse team members is really a key to any collective effort.

#### Yale RWJF Clinical Scholar Leadership (Co-directors)

#### Harlan Krumholz

For my professional outlook – my work with communities as part of RWJ has had a profound influence on my view of the importance of working collaboratively with communities and people who the research is about – the value of partnership and the importance of mutual learning. And this has enabled me to convey these lessons to other organizations, such as PCORI.

#### **Cary Gross**

It had a profound influence on the way I conceptualize the value of a research project, thinking not only of whether a question is novel and "publishable", but whether the information will be useful - and whom might find the results useful.

The CBPR component has engendered a new sense of empathy, and passion, for ensuring that our work is grounded in reality, has true partners, and will make a difference. I hope that in the coming years, we will move even further in a direction of shared commitment, mission, and resources with community partners by emphasizing sustainability and a culture of shared growth and learning.

#### **Leslie Curry**

From my perspective the CBPR component and spirit of the program has had an extraordinarily positive influence on scholar research projects. There is no question in my mind that the research questions are more relevant and the findings have greater impact as a direct result of CBPR training, mentorship and partnership. It is all about making research matter. We could not have gotten there without the program's investment in and commitment to CBPR principles and practices.

## Capacity Building Article with CBPR Faculty, Scholars & Community Partners



## PROJECT MUSE

## **Building Community Capacity: Sustaining the Effects** of Multiple, Two-Year Community-based Participatory **Research Projects** Marjorie S. Rosenthal, Jed Barash, Oni Blackstock, Shirley Ellis-West, Clara

Filice, Gregg Furie, S. Ryan Greysen, Sherman Malone, Barbara Tinney, Katherine

Yun, Georgina I. Lucas

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