

Walk Together Children With No Wasted Steps: Community-Academic Partnering for Equal Power in NIH Proposal Development

Karen Jaynes Williams John Mark Cooks Marlynn May Jane Peranteau More

Progress in Community Health Partnerships: Research, Education, and Action, Volume 4, Issue 4, Winter 2010, pp. 263-277 (Article)

Published by The Johns Hopkins University Press



For additional information about this article http://muse.jhu.edu/journals/cpr/summary/v004/4.4.williams.html



Walk Together Children With No Wasted Steps: Community–Academic Partnering for Equal Power in NIH Proposal Development

Karen Jaynes Williams, PhD, MHSA¹, John Mark Cooks², Marlynn May, PhD, MDiv³, Jane Peranteau, PhD⁴, Elizabeth Reifsnider, PhD, APRN¹,

and Martha A. Hargraves, PhD, MPH¹

(1) University of Texas Medical Branch at Galveston; (2) The Galveston Island Community Research Advisory Committee; (3) Texas A&M University Health Science Center, School of Rural Public Health; (4) St. Luke's Episcopal Health Charities

Submitted 10 October 2009; revised 5 February 2010; revised 30 March 2010; accepted 27 April 2010. A major community contribution of community voice in this manuscript is the manuscript title, *Walk Together Children With No Wasted Steps*. The title of our manuscript comes from a Negro Spiritual *Walk Together Children*. The lyrics of this spiritual are, "Walk together children don't you get weary; there's a great camp meeting in the promised land." These lyrics allude to the scripture "can two walk together unless they be agreed?" (*King James Bible*, Amos 3:3). We as co-authors think that this allusion expresses the substantive challenge but great rewards of our work together.

Abstract

Background: Community-based participatory research (CBPR) approaches equitably involve community members and researchers throughout the research process. A developing literature examines problems in CBPR partnerships, but less is written about community groups using CBPR to access university resources to address community-prioritized health concerns.

Objective: We sought to examine issues in two stages of a National Institutes of Health (NIH)-funded CBPR partnership: (1) joint proposal preparation, and (2) grant administration.

Methods: We used a case study approach to analyze data (partner dialogs, meeting notes, interviews, and press coverage) from a longstanding community–academic partnership.

Results: The partnership received NIH Partners in Research Program funding. During joint proposal preparation, issues included (1) learning to practice operating principles, such as "talking in ways that all people can understand," (2) streamlining proposal design to facilitate communication with community members, and (3) addressing inequities inherent in community–academic budget sharing. During the administration phase, issues included (1) community partner struggles with administrative requirements, (2) inequities in indirect cost (IDC) allocations, and (3) the impact of a natural disaster.

Conclusion: Separately funded CBPR grants can contribute to community partner development, but make substantive demands on small, grassroots community organizations. Funders should consider taking more responsibility in developing community resources and infrastructure to ensure that grassroots community groups have the power to be equal partners. More accurate accounting of costs and benefits of CBPR to vulnerable communities should be in place to ensure communities receive adequate return on the time they invest in partnering with universities.

Keywords

Community health partnerships, community–academic partnerships, community organizing, community development, community building for health

ommunity coalitions are a viable means to respond to complex health issues within communities. Community coalition building for health has included three sometimes overlapping models: (1) locality development, (2) social planning, and (3) social action.^{1,2} Locality develop-

ment emphasizes processes and local culture, social planning favors external expert planning, and social action models favor increasing communities' problem solving capabilities and redressing power imbalances between oppressed groups and society. These models have been criticized by Minkler¹ for 264

downplaying community assets, overvaluing external expertise, and being difficult to apply to nongeographic communities.

One model that addresses some of these criticisms is Braithwaite's community organizing and development (COD) model (Figure 1). Braithwaite's COD model emphasizes the "development and effective functioning of a community dominated and—controlled coalition board" that "undertakes its own community assessment, sets policy, facilitates leadership development" and uses bottom-up planning and community problem solving to develop culturally relevant interventions.^{1,3,4} The COD model embraces a cycle of community-generated and -controlled organizing, learning, assessment, and intervention as a means of improving health outcomes of disempowered communities. Braithwaite's model serves particularly well as a conceptual foundation for partnerships in which community groups initiate and guide research at every step of the process, a characteristic of CBPR approaches.

CBPR COALITIONS

CBPR is a "collaborative, partnership approach that equitably involves . . . community members, organizational representatives, and researchers in all aspects of the research process."⁵ Although community engagement in research is not new, its recent growth in health-related research has been substantial.⁶⁻²³ As CBPR has evolved, so has a literature detailing problems in developing CBPR partnerships and ways to facilitate partnership development.²⁴

Community partnerships for health that have employed Braithwaite's model include coalitions developed to address health empowerment in both urban and rural settings, health activism in minority populations, alcohol, tobacco, and other drug use, cancer prevention, and shortages of health care personnel.3,4,25-27 A study of the development and functioning of 10 rural coalitions in Georgia sponsored by the U.S. Center for Substance Abuse Prevention (Project RECLAIM-Rural/ Empowered Coalitions for Long-Range Approaches to Inside Management) found that successful coalitions had (1) strong interactive leadership, (2) representative input from all factions of the community, 3) shared interest in solving a particular problem, and (4) an adequate, easily accessible operating budget.26 In addition, successful coalitions were composed of more homogenous partners and had focused agendas, a task orientation, and well-functioning work groups.26

The central feature of Braithwaite's model, intensive community involvement and leadership, has become a norm in more recent coalition development, especially those using

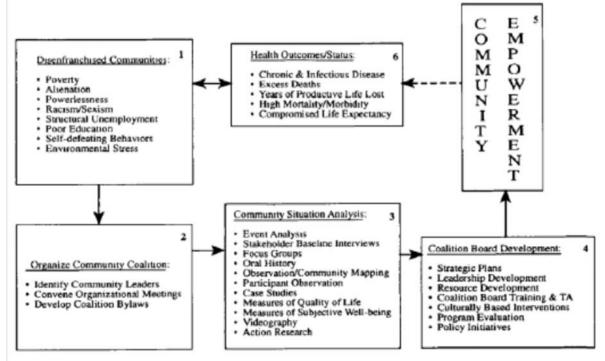


Figure 1. Community Empowerment Loop

From Braithwaite RL, Bianchi C, Taylor SE. Ethnographic approach to community health and empowerment. Health Educ Behav. 1994:21:409-416.

CBPR approaches.²⁸⁻³⁰ However, focusing on the efforts of community coalitions that take a co-equal leadership role, including the use of NIH-funded Community Principal Investigators, has been less studied. The 37 community-academic partnerships funded under the recent NIH Partners in Research program are providing community laboratories for this type of research partnership. At its first annual conference in October 2009, these recently funded partnerships gathered to discuss initial progress in this work. Although published results on these newly funded projects have not been found, a list of the funded grants may be found at http://publictrust. nih.gov/upload/NIH-Partners-in-Research-Program-Awards. pdf. The purpose of this article is to add to the literature on health coalitions using CBPR approaches. We analyze a case study highlighting a series of issues cropping up in two stages of an NIH-funded CBPR partnership: (1) joint preparation of a proposal for the NIH and (2) joint grant administration.

BIRTH OF THE GICRAC PARTNERSHIP

In 1998, Dr. Martha Hargraves, a University of Texas Medical Branch in Galveston (UTMB) researcher, formed a partnership with a local congregation to organize the African American Women's Walk for Wellness Program. Church members walked together for a year and became aware of their need for fitness and the strength that could come from group support. In 2003, Dr. Hargraves led an expanded partnership that obtained funding for the JesusFIT (Fitness Instruction and Training) program, a year-long nutrition and physical activity intervention guided by four local Galveston pastors.^{22,31} In 2005, community members who had been involved in JesusFIT sought to expand the JesusFIT program within the African American community. Dr. Hargraves joined with two other UTMB researchers and members of the Galveston African American community to form the Galveston Island Community Research Advisory Committee (GICRAC), a 13-member, all-volunteer community organization. In 2005, GICRAC and UTMB submitted a grant proposal to St. Luke's Episcopal Health Charities, a nonprofit foundation affiliated with St. Luke's Episcopal Health System. St. Luke's Episcopal Health Charities awarded a seed grant and also provided something more unusual-an experienced facilitator to assist with GICRAC's initial organizational meetings, including development of a mission statement, organizing principles, and list of prioritized community health concerns (Table 1).

THE EVOLUTION OF GICRAC

GICRAC realized that if it was to serve its "community gatekeeper" mission and work with its UTMB colleagues as partners, it had to find ways to achieve and sustain an equal role as a partner with the university. As one community member expresses it, GICRAC needed to help the university learn how to "kiss the community, not rape it," being careful not to exploit the community's assets, interests, and needs. To accomplish this, GICRAC resolved to learn more about the research process and what it is that academics do and believe about research. During 2006 and 2007, with the continued assistance of the St. Luke's Episcopal Health Charities, GICRAC located the curriculum on the Community-Campus Partnerships for Health web site called Developing and Sustaining CBPR Partnerships: A Skill Building Curriculum (available: http://www.cbprcurriculum. info/). GICRAC members were guided by this curriculum in their research learning process. GICRAC also began to review requests for applications and developed its own set of tools, including a research terms glossary, visual metaphors to characterize the relationship with UTMB, and a policy for dealing with university researchers seeking to work with GICRAC.

TOOLS FOR PARTNERSHIP BUILDING

GICRAC members created what they called a "Partic-O-Meter" (Figure 2). Grounded in Arnstein's ladder of citizen

Table 1. GICRAC Mission Statement and PrioritizedHealth Concerns

Galveston Island Community Research Advisory Committee

Working Mission Statement

We are gatekeepers for the health and well-being for African Americans in Galveston County, committed to advocating, participating, and endorsing health research. We <u>must</u> participate in the selection, design and results sharing of research and service projects.

Community-Prioritized Health Concerns

- Children's Health
- Senior Health and Housing Needs
- Need to recapture neighborhood and family role models
- Depression
- Active Living
- Partnership Building
- · Services for ex-offenders returning to community

participation,³² the Partic-O-Meter served to gauge, at regular intervals in the research process, the extent to which GICRAC's participation in a specific project was edging toward little more than tokenism (e.g., signing letters of support upon request without investigating community benefit) or was evolving into truly engaged partnership (e.g., full participation in research design, hiring of research staff, and budget decisions).

266

cipation CIDING 10apt (Encourage options; decide together ('nnsultat you offer options; wait for feat back Information (the least you can do is tell peg participati

Figure 2. Partic-O-Meter Based on Arnstein's Ladder of Citizen Participation

During a GICRAC Planning Retreat in November 2007, GICRAC members, always wary of being "overrun" by UTMB researchers, began to conceive of GICRAC as a "house" in which GICRAC members lived (Figure 3). The "house" metaphor reminded GICRAC and university partners alike that GICRAC needed to (1) get their "house" in order (develop the GICRAC organizational structure), (2) get ready to greet "visitors" to the house (researchers wanting to collaborate), and (3) prepare to "leave the house" (approach university faculty to partner with GICRAC around community-prioritized health concerns).

Accordingly, GICRAC developed one additional tool, a policy to guide GICRAC in working with university researchers seeking to collaborate. This policy required researchers who wanted to work with GICRAC to submit a formal application for a letter of support to GICRAC (Appendix A). The application consisted of the original Request for Applications (RFA) announcement and a summary of a suggested research plan. GICRAC as a whole then assessed the application, using a scoring tool, for a "fit" between the research and GICRAC's mission. If one was found, the GICRAC Chair appointed members to an Intervention Work Group (IWG), a subgroup of GICRAC, to work with the researcher to develop research question(s), design the study, and submit the proposal along



Figure 3. The GICRAC House: An Analogy for Planning

with the requested letter of support to GICRAC. IWGs served as GICRAC's organized, consistent participation in the research process and the community's "eyes, ears, and voice." IWGs serve to carry the community interests into the research process and vice versa.

METHODS

The case study approach allows for detailed analysis of a limited number of relatively complex events. A participatory case study approach is particularly relevant to the UTMB-GICRAC partnership and proposal development because the university-based and community-based researchers routinely practice "learning by doing" and especially appreciate participatory types of research-careful note taking of dialogs, cofacilitation of meetings, conducting interviews (individual and group), and conducting analyses as a collaborative, iterative, reflective process. Case study data were collected as follows. At each meeting, a designated researcher affiliate takes as close to verbatim as possible notes. After the meeting, these notes are used to formulate (1) meeting minutes later approved by GICRAC and (2) dialog notes, a meeting transcript. Data were collected for approximately 18 monthly meetings, a 2-day retreat, and two meetings of the IWG. All meetings occurred between June of 2006 and January 2008 when the grant was submitted. Data were loaded into Atlas.ti and reviewed by the first two authors to determine major themes pertinent to the case study on proposal development. Our study has been approved by The University of Texas Medical Branch's Institutional Review Board.

CASE STUDY RESULTS

Developing a Joint NIH Proposal

In October 2007, the NIH issued a RFA announcing the NIH Partners in Research Program. It solicited applications from community–academic partnerships to (1) study methods to engage and inform the public regarding health science, (2) improve public understanding of the benefits of publicly funded research, and (3) increase scientists' understanding of and outreach to the public (http://publictrust.nih.gov/PIR.cfme). Each application was to represent a partnership between community and scientific investigators. GICRAC and the UTMB decided that they would mutually develop and

submit a grant proposal using CBPR approaches.

In December 2007, a UTMB researcher presented a Letter of Support Application to GICRAC's Proposal Coordinator. As stipulated by the Proposal Policy, the application included the RFA and summary of a proposed research project. GICRAC members scored the application and voted to convene an IWG. Members of the IWG were appointed by the GICRAC chair and included four community members (GICRAC Chair, Vice-Chair, and Proposal Coordinator, and a fourth GICRAC member) and two researchers. Two 2-hour IWG meetings took place over casual evening meals. At the first meeting, the IWG community members noted that although the proposal "sounded important," it lacked significance from a community perspective and was not acceptable. The community members restated their interest in working with the university researcher, however, and voiced the idea that the proposal embrace a single, central, organizing research design principle: CBPR partnerships are not successful until the community itself is organized; until it is organized, the community cannot approach the university as an equal partner. Community members insisted that GICRAC's investment in the project result in primary data collection on the needs of their constituent community, African Americans in Galveston County. In particular, GICRAC community members were interested in using a portion of the research funds to fulfill an earlier goal that had not been achieved owing to lack of resources: a series of "town hall meetings" for GICRAC to listen to community health concerns. It was agreed that these would be part of the research design. Throughout the IWG and GICRAC discussions of the proposal, members repeatedly used the images of the "Partic-O-Meter" and "GICRAC House" to evaluate the project.

Community directives ultimately shaped the research design. In the revised proposal design, Year One would be devoted to assessing GICRAC's understanding, definition, and practice of its role in community research and how that reflected the constituency it claimed to represent. Year Two would focus on understanding UTMB's orientation to CBPR and its embracing of the community's interests, perspectives and role as collaborator. Over the course of the project, GICRAC would evaluate itself through interviews and surveys to monitor the progress of the effectiveness of the coalition and its program.³³ After a second meeting, the IWG recom-

267

mended to GICRAC that the revised proposal be awarded a letter of support. In January of 2008, a proposal *Community and Research: Equal Partners in Health* (CAREPH) was submitted. Of the more than 200 applications submitted, 37 applications were funded, one of which was the CAREPH Partnership project.

Developing a Joint NIH Budget

Preparing the project budget for the proposal proved to be a major issue because it highlighted how power imbalances are subtly built into community-academic partnership practices. This imbalance is illustrated by the following example. The UMTB-PI's salary was large relative to that earned by the GICRAC-PI at his job as an elementary school music teacher (salary base is used for determining allocation of personnel budget items). One approach to addressing this imbalance was to direct greater financial resources (and with it greater financial power) to the community partners by minimizing the UTMB-PI's time on the project to 15%, substantially less time than would eventually be dedicated to the project. In addition, all nonsalary funds were allocated to the community portion of the award. This resulted in a roughly 30% community/70% university split of direct costs. In this attempt at financial power sharing, however, the budget underreported investigator effort. The underreporting, which seemed necessary for this application, is not sustainable for researcher partnerships building a long-term research agenda.

Budget inequities worsened with the (mis)allocation of IDCs. IDCs are a percentage of the direct costs granted by the funder, in part, to support administrative responsibilities of the PI's organization. To receive IDCs, however, the PI's organization as recipient of funding must have negotiated an IDC percentage rate (e.g., 25%, 50%, or 60% of direct costs) with the funding agency.

In the CAREPH partnership, the budgeting of IDC funds had the ultimate effect of decreasing the amount of GICRAC's budget allocation relative to the university's budget. Every dollar of direct cost awarded to the UTMB garnered an additional 51 cents (UTMB has a 51% IDC rate with NIH) to UTMB. However, every dollar budgeted to GICRAC got no IDC add-on because GICRAC had not previously negotiated an NIH IDC rate. The irony in allocating program funding to GICRAC, of course, was that this sharing gave GICRAC more administrative work to do, even though they received no support from IDCs. As becomes apparent in the next section, this administrative twist added stressors to the CAREPH partnership, and especially to the community partner.

Preparing GICRAC to Receive NIH Funding

Preparing a small, volunteer, community organization to receive and administer NIH funding proved challenging, to say the least. Like many small, volunteer, community organizations, GICRAC had not developed sophisticated administrative structures that came close to matching the sophistication and expertise reflected in the research plan. Recognizing this fairly early on, GICRAC slowly, and somewhat haltingly, began building its administrative capacities. It applied for 501(c)3 status, acting also on the belief that doing so would foster its own growth and capacity in arenas beyond the *Partners in Health* grant. Rapidly and uncomfortably, GICRAC had to learn new management skills to manage: (1) NIH just-in-time (JIT) information requests, (2) direct receipts of federal funds, and, perhaps most difficult, (3) the unexpected events that come with any research effort.

JIT Requests. CAREPH received a favorable NIH review and began receiving JIT requests for information from NIH. JIT request are intended to give PIs and their administrative staff a "heads up" regarding information and documents that will be needed, usually with short turnaround times. The university-based PI was familiar with JITs from previous experience and, more to the point, received assistance from the department-level Office of Publications, Grants and Manuscripts and institutional-level Office of Sponsored Programs, all of which were supported in part by IDC funds. On the other hand, UTMB was not organized in a way to help the community-based PI, who was now dealing with the possibility of receiving a separate, but administratively linked, grant award. Administratively, GICRAC now seemed to be on its own.

GICRAC began to receive its own JIT information requests from the NIH at the same time the university did, but struggled mightily with the complex requests. Fortunately, because of the rare interpersonal and organizational skills of the communitybased PI, GICRAC survived the process. A former university employee, the GICRAC-PI had built long-lasting relationships with persons who could now help him, even if they were not formally required to do so. Accordingly, the Director of the Office of Publications, Grants and Manuscripts agreed to help GICRAC prepare its JIT response; the director of the UTMB IRB appointed a staff person to guide GICRAC through the establishment of its own Federalwide Assurance of compliance with federal regulations for protection of human subjects in research.

Direct Receipt of NIH Funds. After it became clear that GICRAC was to receive a separate, administratively linked NIH award, the approach of complex "growth opportunities," accelerated. Most of these opportunities were a surprise, because GICRAC had never received a research award of any type! Initially, the UTMB- and community-based PIs sought a fiscal intermediary to manage the financial components of the award. They approached a GICRAC charter member, also an executive director of a local nonprofit, about allowing her organization process the NIH funds, but the nonprofit's bylaws prohibited this arrangement. The GICRAC-based PI the sought help and found it from National Cancer Institute staff with whom he worked closely to establish mechanisms for NIH funds to flow into a GICRAC bank account dedicated to the project. GICRAC members also began recruiting board members with financial expertise to advise on accounting processes. GICRAC survived and even thrived through all of this. Its experiences and expertise are now available to guide other community organizations in their growth into CBPR.

Unexpected Events

Mother Nature, too, added to the unexpected. In September 2008, days before the notice of award was received from NIH, Hurricane Ike directly hit the community of Galveston, Texas. Thousands of homes on the island and mainland were devastated. Displacement extended from 7 days to many months. After the storm, the city and UTMB closed because of the lack of power, potable water, sewer, telephone, Internet, and other vital services. Residents were barred from the island for many weeks because of dangerous conditions. UTMB faculty were also barred from entering campus buildings and the UTMB-PI was unable to return to her faculty suite until November. The GICRAC-PI was displaced from his home twice. Seven of 13 GICRAC members were displaced from their homes. A reduction in force of one third of the university workforce (including the UTMB researcher who had originally reached out to the African American community), a hiring freeze, and closure of indigent care services strained community– university relations.

These events would significantly impede any research project and could well have spelled doom for the CAREPH partnership. In the midst of recovery, however, the CAREPH partnership itself began to serve as a rallying point. Partners began to see the natural disaster as a natural experiment—a unique chance to observe the sustainability of a community– academic partnership when the existence of both were seriously threatened. The PIs established temporary mobile offices, held frequent meetings, and mobilized GICRAC members to construct alternative rosters for displaced members. Data collection was temporarily suspended as community residents dealt with the loss of jobs, schools, churches, homes, and medical services. Through it all, the NIH strongly supported the recovery by allowing investigators to apply for a funded extension.

DISCUSSION

Braithwaite's COD model emphasizes cultural relevance and the "development and effective functioning of a community-dominated and -controlled coalition board." This type of board's responsibilities include undertaking its own community assessments, setting policy, facilitating leadership development, and practicing bottom-up planning for intervention development. Since its inception, GICRAC has created and maintained an active, engaged, community-led board. This board has acted as a gatekeeper for the health of African Americans and organized to guide and influence the development of research grounded in community prioritized health concerns.

The CAREPH partnership experience, although not generalizable to all grassroots community health coalitions, highlights the significant costs involved in integrating community control and bottom-up planning in research, specifically, in this case, related to receiving NIH funds. It was too easy to underestimate the considerable resource strains on a small, grassroots community group with an all-volunteer membership. GICRAC has been significantly challenged by the administrative burden of the Partners in Research project and occasionally partners have wondered if they taken on a project too large for them to handle. At times, the administrative burdens imposed both by the university and federal funding guidelines have made the project feel much less than participatory. GICRAC has little to no control over mandatory, timeconsuming administrative processes. From the community members' perspective, the project has often felt like a long list of "must do's and have to's" and less like a venture in joint decision making. To use a local phrase, members have wondered if the "juice has been worth the squeeze."

Their concerns have been validated. Both the universityand community-based PIs have spent considerably more time (and even some personal resources) on the project than was budgeted. In addition, the focus on grant administration has distracted GICRAC's energy from more programmatic functions, such as developing health education and service projects. Concerns were also validated from external sources. On June 3, 2009, Community Campus Partnerships for Health sponsored a national teleconference to discuss establishing NIH IDC rates. One speaker suggested that unless community groups have annual budgets of at least \$150,000, it might be better to negotiate subawards or subcontracts (and IDC rates) with university partners rather than the NIH. This was not an option with the CAREPH partnership because of the way the NIH Partnership in Research RFA was framed. However, in future CBPR projects, GICRAC may consider this option as a means of decreasing the administrative burden, even if it decreases control over research funds.

Braithwaite's COD model also emphasizes facilitating community leadership development and policy setting, underscoring the emphasis in the CBPR literature on investing early and intensely in processes and principles of a community academic partnership.³⁴ In its early stages, GICRAC, supported by St. Luke's Episcopal Charities, spent a considerable amount of time developing culturally resonant operating principles and educated themselves about NIH grant making and developing CBPR partnerships. It is difficult to overstate the pride and empowerment felt by GICRAC upon notice of the NIH award. GICRAC has since expanded its board to address the increased administrative requirements and has applied for funds to create its first staff position. Without the push of the NIH funding, however, these changes might have happened much more slowly, or possibly not at all.

Members of GICRAC and researchers were willing to risk personal and professional ease for the privilege of developing a community-controlled board to receive NIH funds. However, this may have a downside. Some members of the research team pose the question as to whether GICRAC is now a step or two removed from addressing community problems. GICRAC, burdened with administrative paperwork related to "metaresearch" (research focused on research partnerships), finds itself with less time for the COD model elements of ongoing community needs assessment and bottom-up intervention development. Although assessment and intervention development are part of the CAREPH research plan, research partners sometimes wonder whether GICRAC has built a solid base for addressing community-identified health concerns in the future, or has rather created an administrative infrastructure somewhat duplicative of its university partner.

Approaching equal power sharing between university and community partners through equal sharing of budgets has wonderfully admirable elements. Perhaps, however, splitting budgets in half is too blunt a tool for the fine work of building community capacity and equal partnerships. Exploring more nuanced mechanisms to balance power between community and academic partners deserves further investigation. Federal and nongovernmental funders should consider taking more responsibility in developing community resources to build the infrastructure necessary to ensure that grassroots community groups have the power to be equal partners. Funders should assist in identifying organizational components (budgets, staffing, and expertise) that need to be in place for receiving awards. Funders should also provide training opportunities for community-based researchers in proposal development and management and clearly identify the roles and responsibilities of funders, universities, and community partners in CBPR.

Finally, this case study suggests that a more accurate cost accounting of the very real costs of "doing CBPR" is needed. Why is it that the costs of CBPR are so often borne by the same, vulnerable communities that are least able to bear them? The community control advocated by Braithwaite is admirable and desirable, but does not come without significant cost to communities. Some communities are willing to bear this extra cost whether or not they can really afford to do so. For these communities, working with university researchers to create culturally appropriate research projects and interventions follows the directive from scripture and song to "walk together children with no wasted steps." Because these communities are taking many risks and expending significant amounts of creativity and energy, they should be showcased and sought out by federal, state, and local agents and agencies interested in developing and sustaining CBPR partnerships. But even being "sought out" to receive resources will dearly cost the community that participates as a true partner. Again, in the words of one researcher turned community member, "Let's hope the juice is worth the squeeze."

ACKNOWLEDGMENTS

The authors extend special thanks to the members of the Galveston Island Community Research Advisory Committee

(GICRAC) that assisted with this proposal including Sally Coleman, Valerie Hall, Norma Mitchell, and Reverend Charles Wheat. The authors would also like to thank Mac McConnell, Director of the Office of Publications, Grants and Manuscript Services of the Department of Obstetrics and Gynecology and April Vanderslice of the Institutional Review Board, both of The University of Texas Medical Branch for their support of the community partner in preparation of the proposal. GICRAC especially thanks Dr. Martha Hargraves for her dedication to partnership with the Galveston African American community since 1998.

REFERENCES

- Minkler M. Community organizing and community building for health. 2nd ed. Piscataway (NJ): Rutgers University Press; 2004.
- Rothman J. Models of community organization and macro practice: Their mixing and phasing. In F. M. Cox, J. L. Ehrlich, J. Rothman, J. E. Tropman (Eds.), Strategies of community organization. 4th ed. Itasca (IL): Peacock; 1987.
- Braithwaite RL, Bianchi C, Taylor SE. Ethnographic approach to community organization and health empowerment. Health Educ Q. 1994;21, 407-16.
- Braithwaite RL, Murphy F, Lythcott N, Blumenthal DS. Community organization and development for health promotion within an urban black community: A conceptual model. Health Educ. 1989;20:56-60.
- Israel BA, Schulz AJ, Parker EA, Becker AB. Communitybased participatory research: Policy recommendations for promoting a partnership approach in health research. Educ Health (Abingdon). 2001;14:182-97.
- Ahmed SM, Beck B, Maury B, Newton G. Overcoming barriers to effective community-based participatory research in US medical schools. Educ Health. 2004;17:141-51.
- Coe K, Wilson C, Eisenberg M, Attakai A, Lobell M. Creating the environment for a successful community partnership. Cancer. 2006;107:1980-6.
- Goodman RM, Yoo S, Jack L, Jr. Applying comprehensive community-based approaches in diabetes prevention: rationale, principles, and models. J Public Health Manag Pract. 2006;12:545-55.
- Green L, Daniel M, Novick L. Partnerships and coalitions for community-based research. Public Health Rep. 2001;116:20-31.
- Green LW, Mercer SL. Can public health researchers and agencies reconcile the push from funding bodies and the pull from communities. Am J Public Health. 2001;91:1926-9.
- Israel BA, Eng E, Schulz AJ, Parker EA. Methods in community-based participatory research for health. San Francisco: Jossey-Bass; 2007.

- Kegler MC, Norton BL, Aronson R. Skill improvement among coalition members in the California Healthy Cities and Communities Program. Health Educ Res. 2006;22:450-7.
- Leung MW, Yen IH, Minkler M. Community based participatory research: A promising approach for increasing epidemiology's relevance in the 21st century. Int J Epidemiol. 2004;33:499-506.
- Minkler M, Blackwell AG, Thompson M, Tamir H. Communitybased participatory research: Implications for public health funding. Am J Public Health. 2003;93:1210-3.
- Parrott R, Steiner C. Handbook of health communication: Lessons learned about academic and public health collaborations in the conduct of community-based research. Mahwah (NJ): Lawrence Erlbaum Associates; 2003.
- Punzalan C, Paxton KC, Guentzel H, Bluthenthal RN, Staunton AD, Mejia G, et al. Seeking community input to improve implementation of a lifestyle modification program. Ethn Dis. 2006;16(Suppl):S79-S88.
- Sampselle CM. Nickel-and-dimed in America: Underserved, understudied, and underestimated. Fam Community Health. 2007;30:S4-14.
- Savage CL, Xu Y, Lee R, Rose BL, Kappesser M, Anthony JS. A case study in the use of community-based participatory research in public health nursing. Public Health Nurs. 2006;23:472-8.
- Seifer SD. Building and sustaining community-institutional partnerships for prevention research: Findings from a National Collaborative. J Urban Health. 2006;83:989-1003.
- 20. Seifer SD, Sisco S. Mining the challenges of CBPR for improvements in urban health. J Urban Health. 2006;83:981-4.
- Tajik M, Muhammad N, Lowman A, Thu K, Wing S, Grant G. Impact of odor from industrial hog operations on daily living activities. New Solut. 2008;18:193-205.
- Williams KJ, Hargraves MA, Cornelius L, Faniuel S, Ruffin R, Anderson GD. Using community-based participatory approaches to understand barriers to health in African American populations. Ethn Dis. 2006;16:05-048.

23. Williams KJ, Bray PG, Shapiro-Mendoza CK, Reisz I, Peranteau J. Modeling the principles of community-based participatory research in a community health assessment conducted by a health foundation. Health Promot Pract. 2009;10:67-75.

272

- May M, Law J. CBPR as community health intervention: institutionalizing CBPR within community based organizations. Prog Community Health Partnersh. 2008;22:145-55. May. (2008).
- 25. Braithwaite RL, Lythcott N. Community empowerment as a strategy for health promotion for black and other minority populations. JAMA. 1989;261:282-3.
- 26. Braithwaite RL, Taylor SE, Austin JN. Building health coalitions in the Black community. Thousand Oaks (CA): Sage; 2000.
- Arriola KR, Braithewaite RL, Kennedy S, Hammet T, Tinsley M, Arboleda C. A collaborative effort to enhance HIV/ STI screening in five county jails. Public Health Reports. 2001;116(6)520-9.Braithwaite, et al. (2001).
- Harvey IS, Schulz AJ, Israel BA, Sand S, Myrie D, Lockett MP, Weir S, Hill Y. The healthy connections project: a communitybased participatory research project involving women at risk for diabetes and hypertension. Prog.Community Health Partnersh, 2009:3(4)273-4.Harvey 2009

- Johnson JC, Hayden UT, Thomas N, Groce-Martin J, Henry T, Guerra T, Walker A, West W, Barnett M, Kumanyika S. Building community participatory research coalitions from the ground up: the Philadelphia Area Research Community Coalition. 2009;3(1)61-72.Johnson, 2009
- Marcus M, Walker T, Swint JM, Smith BP, Brown C, Busen N, Edwards T, Liehr P. Taylor WC, Williams D, von,Sternberg K. Community-based participatory research to prevent substance abuse and HIV/AIDS in African American adolescents. Journal of Interprofessional Caare. 2004:18(4):347-59.
- Hargraves MA. JesusFIT-a faith-based approach to physical activity and nutrition among African American women. Ethn Dis. 2006;16.
- 32. Arnstein SR. A ladder of citizen participation. Journal of American Institute of Planners. 1969;35:216-24.
- 33. Butterfoss FD. Coalitions and partnerships in community health. San Francisco: Jossey Bass; 2007.
- 34. Israel BA, Lichtenstein R, Lantz P, McGranaghan R, Allen A, Guzman JR, et al. The Detroit Community-Academic Urban Research Center: Development, implementation, and evaluation. J Public Health Manag Pract. 2001;7:1-19.

APPENDIX A.

Galveston Island Research Community Research Advisory Committee (GICRAC) Letter of Support Policy and Procedures

273

Introduction

The Galveston Island Community Research Advisory Committee (GICRAC) is committed to the development of community-based participatory research to address the health and well-being of the African American community of the city and county of Galveston, Texas.

GICRAC's Working Mission Statement

We are gatekeepers for the health and well-being for African Americans in Galveston County, committed to advocating, participating, and endorsing health research. We <u>must</u> participate in the selection, design and results sharing of research.

Procedure

- 1. A researcher who is interested in obtaining a letter of support and obtaining meaningful and substantial input into the project from GICRAC should contact the GICRAC Proposal Coordinator or Assistant Coordinator.
- 2. The GICRAC Proposal Coordinator or Assistant Proposal Coordinator will instruct the researcher how to request a letter of support from GICRAC. The requesting researcher should submit the following via hard copy or email to the Proposal Coordinator:
 - A. A copy of the grant announcement.
 - B. A completed GICRAC Letter of Support Request Form (Attachment A)
 - C. Address information for letter of support
- 3. The Proposal Coordinator or Assistant Proposal Coordinator will present the materials to the entire GICRAC. Based on the materials submitted, GICRAC will determine if they are interested in working with the researcher.
- 4. If GICRAC decides to work with the researcher, an intervention work group (IWG) is formed of those interested in working with the researcher. An IWG Chair is selected, and an initial plan for meeting is determined. The Proposal Coordinator notifies the researcher of this information and the researcher works with the IWG Chair from this point on.
- 5. If GICRAC decides against working with the researcher, the Proposal Coordinator notifies the researcher of GICRAC's decision.
- 6. Using the *Letter of Support Evaluation Form* (Attachment B) and *Questions to Guide Our Review of Research Proposals in the Community* (Attachment C), the IWG meets to review documents presented by researcher.
- 7. The IWG may meet with researchers to ask questions, suggest changes, and enter a negotiation phase.
- 8. The IWG determines whether to recommend a letter of support from GICRAC. The IWG Chair drafts a final written response of endorsement or non-endorsement and forwards the final recommendation to the GICRAC Proposal Coordinator.
- 9. The Proposal Coordinator forwards the recommendation and draft letter to the GICRAC Chair.
- 10. The GICRAC Chair prepares the final letter, submits the letter to the researcher, and copies a) members of GICRAC, b) the Department Chair of Obstetrics and Gynecology, and c) the Dean of the School with which the researcher is affiliated.
- 11. The Proposal Coordinator or Assistant Proposal Coordinator keeps a log of researchers' requests for support, IWG recommendations, letters from the GICRAC Chair, and final disposition of proposals (funded or non-funded).

Current Contact Information: GICRAC Proposal Coordinator GICRAC Assistant Proposal Coordinator

Attachment A.

Galveston Island Community Research Advisory Committee Letter of Support Request Form

Name of Principal Investigator (person responsible for the grant or project):
Affiliation:
Name of Co-Principal Investigators and Co-Investigators:
Address of Principal Investigator:
Street:
City and State:
Zip Code:
Phone Number:
Fax Number:
Email:
Title of grant or research project:

1. Please attach an abstract or brief summary of your project (e.g. purpose of the study, hypotheses, methods, implications, plan for dissemination of research findings, etc.) 500 word limit

Abstract Attached? ____Yes ____No

274

- 2. Why are you requesting a Letter of Support from GICRAC?
- 3. If funded, how will your work improve the quality of research to address health issues in the African American or potentially other underserved communities?
- 4. What efforts have you made to ensure that the research team has the sensitivity to understand the social, cultural, and environmental context of the community of focus?
- 5. What is the racial and ethnic composition of your community of focus?
- 6. Are you or anyone on your team a member of GICRAC? If not, how did you learn about GICRAC?

Attachment B.

275

Galveston Island Community Research Advisory Committee Letter of Support Evaluation Form

To be completed by GICRAC Proposal Coordinator and forwarded to IWG Chair:

Principal Investigator:
Project Name:
Type of Study:
Target Population:
Request submission date:
Notification date:
The evaluation score provided by each member of the GICRAC IWG will assist in determining whether a letter of support is appropriate. To be completed by each member of GICRAC Intervention Work Group
Scoring (Scale ranges from 0 to 5)
Question #1: How closely is the proposed project matched with GICRAC's Mission Statement? 5-Close match with GICRAC's mission statement. 3-Partial match with GICRAC's mission statement. 0-Inconsistent with GICRAC's mission statement. Not applicable/Other Comments:
Question #2: Are the reasons for requesting a letter of support convincing? 5-Very convincing 3-Somewhat convincing 0-Not convincing Not applicable/Other Comments:
Question #3: Does the research/grant project have the potential to advance the health in the community of focus? 5-Highly likely to advance the field of African American health. 3-Likely to advance the field of African American health. 0-Probably not likely to advance the field of African American health. Not applicable/Other Comments:
Question #4: Are efforts to ensure sensitivity to understand the social, cultural, and environmental context of the community of focus convincing 3-Somewhat convincing 0-Not convincing Not applicable/Other Comments:
Total Average Score:
Please send your completed forms to Scores will be tallied and sent to the Chair to guide discussion on projects that were submitted for review. 3.5 to 5.0: Very acceptable 3.0 to 3.4: Acceptable

Less than 2.9: Marginal/Not Acceptable

Attachment C.

Questions to Guide Our Review of Research Proposals in the Community

Who?

Who is asking to do research in our community?

Do any of us know the person(s)?

What is their research interest? What do they want to study?

What have they published, on this issue or other issues?

Can we get copies of their published work?

What school is involved? More than one school?

What is their position at the school? How long have they been there?

What department are they in?

What is their experience working in the community? With which communities (in Galveston or elsewhere)? Do they have a history with this community?

Are any other organizations, churches, or community groups involved? Are we the only ones who got the letter?

How is the study funded? By the school, by the government, by other funders?

Will any community members be involved with planning and implementing the study?

Is there a collaborative? How were they chosen? Are they representative of our community? Are they representative of the people being studied?

Can we have representation on the collaborative?

What are their plans to include community in the study?

Can the group have input in study design and implementation?

What is the study procedure?

What are the expected outcomes?

What?

What is the purpose of the study?

What do they hope to find out?

Is this of concern to us?

Is it a significant or pressing concern to the community? For example, Dr. Reifsnider's study is about obesity among children. Is this a concern for us?

What do we think is important to study in our community? Is this issue important enough to study and important enough to study now?

Where?

Where will they conduct the study? In the home? At the university? Somewhere in the community?

Who decided where the study will be conducted? Did participants or community members have input on the location?

Is it convenient for community members?

Will transportation be a problem? Is there a transportation cost to participants? If so, will the researchers help with the cost of transportation?

Will researchers need to provide child care, car seats?

When?

When will the study be conducted?

Does this give us time to review the study?

Is there time for us to become involved, on the study collaborative or on the planning of the study?

Is the time good for the community? Is it a convenient time? For example, is it after school is out or around a holiday, important church dates (such as a pastor's anniversary) or in the evenings?

Do the times of participation effect who can participate in the study, e.g., it is during work hours or at night or on the weekends?

How?

What do they want to do?

With what group(s)? Parents, women, men, seniors? Why?

How will they do it? By phone? In person? In groups?

Is it a survey or a face-to-face interview or group process?

How long will it take?

Will it be tape recorded? What will be done with the tapes? Who will hear them?

Where will they be kept? Under lock and key?

What questions will be asked? Can we see them? Are we comfortable with them? Is the language understandable? Can we have input on the language and/or questions? Do we know why these particular questions are being asked? Are any of them offensive to us? Are any of them embarrassing? Is there a good reason for asking these questions? Who will be asking the questions? For example, will men be asking men and women asking women? Will the people asking the questions be students? Will they be the same race as the participants?

How and who will be asked to participate in the study? Is anyone excluded? If so, why?

Will their privacy be protected?

Will they be protected otherwise?

What happens to study results? Will they be published? If so, where? Will there be a press release in the local paper(s)? Are community members involved in the writing of the final report or article? Will results be presented to the community? Where and how?

Are participants involved in the presentation? Can they have input on where and how study results are made public?

Will results affect the participants and/or the community? How?

Who else will the results be disseminated to, e.g., city government, local organizations, churches, other interested parties?

What happens after the study is over? Will the collaborative be disbanded? Will there be an intervention? If so, who will do it, where, when, with whom? Will community members be involved? Do community members have input on the design and implementation of the intervention? Will researchers continue to work with the community? Do they have plans for more research with the community or other interventions? Will they support the community's efforts if the community continues to work on the research issue or intervention?

At What Costs?

What's the cost of participation in the study, e.g., time, convenience, money, comfort zone?

Will participants be made uncomfortable in any way? For example, will they be asked personal questions? Will they be asked questions about money or relationships or health or sex or personal beliefs? Will they be embarrassed if anyone finds out they participated in this study? Will they be embarrassed if anyone sees what they said?

Are they told about questions ahead of time so they can choose to participate or not?

Can they refuse to answer any question at any time?

Can they leave the study any time they want to? If they leave, do they still get incentive?

Is their name and identity protected? Are their words kept private, under lock and key?

Can anyone see their words or know their name? Is their name kept separate from their words? For example, are they assigned a number so that their name isn't used? Will their words be used in any publication or newspaper?

Are incentives offered for their participation?

What kind of incentives?

277

Is the incentive appropriate, e.g., is it a fair amount of money or is it a gift certificate to a place where they shop? Is it something participants care about or will want?

Is the incentive so much money that a poor person would feel compelled to participate even if they did not feel comfortable participating?

Who decided what the incentive would be? Did community members or participants have a say in this?

Are participants told ahead of time that they must give their social security number to the researcher in order to get the incentive? Can they get the incentive without giving their social security number?

Do people have to give out personal information in order to participate in the study (e.g., phone number, address, email)?

Will people be treated with respect?

Can they say "no" to anything at any time?