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Community ACTION Boards: An Innovative Model for Effective Community–Academic Research Partnerships

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Abstract

Background—Community-based participatory research (CBPR) requires equitable partnerships between community stakeholders and academics. Traditionally, researchers relied on community advisory boards, but these boards often play a reactive role on a project-by-project basis. The East and Central Harlem Health Outcomes (ECHHO) Community Action Board (CAB), however, is an effective, proactive group.

Objectives—The ECHHO board sought to identify key strategies and tools to build and employ a partnership model, and to disseminate lessons learned to other community–academic partnerships.

Methods—Current and former board members were interviewed and a wide range of related documents was reviewed.

Lessons Learned—The board became effective when it prioritized action and relationship-building, across seven key domains: Shared priorities, diversity, participation, transparency, mutual respect and recognition, and personal connections. The model is depicted graphically.

Conclusion—Community advisory boards may benefit from attention to taking action, and to building relationships between academics and community members.

Keywords

Community-based participatory research; community health partnerships; health disparities; power sharing

CBPR diverges from traditional research by expanding the role of the community beyond serving as subjects, to sharing with academics the resources and processes of research.[1] CBPR holds great promise for helping to move biomedical breakthroughs from the laboratory into the community and for addressing racial and ethnic disparities in health.[2] CBPR may also help to identify and eliminate the reasons that some interventions and therapies have not generated the hoped-for changes in combating diseases.[3]

By nature, effective CBPR requires an equal partnership between community stakeholders and academics. Researchers have traditionally relied on community advisory boards to provide community input, but these often relegate community partners to reactive roles. Those who seek more active participation may become bogged down in developing

procedural guidelines for partnering and have difficulty merging this process into concrete steps leading to research activities that improve local health. Such challenges lead to the search for new models.[4]

The ECHHO CAB formed in 2002 as a core component of an National Institutes of Health-funded EXPORT (Excellence in Partnerships for Community Outreach, Research on Health Disparities and Training) center at a large, urban, academic medical center.[5] At its inception, the CAB was a passive, wary group that adhered primarily to the traditional, reactive advisory board model. Its early meetings were often exhausted by procedural matters, such as drafting bylaws and agendas. For example, early on the CAB expended several hours debating a request for comment from a federal legislator: Who should draft the letter? Sign it? Deliver it? As a result, the group missed the deadline and an opportunity to provide input on a matter critical to the community.

Also, the group as originally constituted was unmanageably large—24 members, including representatives of community-based health and social service organizations, religious institutions, and senior and tenant organizations, as well as small business owners. As the group started to meet, it emerged that several members had dual agendas, including a community leader who was so openly skeptical and mistrustful of the academics that he resigned when he judged the delay between grant submission and decision unduly long. Another member had a business that provided services to local non-profits; he left when he failed to see a direct benefit from his participation. In all, about half the original board members left the group during its first year; since then it has averaged 12 members.

In its first year, the board approved an investigator-initiated project on cardiovascular disease: but the board's continued participation was not invited or encouraged. As a result, the project's recruitment and impact were limited (data unpublished). In preparing the project's continuation, the investigators sought strategies for addressing the limitations that had crippled the first round, becoming open to suggestions.

The researchers and the board worked together to redesign, implement, and evaluate the effectiveness of a new stroke prevention intervention. The CAB recruited members who had experienced stroke. Focus groups of stroke survivors were convened, with CAB members helping to facilitate and then to publish and co-present the data.[6] Later, CAB members were trained as peer educators and led the intervention with researchers. The academics worked closely with CAB members, explaining the research process thoroughly, providing opportunities for research mentoring, and including CAB input substantively in all aspects of the project. These practices have been institutionalized and continued by, for example, providing input on several surveys, such as those related to breast cancer and postpartum depression. The group's input has covered not just disease perception, but also care experience.

Similarly, prompted by its missed opportunity for input, the board resolved to avoid distractions, packing its agendas with action items that are raised, addressed, and resolved in meetings rather than deferred or delegated. Prospective members are carefully vetted, and they are accepted only after committing to substantial investments of time and energy.

As a result of these (and other) early experiences, the board evolved into a lively, proactive group that has served as a rich resource for research projects and for local communities. This paper examines key strategies used to build and sustain this innovative model (Figure 1).

METHODS

As its effectiveness and productivity grew, the board decided to identify the reasons for its success. A subcommittee of board members was formed and used a qualitative approach to review documents such as meeting agendas, minutes, correspondence, and reports. Over 18 months, the subcommittee met weekly, then monthly, with academics who provided formal and informal instruction on qualitative research. Subcommittee members also had access to support from research assistants, student volunteers, and an expert in professional writing.

The CAB decided to interview former and current members and formulated a semistructured interview guide in conjunction with academics with expertise in qualitative methods. The interview asked about (1) why they joined the CAB, (2) accomplishments they were most proud of, (3) how they accomplished their work, (4) what they learned about researchers and what they thought researchers learned about the community, (5) how they built trust, (6) how challenges and mistakes were avoided or handled, and (7) (for current members) what kept them coming back to the CAB. The interview was reviewed and approved by an institutional review board.

Two graduate students with no previous relationship with the CAB were trained to conduct the interviews by telephone or face to face. The interviewers took extensive notes, blinded participants' names, and shared the results with the subcommittee. In a series of meetings, the subcommittee reviewed the notes. They selected excerpts that best captured the interview themes and identified specific strategies that supported the CAB's establishment and growth. Finally, all subcommittee members received training in writing for scientific audiences[7] and collaborated on drafting the article, returning as needed to the full board for input.

RESULTS

The students interviewed 16 current and former members of the ECHHO CAB: All 10 current board members and 6 former members. Four former members could not be reached: Two were deceased, one had moved outside the country, and one declined to participate because of time constraints.

The subcommittee identified two key principles that distinguish its work: Action orientation and relationship building. The group also elucidated seven domains of action that allow the CAB to thrive as a proactive, valuable entity.

Two Key Principles: Action Orientation and Relationship Building

First, the board consistently responds to its members' desire to take action. In other community work, board members often watched as their volunteered time was occupied with developing rules for engagement and collaboration. Although these efforts are critical to ensure consistency and credibility, members felt that groups often became bogged down. Furthermore, many concrete ideas they shared with the same agencies that convened their boards were received politely but never acted on. Seasoned community members described being unable to alter a history of academics descending on the community, collecting data, and then leaving, without providing study results or any discernable improvements in health (described as "drive-by research").

In contrast, the ECHHO CAB developed strategies to move into action quickly and develop policies and procedures only when needed. For example, when asked for a letter of support by another group, the board quickly identified and evaluated options regarding content,

phrasing, and timing, among others. The entire matter was handled as a single agenda item and now stands as the policy going forward.

Second, both community members and academic partners alike place the highest value on close-knit relationships with each other. Those who had been part of other research endeavors described a distance between academics and themselves. The ECHHO CAB builds common ground in a variety of ways. The group shares a meal at every meeting. Icebreakers and personal updates cement connections on a regular basis. Community partners collaborate with academics on a wide variety of research-centered activities, including local and national presentations, newsletters, journal articles, and responding together to new ideas and opportunities from external academic and community groups. Academics also respond to community needs for assistance outside the traditional research purview, including navigating health systems and conducting workshops and lectures in the community.

Seven Domains of Action

The subcommittee identified seven domains where the principles of action orientation and relationship building have the greatest impact on the group's transformation (Figure 1).

Shared Priorities: Issues Most Common in Harlem—"The whole group looks at issues most common in Harlem where there are the most disparities," said one CAB member. The group knows that ECHHO cannot tackle every health disparity in Harlem, however, and is careful not to duplicate the work of other local groups. Thus, board members often collaborate with other groups on issues they are interested in. However, the CAB works with the academic researchers on shared priorities, such as stroke prevention, postpartum depression, and breast cancer, which are largely unaddressed by other groups. ECHHO also widely disseminates information about its work to the community through newsletters, legislative breakfasts, and local presentations.

Diversity in Membership: Reaching Out to All People—The ECHHO Board aims to recruit members who reflect the community's variations in age, gender, ethnicity, and race, and who represent different grassroots and organizational constituencies in Harlem. This helps to foster new ideas, a variety of opinions, strong connections with the community, and new collaborations among community stakeholders. For example, a restaurant owner, a tenant association president, and a health ministry volunteer wrote about their experiences with preterm deliveries for the CAB's newsletter. One member likened this approach to making a soufflé using "ingredients" that are distinct yet complementary, "having a plan for carefully blending the ingredients, and, once formed, taking tremendous care to ensure that the soufflé rises rather than falls."

Substantive Participation: We're All at the Same Level—Authentic community ownership is critical to the sustainability of academic–community partnerships, and the key to that ownership is involving community members in the partnership's work.[8] To improve the health of their community, CAB members feel they must be deeply involved in major research efforts—insiders rather than outsiders. Based on their prior experiences, they were initially skeptical that their research partners had the community's best interests at heart. Nonetheless, they know that their genuine participation is critical to success. Established CAB members formally orient new members to ensure that they are ready to participate. Partnered activities detailed in other sections also foster active participation and influence over research.

Transparency: We Learned How to Share Ourselves—All those interviewed identified a strong sense of openness as critical to the board's success. One member commented that in the board's earlier days, a researcher hesitated to share data with community partners and strongly resisted new ideas. As a result, one project was dropped and another had limited recruitment. In another example, a CAB member refused to share his knowledge of available church spaces, so that the board had only limited access to sites for its programs.

The dynamics changed once members embraced transparency. "They learned how to share themselves; the community taught [researchers] that," stated a board member. Another said, "The community members have a lot to bring to the table and [they] definitely bring a lot of perspectives into how research can be done, and how to achieve success in the community."

Mutual Respect and Recognition: A Marvelous Meeting of the Minds—Researchers often come to projects with limited understanding of community, the expertise that community can bring to research, and the tangible impact of health disparities. Community members often begin with limited understanding of the promise and practice of research and the field of health disparities. The CAB's regular meetings and project-specific activities allow researchers to become part of the community, and community members to become part of the research operation. As one board member said, "I think by networking within this organization it gave [researchers] insight into who the people are and what their greatest needs are." Another CAB member said, "I got insight into how these things are done and how to write the kind of proposals that would keep the interest … [of funders] so that the work can be continued."

Several activities are particularly helpful in this area. First, the CAB produces a quarterly health disparities newsletter, with all articles co-authored by community and academic partners. Second, because community partners often join the board with little experience in the rubrics of scientific writing, manuscripts are "created" by a team rather than "written" by a single academic author. This process includes group meetings where an academic types ideas from community members into the manuscript. Tape recorders are provided to community co-authors so they can verbalize ideas that are later transcribed. Third, local and national posters and presentations are co-developed and co-presented. Local activities include workshops for physicians on how to give community-based health lectures, and a speakers bureau that provides presentations by community–academic teams on health disparities topics. Nationally, activities include leading workshops on conducting and publishing CBPR, and oral presentations and posters co-delivered by partners. Over time, these activities have transformed board members, as one stated, from feeling like a "fly stuck in molasses. Researchers showed me love and kindness, helping me move forward and inspiring me to share my message."

Orientation to Action: A Goal of … Making It Happen—CAB members attribute the board's success to its becoming proactive and focusing on social action. One member remarked, "[We] have consistently moved forward … with what we accomplish and do…. Some groups only last a while, while [our] continuity has existed over the years." Members believe this is possible because community partners have become experienced at setting realistic goals and taking action, and because the academics are responsive.

Personal Connections: You Become a Part of the Family—The strong personal bonds formed among researchers and community partners were critical to making the ECHHO CAB a cohesive and forward-thinking group. One CAB member said, "We like the work we do, and the leadership, we love that … but we really like each other. Everyone that

comes into the CAB … they're accepted as though they've been there all the time. You become a part of the family."

DISCUSSION

In the traditional research model, many community boards are launched with an extended discussion of their mission and rules of engagement.[9] Although structure is important, the group can become frozen in protocol development, which does not speak to the passions of board members—especially those who are frustrated with the poor health of their community and impatient to roll up their sleeves and generate positive, rapid and tangible change.

The ECHHO CAB took a different route. Over eight years and two health disparities center grants, the CAB moved from reacting to well-formed ideas presented by researchers, to acting assertively and participating fully in research projects.

ECHHO attributed its initial struggles as a community–academic partnership to a perceived lack of shared priorities and an absence of mutual respect and recognition. Academics prioritized funding, professional advancement, project completion, and publication; their strengths were the skills, education, and contacts needed for successful research. The priorities of community members, on the other hand, were to improve the health of their neighborhoods, secure useful resources and information, and inform and influence health policy. Their strengths included their experience as research subjects, a firm grasp of the meaning and impact of local health problems, and familiarity with local assets and barriers.

At first, these difficulties (as shown at top of Figure 1) were a breeding ground for skepticism and mistrust. Neither side fully appreciated the advantages of forming a lasting partnership with the other. Nonetheless, academics managed to reap substantial benefits. The community, however, did not see rewards: Any new resources provided were temporary, as was any improvement in health status.

Over time, researchers and community partners have transformed the ECHHO CAB by emphasizing action and building relationships across seven key domains (as shown in gray box in Figure 1): Shared priorities, diversity of membership, substantive participation, transparency, mutual respect and recognition, and personal connections. Disparate goals became shared academic and community goals: Sustainable improvements in local health and resources, successful conduct of groundbreaking research, and dissemination of lessons learned. Today (as shown in the bottom of Figure 1), community members collaborate with academics to develop and plan research projects, author papers, present at local, national, and international conferences, partner with other CBPR groups to co-sponsor initiatives, host legislative breakfasts, and disseminate information about health disparities and research in Harlem.[11-13]

These successes have provided great hope and energy for the ECHHO CAB. To share its success and lessons learned, board members collaborated on this article to describe what they did and how they did it. Figure 1 illustrates their approach graphically, comparing the traditional and new models and identifying the seven vehicles for this transformation. However, the board did not investigate the applicability of the model to community boards with different structures. For example, the membership of some boards is based on job title, so that a human services agency might designate its executive director to sit on an advisory board. In contrast, most members of the ECHHO CAB were chosen as individuals, as neighborhood residents, and grassroots community leaders. The ECHHO CAB therefore encourages other communities to tailor the model to suit their unique needs and strengths.

Today, ECHHO researchers are part of the community and community partners are researchers. They share their personal passions and interests, welcome and trust each other, and generate fresh ideas for research, education, and dissemination. With significant rewards clearly visible to both groups, the partnership continues to thrive.

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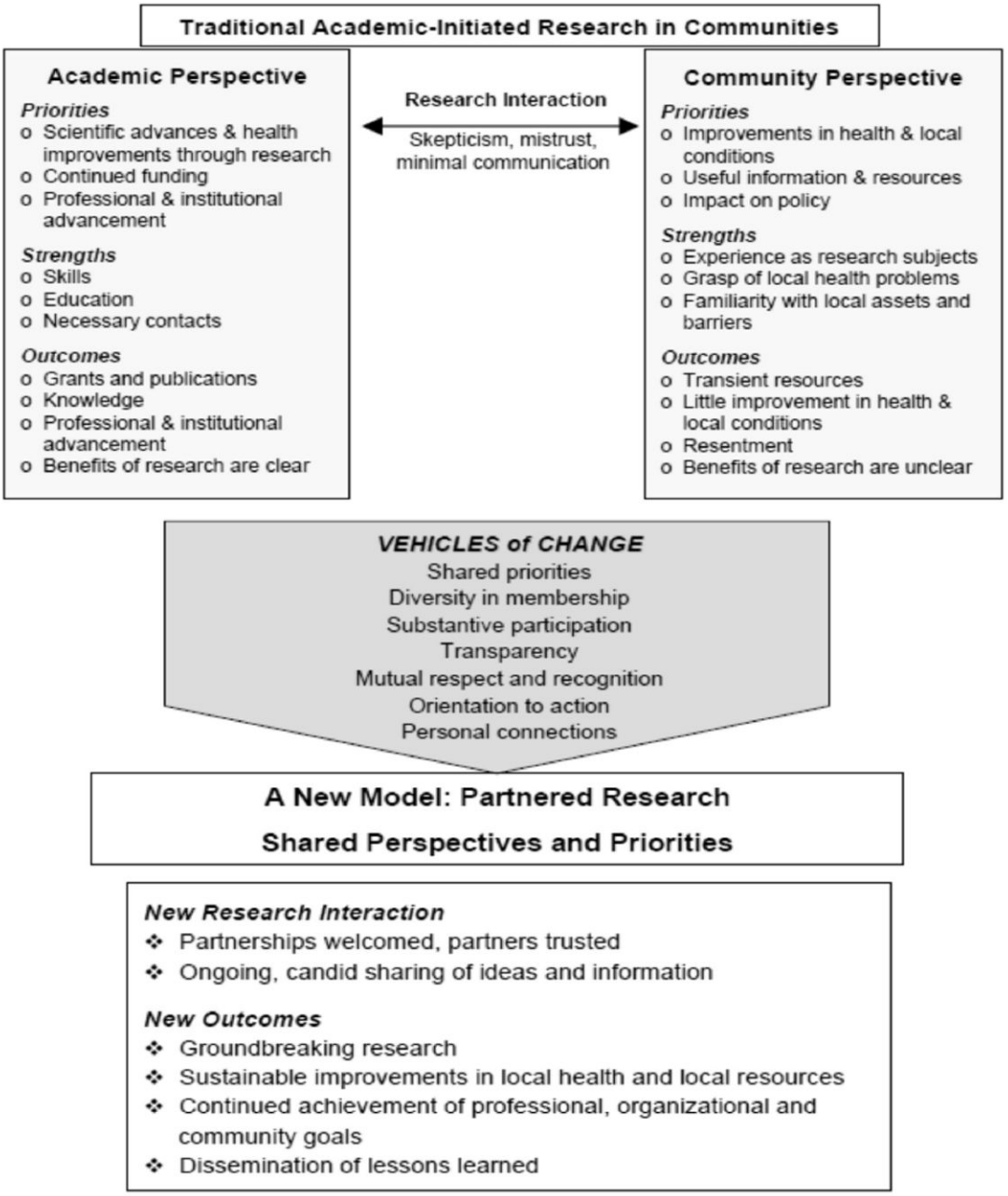

Figure 1.
Transforming Partnered Research in Communities