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The Healthy African American Families (HAAF) Project: From Community-Based Participatory Research To Community-Partnered Participatory Research

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Abstract

During the past two decades, there has been an increased use of community-based participatory research in public health activities, especially as part of efforts to understand health disparities affecting communities of color. This article describes the history and lessons learned of a long-standing community participatory project, Healthy African American Families (HAAF), in Los Angeles, California. HAAF evolved from a partnership formed by a community advisory board, university, and federal health agency to an independent, incorporated community organization that facilitates and brokers research and health promotion activities within its community. HAAF created mechanisms for community education and networks of community relationships and reciprocity through which mutual support, research, and interventions are integrated. These sustained, institutionalized relationships unite resources and both community and scientific expertise in a community-partnered participatory research model to address multiple health problems in the community, including preterm birth, HIV, asthma, depression, and diabetes. The HAAF participatory process builds on existing community resiliency and resources and on centuries of self-help, problem-solving, cooperative action, and community activism within the African American community. HAAF demonstrates how community-partnered participatory research can be a mechanism for directing power, collective action, system change, and social justice in the process of addressing health disparities at the community level.

Keywords

Community-based Participatory Research; Community-partnered Participatory Research; African American; Family

Introduction

Over the past two decades there has been an increased use of community-based participatory research (CBPR) in public health activities in the United States.¹⁻⁴ CBPR has been particularly advocated as part of efforts to understand the persistent increased risks of adverse health outcomes and to develop culturally-appropriate disease prevention and health promotion strategies in communities of color.^{1,4-7}

Participatory research is the “systematic investigation, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change.”⁸ Its premises include: 1) participation is a fundamental value and right; 2) relevant expertise exists within both science and community perspectives; 3) community representatives are actively and equitably involved in all aspects of the research process; 4) utilization of community resources and building of community capacity; and 5) research is directly and immediately linked to subsequent action within and for the participating communities.^{3,5,8–11}

As the community is a unit of identity in CBPR, its definition is important.^{2,5} Generally, community refers to a geographic, ecological, and social system.^{2,5,12} Community members have common interests, experience, history, culture, and self-identification as a group. This sense of sharing and internal coherence makes community representation possible.¹² However, community diversity also emphasizes a need for appropriate representation and participation opportunities for different sectors.

This article describes the history and lessons learned in a long-standing community participatory project, Healthy African American Families (HAAF), in Los Angeles (LA) County, California. HAAF evolved from an initial partnership between a local community advisory board, a university, and a federal agency to an independent, incorporated community organization that facilitates and brokers research and health promotion activities within its community. Building upon the participatory and self-help aspects of African American culture, HAAF created mechanisms for community education and networks of community relationships through which mutual support, research, and interventions are integrated. These sustained, institutionalized relationships unite resources and expertise in a community-partnered participatory research (CPPR) model to address multiple health problems.

Over time, HAAF achieved a joint voice and an identity as a partnership that is greater than its separate components. There was a coalescence and synthesis of community, federal, and academic perspectives by working collaboratively for many years on a mutual vision and its realization. Throughout HAAF’s history, there have been respected places for both scientific and community voices and evidence.

HAAF serves as a prototype for effective, independent CPPR organizations. Its practices have influenced participatory public health research throughout the United States. The coauthors of this article give attribution of its contents to the collective wisdom of the local community, HAAF participants, evaluators, and partners.

Healthy African American Families(HAAF)

HAAF has had three overlapping developmental phases characterized by different relationships between partners and different balances between the community’s reactive and proactive orientations to research, capacity building, and sustainability.

Phase I

Between 1990 and 1993, the Centers for Disease Control and Prevention (CDC) created a portfolio of work on the study of racial/ethnic disparities in preterm delivery (<37 weeks gestation).¹³ This work included research on the contexts in which social behavior, cultural, historical, political, and economic forces influence health during pregnancy and on the incorporation of community participatory research approaches. As part of this work, HAAF originated from a partnership created for a university research contract to conduct community participatory research with the African American community in LA. In this

phase, the local community was primarily a reactive partner, joining a project originally conceived by CDC. There were 3 initial objectives: 1) to conduct ethnographic research on maternal health during pregnancy and pregnancy outcomes among African Americans using community participatory methods; 2) to investigate community concerns about research; and 3) to evaluate the processes of active community participation in the research conducted. The primary results of the ethnographic research and the evaluation are published elsewhere.^{14,15}

Although the original project's broad objectives and intent were pre-determined, it was funded with a planning year to develop the community partnership, specific research questions, and study protocol. Community definition and partnership design were decided on within the collaborative process as were the specific study design, methods and conduct, and research domains. Initially, "community" referred to those African Americans who do business, find entertainment or fellowship, work, live, attend religious services, obtain health care, or have significant affinal or familial relationships in the South Central, Compton, and Baldwin Hills neighborhoods of LA county.⁵ Population movements and changing demographics over the past decade led HAAF to become involved in other geographic areas within the county and to develop participatory relationships with local Latino communities. Other participatory aspects included: ethnographers and evaluators from the community; a proactive community advisory board (CAB); regular community meetings; continual community networking and outreach processes, and; ongoing dialog among the three primary partners (the university, the CAB and the CDC).¹⁶

The simultaneous processes of CAB development and of community engagement were critical elements in HAAF's creation. The CAB was convened to work on community definition, community entry, engagement in the planning and research processes, research domains, identification and training of field researchers (ethnographers), and participant selection.¹⁶ A twelve-member CAB, with an elected chair (Ms. Jones), was identified by interviewing and networking with community leaders and gatekeepers about research concerns and project goals and structure.¹⁶ CAB members had long-standing histories in the local community, including outreach, health care, social service, and research experience. They participated in HAAF because they: 1) were tired of research as usual in their community; 2) wanted to protect and proactively represent community interests; 3) wanted direct community benefit, and; 4) felt the project could aid their own community work.

The CAB had direct operational functions throughout phase I.¹⁶ The CAB worked directly with CDC, university, and field research staff to develop independent relationships with each. The CAB served as researchers influencing all aspects of study design and conduct, including the informed consent language, staff training, development of community-appropriate research questions, identification of sampling schemes, collection of information, data interpretation, and document production, review and approval. They were community advocates, serving as gatekeepers, liaisons, and agents of change within the project.¹⁶ A key role was encouraging lasting community impact and benefit from the project through employment, collection of useful data, and knowledge transfer (data translation and dissemination). HAAF strove for immediate and direct community benefit to be received from the project before academic benefit was received.

The CAB met at least monthly with the other partners in community locations. Although CAB members received a small stipend for travel expenses and time, members invested much uncompensated time on the project, ranging from 5 to 30 hours per week. The CAB had no independent financial resources. This created a functional barrier within the project because the CAB had to depend financially on the university or use personal resources to accomplish its work. Without independent funding, the CAB had less power when conflicts

arose. In spite of this limitation, and also because of it, the CAB was crucial in the development of the participatory elements of the project and repeatedly challenged other partners to examine what it meant to be participatory and how this was to be realized in an African-American community.

Four major community products emerged in phase I: 1) the renaming of the project to HAAF; 2) a community-generated definition of a healthy African American family; 3) documentation of community concerns about research; and 4) direct advocacy with the university researchers and funding agency. The community ethnographers advocated changing the initial project title from Pregnancy Among African American Women in Los Angeles, which reflected a scientific concern, to Healthy African American Families, which reflected the community's perspective that pregnancy was inseparable from issues of family.¹⁶ Thus, the issue of African American pregnancy health was reframed into an issue of family and family preservation.¹⁷ The new name and reframing of the study issue rejected use of a deficit approach and focused research efforts on the collective strengths of the community.⁵ In accordance with this reframing, a definition of a Healthy African American Family was developed through community dialog groups (Table 1). This definition, which is not kinship-based, emphasizes resiliency, strengths, values, culture and traditions, skills, and competencies as the foundation for wellness and health. HAAF's orientation to family has been expressed in many ways throughout the project, including assessing the impact of health and disease within the family as well as simply bringing babies to meetings and issuing participation certificates to both babies and mothers.

The investigation of community concerns about research occurred simultaneously with HAAF's development. The community concerns were in three areas: distrust, reciprocity, and direct community benefit.¹⁶ The CAB invited government staff to directly address these concerns and openly voiced frustrations and anger about community-abusive research. The frustrations were summarized in examples from *A Dictionary of Bad Words* (Table 2).¹⁶ As shown, these common research- or scientific-related words had different connotations to community members because of decades of exploitation.

CAB advocacy also addressed staff pay structure, data interpretation, data housing, and honoring of community voices.¹⁶ The CAB advocated equal pay for equal work among both community (non-student) and university student ethnographers. Concerned about misinterpretation of ethnographic interviews and about the potential publishing of findings emphasizing community or individual deficits, the CAB reviewed all reports to ensure a transparent process, validity of results, and inclusion of community perspectives and language. Because the original research was funded as a federal contract, the data collected belonged to US citizens. The CAB negotiated with the other partners to store the data in the community so it was available for long-term community use. Finally, the CAB held a series of meetings with CDC representatives, which included the CDC Director, to assure that community voices were honored and to present its ideas on community participatory approaches.

Transition to Phase II

As the initial contract period neared its end, the university researchers reduced their activity and presence on the project; however, the pregnancy-related ethnographic data were not analyzed. Consequently, the project was threatened with the possibility of not finishing and not developing community interventions. To ensure continued community benefit, the CAB worked directly with CDC to continue the project at another local university. Although the transition to phase II was difficult, ultimately this adversity further united community members. During this process, the CAB started the incorporation process and HAAF began its transition from primarily reactive to proactive partnering.

Phase II

In late 1995, HAAF phase II formally began with an open house in a new community office. The goal of the open house was to demonstrate that HAAF was trying something new within, and for, the local community. Local children's music groups performed and all partners were there to meet with community members.

Phase II focused on the analysis of the ethnographic data on pregnancy health, community dissemination of results, and planning local prevention and intervention strategies. There was an increased focus on partnering with other community-based organizations, academic institutions, and local government to create broader conduits for the exchange of needed information to address pregnancy and other community health issues. The HAAF staff began working on other community health issues, such as HIV, violence, and physical activity. Community meetings were expanded into a conference format to train community members about scientific ethics and relevant research advances, to present local study results, and to solicit community perspectives on health issues.¹⁸ Phase II was thus characterized by a continuation of phase I reactive partnering and the initiation of proactive partnering for new community-originated projects.

In Phase II, the CAB assumed leadership for data interpretation and dissemination within the project. The CAB increased to 18 paid members and a chair and included community leaders, elected officials, business representatives, community health advocates, and experts in social service, medicine, and psychology. The CAB continued its roles as community watchdog and as active researchers involved in all aspects of the research cycle.

The primary products from HAAF phase II were: 1) the completion of the ethnographic data analysis; 2) presentation of results to local and national audiences, and; 3) the initiation of intervention development based on research findings. The results indicated women wanted more emotional and material support and assistance from both family and community members during pregnancy.¹⁴ They also wanted more information about preterm birth risks and how to have a healthy pregnancy so HAAF collaborated with other partners to develop a risk communications strategy to address these needs within its community.¹⁹ The products included: *One Hundred Acts of Kindness toward a Pregnant Woman*; a billboard campaign to increase family support of pregnant women, and; a doorknob hanger identifying premature labor signs and symptoms (described elsewhere in this issue).^{19,20}

Phase II had its own challenges, including university staff changes and administrative systems unfamiliar with participatory research and its requirements. The struggle through these issues further deepened community ownership of HAAF and led to additional community collaborations and partnerships, including other community-based organizations (CBO), universities, health clinics and hospitals, and the local health department, to reduce dependency on any one partner.

Phase III

Phase III, begun in 2001, is the current phase. The organization now has the infrastructure, functions, and partnerships with community-based academic scholars to initiate its own projects to address community health issues. Phase III uses a CPPR approach to proactively partner with others to achieve goals set forth by community members. Although HAAF remains a partner on research projects originated by others (reactive partnering), this occurs at a lesser extent than in the previous phases. Key aspects of phase III are underlying principles of trust, respect, participation, and knowledge sharing.^{2,10,21}

The HAAF organization is now a community-initiated, 501c3 entity whose mission is “to improve the health outcomes in African-American communities in LA County by enhancing

the quality of care and by advancing social progress through education, training, and collaborative partnering with community, academia, researchers, and government.” Its goal is to provide a forum to enable community leadership in health promotion. HAAF acts as a broker and facilitator – a bridge builder between community members and researchers. Structurally, HAAF consists of an Executive Director (Ms. Jones) and a governing board. The organization collaborates: locally, with multiple institutions, including universities, CBOs, and local and state government; nationally, with other state health departments, federal partners, and professional organizations, and; internationally, with a HIV-related prevention collaborative across multiple countries.

While HAAF originally focused on pregnancy experiences, reproductive health was never viewed as separate from other health issues or community problems. Thus reproductive health is viewed as interacting with other health aspects, in psychosocial and environmental contexts, within the family and the community and across the life course. Ethically, all needed to be addressed. Thus HAAF has also worked on HIV, asthma, physical activity, diabetes, depression, hypertension, obesity, heart disease, kidney disease, cancer, pain, violence, and environmental health issues such as lead toxicity and mold.

In its CPPR activities, HAAF uses a community assets model which focuses on capacity building by mobilizing and leveraging existing community resources.²² This model is similar to the childhood story of *Stone Soup* where none of the town members individually had enough items to make a nourishing soup but when resources were combined, they were able to make the soup.²³ Assets come from within the community itself and are based on African American cultural traditions of self-help and mutual obligation and responsibilities. Over half of the annual budget is obtained as in-kind contributions, such as volunteer services and employment training. The organization solicits other community organizations and businesses to provide in-kind, no-cost resources, including media services, apprentices and trainees from training programs, and products.

The organization’s functions and activities are outlined in Table 3. Briefly these include qualitative and quantitative research, evaluation, networking, consultation and collaboration, community education, community information gathering and sharing, needs assessment, training, and meeting hosting or provision of space. Qualitative methods were particularly valuable for the witnessing of African American experience in LA. Witnessing allowed community perspectives, stories, concerns, needs, and successes to be voiced, acknowledged, and documented.²⁴ These activities then helped mobilize community members for further action and inquiry. For example, HAAF dialog groups on a specific health issue often continued to meet after the original group objectives were met because the dialog process increased participant interest in the issue, in the need for networking and social support, and in developing intervention strategies.

The community meetings that originated in phase I evolved into the primary way HAAF initiates collaborative projects and provides opportunities for building skills, networking, and sharing information between community members and scientists.¹⁸ These meetings are participation in action and occur as conferences, symposia, lunch-box meetings, or workshops. They are oriented to a diversity of community participants and use multiple modes of information sharing, such as video, which are more effective with African American audiences.^{25,26}

Training for lay community members on scientific methods and research findings and for scientists on community perspectives are important aspects of HAAF’s research facilitation.⁵ For community members, this training includes the research process and methods, human subject protection, informed consent, and the potential of research to

address community problems. For scientists, this training includes reframing scientific issues to include community perspectives.

Community Engagement, Partnership, and Reciprocity

Relationship building is the heart of community engagement, partnership development, and reciprocity in CPPR. For HAAF, this includes engaging a wide sample of community involvement, having continual outreach, networking through every contact and referral, conducting resource interviews, responding promptly to requests for information, and participating in other organizations' work.¹⁶ Participation in HAAF projects is open to any individual or organization that wants to actively participate and agrees to CPPR principles. The level of activity from other community or academic partners ranges from self-selected minimal to substantial input. Partners may also "get on and off the bus," meaning they may choose to initially participate, then reduce participation, and then resume participation later.

The organization collaborates with both health- and non-health-related partners. Health-related partners include local and state health departments, local clinics and hospitals, and organizations such as the Los Angeles Best Babies Coalition, Planned Parenthood, and the Women Infants and Children program. Non-health-related partners include schools, churches, advertisers, family preservation services, youth organizations, businesses (eg, restaurants, drug stores, and groceries), media (eg, radio stations), and other local government departments.

Just as HAAF asks others to partner with them, HAAF reciprocates as a partner on other community activities in myriad ways.¹⁶ The organization is involved in the community through: teaching and training; proposal writing; participation in community health fairs; distribution of community newsletters and maintenance of a health library; hiring of community workers; creation of community health profiles; maintenance of community networking databases; community conferences and workshops, and; serving on other organizations' advisory boards, working committees, and human subjects review committees. The organization provides free physical meeting space for: music and dance lessons; grant writing training; GED classes; medical resident and fellow training; other community participatory projects; other committee and work group meetings, and; parenting classes.

Similarly, as the local community was asked to participate in research with university and federal partners, community members expected researchers and funders to participate in communities. Throughout HAAF's history, there has been the expectation of reciprocity from federal and academic partners, especially principal investigators. This includes being present and engaged with the local community by providing service, participating in community events, and being visible on the streets. The partners develop teaching and training modules for skill building and science education, help in proposal preparation, attend health fairs, assist in developing community profiles, newsletters, and libraries of health information, and hiring community members where possible. These activities led to reduced barriers between community members and researchers, improved community relations, and sustained involvement in community.

The primary phase III products include publications, presentations, health education products, community engagement activities and conferences, networking, and development of new research and prevention areas.

Discussion

Healthy African American Families is a sustained community participatory organization that conducts research on pregnancy health and other public health issues in LA. The organization transformed the use of community-based participatory research into a productive model of community-partnered participatory research. In this work, the local community is actively engaged in participatory projects where the locus of control and ownership is mutual between partners and where there is respect, collaborative leadership, reciprocity and sharing, mutual learning, relationship building, problem solving, and joint action. In CPPR, the local community is not researched, rather research is conducted with the community as a full partner in the endeavors.^{2,3,5} The organization proactively initiates its own projects, soliciting its own partners, in response to community-identified needs.

Healthy African American Families is an intermediary link and catalyst between community and science expertise, voices, and resources for local public health advocacy, data, and research for local benefit. Throughout its development, HAAF has addressed key questions about the conduct of research with a community of color, such as “What does it mean to be participatory in an African American community?”, “How is equity among partners possible when there are underlying power differentials?”, “How do we move from a hierarchical to an egalitarian project structure?” and “How do we increase ownership of both issues and solutions?” In addition, HAAF has considered what kinds of information are needed to address community public health issues, how should this information be presented, how to recognize, share and respect voices and expertise from both science and community, and what skills and resources are necessary at the community level for research and for intervention development.

Despite an increased sustainability throughout more than a decade of work, HAAF still sits precariously. As with many CBOs, financing is an ongoing issue. Active involvement of key people remains important in the project’s conduct and survival.¹⁰ The organization could have ended at several key points of struggle and conflict during its history but it survived largely because of the individual resolve of the coauthors and CAB members to work through bureaucratic issues and to openly address challenges in working with a historically oppressed community. These challenges included distrust, conflict over community benefit and interventions, and data access and usage.

When HAAF began, government and academic institutions were not trusted in the local community for a variety of reasons. Some of this distrust was related to the legacies of Tuskegee and of scientific racism.^{27–30} However, the original project was also initially perceived as yet another program coming into the community as a result of the 1992 LA riots.¹⁶ It was suspiciously viewed as another “here today, gone tomorrow” project with no real intent to provide community benefit.¹⁶ The distrust was based on prior local community experience with research projects with preset agendas, no clear or immediate community benefit, unequal power relationships, disrespect for community knowledge, and that allowed community victimization, humiliation, and stereotyping.^{5,16} Furthermore, previous research did not address questions immediately important to communities, nor help community members to investigate these, and did not examine environmental and broader social factors related to disease occurrence.^{5,16} Data concerns included having culturally-informed interpretation of community data, community access to collected data, and translation and dissemination of findings to community audiences.^{5,16} Within HAAF, we repeatedly addressed these issues openly and honestly and worked to ensure project follow-up, data access and dissemination in lay language, and direct community benefit in multiple ways throughout the project.

The conduct of CPPR requires an honest assessment of the strengths and limitations of each partner so that strengths may be shared and limitations addressed by addition of new partners. Community-partnered participatory research partnerships also require time, commitment, patience, mutual respect, labor, money, structure and flexibility, problem-solving, evaluation, and appropriate personalities for collaborative work.^{2,21,31,32} Within HAAF, we found that when these elements did not exist, the partnership was divisively and antagonistically pulled into its separate member components. We then depended on our long-standing commitment to the project to resolve the underlying issues.

The HAAF CPPR process builds on already-existing community resiliency and resources, and on centuries of self-help, problem-solving, cooperative action, and community activism within the African American community.^{1,33-39} This commitment to caring for neighbors is an African American cultural strength. This is a radically different perspective of African American communities, which have previously been viewed as deficient.^{5,34,35} The commitment to collective action, traceable to African cultures and reinforced and modified during slavery and post-slavery, provided group survival, care, resources and information not available through the dominant society. Collective action and self-help created mutual social obligations, responsibilities, and interdependence. This occurs between individuals, within family and social networks, and in the broader community. Historically, these activities occurred through individual and family action, churches, clubs, secret orders, mission societies, hospitals, and auxiliaries and often included working with federal, state, and local governments.^{1,33-39} This rich history and cultural dynamics provided the foundation for the development of HAAF. In essence, the African American participatory approach was already established historically - nothing new needed to be created.

The HAAF CPPR model is a valuable public health approach for working with communities of color. Community partnering, with mutual ownership, responsibility, liability, and benefit, is the heart of the CPPR process. In CPPR, an intimate relationship is formed where communities are not merely advisors to academic or clinical partners, nor do they act in a time-limited way. Rather community members/representatives are fully and equitably engaged as committed stakeholders and owners in the entire research process, directly participating in problem-solving, project conduct, and benefits over a long time period.

The CPPR process by itself cannot be the sole solution to decades of racism, job loss, environmental injustice, and neglect of infrastructure within disenfranchised communities. However, CPPR, as exemplified by HAAF, can become one means for tackling broader social, economic, and environmental issues by increasing community needs assessments and community voices against adverse outside influences. Community-partnered participatory research can be a community-oriented, self-help mechanism for directing power, collective action, system change, social justice, and civil rights in addressing health disparities at the local level.

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Table 1**Definition of a Healthy African American Family: Healthy African American Families project, Los Angeles, California**

A Healthy African American Family is a unity of people of African American descent who:

- Bond together through love, trust, commitment and respect
- Are mutually concerned for each other's welfare, preservation and development (physically, spiritually, economically, mentally, and socially)
- Work under a spiritual realm
- Provide unconditional love
- Have respect for one's headship (leader/leaders) and self

The commitments of a Healthy African American Family include:

- Educating members of the group to operate successfully and competently in society
 - Taking responsibility for providing a spiritual foundation and skills to overcome past oppressions
 - Transmitting values that help the group to fully reach its collective and individual potentials and goals
 - Promoting a positive cultural sense of self and reconnect to our powerful cultural roots and practices
 - Instilling social skills that transmit resiliency, mutual respect and support
 - Providing protection to insure the safety of our children and all family members
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Table 2

Examples from the Dictionary of Bad Words: Healthy African American Families project, Los Angeles, California

Research Term	Community Translation
Researchers	Takers
Informants	Spies
Subjects	Slaves
Data	Stolen goods, people as objects
Anonymous	Secret purpose
Collaboration	New exploitation of community
Public health	Free mistreatment in a health clinic
Empowerment	Perception that I have no power
My research	Who does it belong to?

Table 3

Healthy African American Families organizational functions

- Conduct qualitative and quantitative research on African American health issues
- Evaluate community processes of participation in research
- Identify and network with community members, organizations, and businesses that may have a strategic role in the development of public health
- intervention and prevention activities in the community
- Provide health and community data to community organizations, community members, and outside researchers
- Facilitate contacts and contracts between agencies and minority groups within the community
- Provide consultation on the processes of working within minority communities and on the health needs of ethnic minority families
- Participate in health department planning activities
- Participate on advisory councils
- Participate in local health fairs and other events within the community
- Function as a liaison for recruitment and retention of participants in community-based investigations
- Develop culturally-appropriate health promotion materials
- Provide training in community-partnered participatory research to medical students, fellows, and residents
- Provide training in scientific methods, informed consent and IRB processes, and health issues to community members and students
- Provide training at universities on ethnic minority health and social issues
- Host meetings for health and social services programs within minority communities
- Provide meeting space for community meetings held by CBOs or community members and for other community activities
