## WITNESS FOR WELLNESS: PRELIMINARY FINDINGS FROM A COMMUNITY-ACADEMIC PARTICIPATORY RESEARCH MENTAL HEALTH INITIATIVE

Quality improvement programs promoting depression screening and appropriate treatment can significantly reduce racial and ethnic disparities in mental-health care and outcomes. However, promoting the adoption of quality-improvement strategies requires more than the simple knowledge of their potential benefits. To better understand depression issues in racial and ethnic minority communities and to discover, refine, and promote the adoption of evidence-based interventions in these communities, a collaborative academiccommunity participatory partnership was developed and introduced through a communitybased depression conference. This partnership was based on the community-influenced model used by Healthy African-American Families, a community-based agency in south Los Angeles, and the Partners in Care model developed at the UCLA/RAND NIMH Health Services Research Center. The integrated model is described in this paper as well as the activities and preliminary results based on multimethod program evaluation techniques. We found that combining the two models was feasible. Significant improvements in depression identification, knowledge about treatment options, and availability of treatment providers were observed among conference participants. In addition, the conference reinforced in the participants the importance of community mobilization for addressing depression and mental health issues in the community. Although the project is relatively new and ongoing, already substantial gains in community activities in the area of depression have been observed. In addition, new applications of this integrated model are underway in the areas of diabetes and substance abuse. Continued monitoring of this project should help refine the model as well as assist in the identification of process and outcome measures for such efforts. (Ethn Dis. 2006;16[suppl 1]:S1-18–S1-34)

**Key Words:** Community Capacity Building, Depression, Participatory Research

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#### INTRODUCTION

Depressive disorders are a leading cause of illness and of disability worldwide, including in developed countries such as the United States.<sup>1</sup> Despite the availability of treatments of established efficacy for depressive disorders (ie, antidepressant medications and specific forms of psychotherapy for depression), many people with depression do not receive care that is consistent with national guidelines for appropriate care.<sup>2,3</sup> Rates of appropriate care are particularly low among racial/ethnic minority groups, both in representative household studies and in studies of patients receiving primary care.<sup>2,4-6</sup> Many people with depression receive their only care in primary-care settings.<sup>3,6,7</sup>

Programs that improve the quality of care for depression in primary-care settings, based on the collaborative-care model of chronic disease management, can improve clinical and functional outcomes, including employment status, from 6 to 52 months of follow-up, and are effective for adolescents, adults,

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Address correspondence and reprint requests to Ricky N. Bluthenthal, PhD; Charles R. Drew University of Medicine and Science; 1731 E. 120th Street, Building N; Los Angeles, CA 90059; rickyb@rand. org Rates of appropriate care [for depressive disorders] are particularly low among racial/ ethnic minority groups, both in representative household studies and in studies of patients receiving primary care.<sup>2,4-6</sup>

and the elderly.<sup>8-19</sup> Several such programs yield favorable cost-effectiveness ratios, relative to usual care or to other widely used medical treatments, in some studies among sicker patients or high utilizers of services.<sup>16,20,21</sup> In addition, findings from the Partners in Care study suggest that such programs can reduce or eliminate racial and ethnic disparities in health outcomes for depressed primary-care patients during a 6- to 12month period of program implementation and at five-year follow-up.<sup>4,18</sup> How can such programs become available within historically under-served, racial and ethnic minority communities who might have the most to gain from them? What model of promoting access to such programs is feasible, effective, and culturally appropriate? These questions are particularly salient in light of widespread concerns that social stigma of mental illness reduces access to mental health services, including among racial and ethnic minority groups,<sup>5,22</sup> and that high rates of uninsurance

further limit access to appropriate care within under-served racial and ethnic minority groups.<sup>23–25</sup>

In the face of these challenges, racial and ethnic minority communities have developed community-based service providers, advocacy organizations, and professional networks to improve access and quality of care in their communities. These indigenous organizations are or should be a primary focus of quality improvement efforts since they disproportionately serve the racial and ethnic minority communities that have the most to gain from evidence-based practices. However, involving such groups and communities in evidencebased practice has often been impeded by the "top-down" nature and narrow focus of many evidence-based initiatives.<sup>26,27</sup> One implication of this is that racial and ethnic disparities in health care and outcomes are not likely to improve without engagement and empowerment of racial and ethnic minority service providers and communities.28

In response to this concern, the Witness for Wellness (W4W) project integrated two community development approaches-one an academic and community-based quality improvement trial and the other a community-based partnership model. The academic model drew on the findings and toolkits from the Partners in Care study,<sup>18,19</sup> considered for this purpose as an evidence-based program for reducing racial/ethnic disparities in quality and outcomes of care for depression within primary-care settings. The main project method for exploring how these resources might be used was a community participatory partnership research (CPPR) model, developed through a community-based organization, Healthy African-American Families (HAAF), with funds from the Centers for Disease Control and Prevention (CDC) to address disparities in infant mortality in the south Los Angeles area. Relative to the original version of that HAAF model, the W4W project required more active academic partnering to maintain the evidence-based toolkit and findings as a reference point. Relative to a traditional health services research demonstration, the CPPR approach necessitated greater flexibility in all aspects of program development, research design, and project implementation to achieve community partnership in the research. The blend of research paradigms is similar to the negotiated, participatory research model for developing intervention research described by Wells et al.<sup>29</sup> The W4W project is in some respects a feasibility pilot study of this negotiated approach, with a stronger focus on participatory, partnered program development, implementation, and research.

This paper describes the development of the W4W project up to the formation of community working groups to conduct the main project work and research. A second goal of this paper is to illustrate the research evaluation approach for the project through presenting descriptive data from two conferences held within the project's first six months: a conference about depression and wellness for the community and an orientation meeting to formulate the goals and functions of community-academic working groups. We also discuss what we have learned about the feasibility, acceptability, and potential of the model.

## **METHODS**

We provide a case-study description of the W4W project, a pilot of a community capacity development project jointly initiated by an academic-based program to build on the findings and resources of the Partners in Care study and by a communitybased organization and its community agency network, seeking to extend its model of community mobilization and planning to additional health and healthcare disparity concerns of importance to the community it serves.

#### Healthy African-American Families' (HAAF) Mobilization and Community Planning Model

The community partner and project host for the W4W project is HAAF. This program began as a community advisory board for a University of California-Los Angeles (UCLA) study funded by CDC that, within several years, evolved into a standalone, nonprofit agency aimed at improving the health of African Americans and Latinos in Los Angeles. Since its inception in 1992, HAAF has developed health promotion partnerships with UCLA, Charles R. Drew University of Medicine and Science, the State of California, First 5, and Cedars-Sinai Medical Center among others. Communityplanned and initiated health promotion campaigns that had previously been developed in the areas of substance abuse, preterm birth, asthma, depression, and diabetes are now being implemented.

The HAAF model acknowledges the unique capacity of communities to frame health issues in a language that is likely to resonate with community perspectives, strengths, and resources. A central role is played by HAAF in providing technical assistance through its conferences and planning processes to a wide range of community-based service providers and government agencies at local, state, and federal levels. It also serves as an incubator or holding company for emerging community-based projects and organizations. However, its primary activities involve empowering community members and organizations to take an active role in health promotion, development of innovative interventions, and policy advocacy.

To accomplish these goals, HAAF starts by bringing together academic experts, community-service providers, and members (including gatekeepers, indigenous leaders, and grassroots ex-

perts or community PhDs) to initiate dialogue about a health-related issue. Next, HAAF initiates a community planning process to develop concrete and easy-to-enact action plans for responding to an issue. Their model involves project oversight by a coordinating council that represents key stakeholder agencies pertinent to the health condition and key community gatekeepers who are well connected, respected, and known in the community. The main work of the project is conducted through working groups that collaboratively identify and address different aspects of a health issue. These groups, co-lead by community members and using academic partners for support, collaboration, or consultation, develop separate action plans to mobilize community change around the identified health concern. In collaboration with academic and community partners, HAAF provides community education concerning the science issues underlying the health condition. In addition, HAAF provides training and support for academic participants, helping them to understand community perspectives and participate appropriately in the model.

#### Depression Quality Improvement Model

The academic partners for W4W developed and evaluated quality-improvement programs for depression in primary care, across diverse age, gender, and cultural groups.<sup>4,17,25,29–31</sup> The group followed the multimodel strategy for quality-improvement programs recommended under the collaborativecare approach, which addresses patient, provider, and system-level barriers to providing quality care.<sup>32,33</sup> The central goals in Partners in Care are to support patients and their providers in using clinical services for depression that are consistent with national guidelines, ie, evidence-based psychotherapy for depression and antidepressant medication, while maintaining patient and provider choice of treatments, acknowledging variability across practices in clinical care goals and resource constraints, and assuring the inclusion of under-served populations.<sup>34–38</sup>

After finding that the Partners in Care interventions reduced health outcome disparities,<sup>18</sup> the project leaders explored ways to engage with communities of color in implementing interventions based on the principles and programs in Partners in Care, particularly, the application of CBPR and other community intervention models.<sup>8,25,29</sup>

## Witness for Wellness

The project's goal is to reduce the burden of clinical depression and promote wellness among all racial and ethnic groups residing, working, or conducting other regular activities within historically under-served and predominantly minority communities in Los Angeles, particularly south Los Angeles. While the initial impetus to focus on depression derived from the academic partners, HAAF leaders explored interest in this focus with its community partner network and determined that this was an important if largely unacknowledged priority. Based on this feedback, HAAF hosted a planning meeting in April 2003, involving HAAF staff, leaders of the NIMH UCLA/RAND Center for Research on Quality in Managed Care, the UCLA/ Drew Project Export Center, the UCLA RCMAR Center, RAND Health, and key healthcare and community organization partners of HAAF (for example, Los Angeles Departments of Health Services and Mental Health, Los Angeles Child Guidance, Best Babies Collaborative, California Hospital Medical Center). The interest within this group for a project on depression was high, and a standing Wellness Council (the coordinating council for this effort) was convened to develop the project (a complete timeline of project activities is available at www. witness4wellness.org).

The Wellness Council met weekly for two hours for three months and monthly thereafter. The council was cochaired by the HAAF executive director (Jones) and the UCLA/RAND NIMH Center director (Wells). The council established an executive committee, including key leaders from HAAF and the academic institutions, and approved a motion that all main project components would have academic and community co-chairs.

One of the first activities of the council was to develop the collaborative partnership agreement following HAAF principles. This agreement specifies rights and responsibilities on all participants in the W4W project. The document explicitly builds on community participatory research principles and ensures that both community partners and academic institutions share ownership of data collected and collaboratively participate in research design, data collection, data analysis, interpretation, and write-up and dissemination of project findings. Should disputes or questions arise regarding any issue, the collaborative agreement identifies the Wellness Council as the final arbiter of these matters. The agreement is available on the project website.

An early activity of the council was to share perspectives and views on depression. This activity was stimulated by having council members provide examples and share definitions of depression, by reviewing articles and websites on depression, reading the book Beating Depression, a book for the public about the Partners in Care approach to improving depression care and outcomes,<sup>2</sup> and descriptions of available services and barriers to care from the testimony of local providers, agency directors, consumers, and grassroots community members. These discussions revealed substantial variations in views of depression: researchers and clinicians tended to emphasize a clinical perspective that highlighted diagnoses and treatments, while community members and social service agency providers emphasized how depression was related to stress, community violence, the stigmatization of mental illness, substance abuse, and mood problems in complex, inner city urban life. An example of an important exchange that moved the group toward a shared understanding was reading a letter from a depressed participant in the Partners in Care study and a story shared by a community-service provider of attempting to help a homeless woman with depressive symptoms who was living with her children in her car. This exchange evoked strong emphatic responses across academic and community participants and reminded researchers in particular of the limits of existing evidence-based models for broad community application. Another consequence of such exchanges was the emergence of the importance of a strength-based approach that sought to enhance wellness and celebrate community strengths while addressing underlying sources and consequences of depression in the community.

The first major activity of the Wellness Council was to sponsor a Kick-Off Conference on depression to evaluate and generate interest in using a community approach to addressing depression. In planning the Kickoff Conference, the Wellness Council faced several issues: 1) What were the conference goals? 2) What processes should be used in the conference to achieve them? 3) Who would present the goals to the community? 4) What would be the balance of education/ community engagement activities, and research? 5) What would be the role of the academic and community partners in each aspect of the conference? These questions were addressed through council discussion and votes under Robert's Rules of Order, while fostering an equal voice for academic and community partners by asking each member present to offer an opinion on each major issue. The conference goals that emerged from these discussions were: 1) to demystify the concept of depression and share its importance with the participating communities; 2) to promote sharing of community views of depression, treatment, barriers to care, and ways to improve things; 3) to celebrate community strength and resources; and 4) to determine if broad consensus existed on the desirability of a community-wide project on this topic, and if so to initiate recruitment of interested members.

To promote a research effort within the conference that also reflected the partnership goals, the council established a research committee consisting of community and academic members. A research plan was developed for the conference that included a pre- and post-conference survey and qualitative field notes (referred hereafter to as "scribing") of roundtable discussions at the conference. As described below, the council reviewed the goal of each conference component and the overall goals of the project and iteratively worked with the research committee to develop, review, and modify all survey items and the questions for the roundtable discussions. These efforts were supplemented with presentations and discussions on research methods (ie, one presentation was on constructing culturally appropriate health measures from an expert in item response theory.)<sup>39,40</sup>

The council used several features of the HAAF CPPR model to facilitate group development. Attempts to expand the inclusiveness of council representation were stimulated through questions posed during meetings such as "Who's at the table? Who's not at the table?" Moreover, questions such as "What's cooking?" were used to encourage the group to consider any unspoken concerns that might be troubling the group about the work or process. On occasion, sharing of perspectives and inclusion of less active members was stimulated by asking each council member to respond to key

issues. Rituals were used to develop group identity, stimulate creative thinking, or overcome member isolation or create new alliances among members. One ritual involved members' receiving tags that represented different kinds of people in a community and then speaking from the perspective of that person. Balls of colored yarn were used to illustrate connections among different types of people. Folk stories were used to inspire the group (for example, one African folk story, "Stone Soup," conveyed the message that by working together, the group could generate enough resources to sustain everyone). Such activities were balanced by presentations from key leaders in the community and discussions of research findings and methods.

In addition, individual group members exchanged ideas for consulting across agencies or collaborating in providing services or developing proposals for funding programs. More personal exchanges included suggestions for how academic leaders could fit in better with community culture and requests by individual community group members for explanations of terms commonly used in research.

In July of 2003, the Wellness Council convened the Kick-Off Conference. Healthy African-American families (HAAF) advertised for the conference through its extensive list of community organizations and prior HAAF program participants, coupled with local media coverage. Community interest in the conference was apparent early through higher-than-expected registration, including from sectors of the community, such as representatives of criminal justice agencies, not previously represented in HAAF conferences. More than 500 community members attended the conference, held at the Los Angeles Science Museum. At this conference, community, clinical, and research leaders provided information to participants about depression and its impact on individuals and the community,



Fig 1. Witness for Wellness project logo illustrating goals, principles, guiding pathways

treatments, barriers to treatment, and approaches to improve services delivery. Examples of academic presentations included a review of the findings from Partners in Care and presentations on the biological mechanisms underlying depression during pregnancy. Community presentations included a presentation on services offered through a children's services agency and a description of the salience of depression for participants in the dispute resolution program of the City Attorney's Office. Participants at the conference who were clinicians received continuing medical education credits. Conference participants received a briefing book including key project materials, such as articles, referral sources, and internet websites on depression.

In the second half of the conference, participants broke into small groups of  $\leq 10$  to discuss how the community viewed depression, barriers to treatment, and approaches in the community to improve services or care or build community strength. After these discussions, participants were invited to sign up for an ongoing effort to address issues of depression in the community. Substantial enthusiasm was expressed for the ongoing effort, and >100 participants signed up.

After the conference, the council reviewed its impression of the issues raised during the conference, developed analysis teams to review the Kick-Off Conference survey data, and developed materials to frame the project's themes and structure based on the feedback at the conference. Lead social scientists and community members were identified to facilitate analysis of the quantitative and qualitative data.

The project's name was developed through an iterative process and repre-

sented the desire to emphasize the strength-based model (wellness) and honor the importance of religion as a source of healing and help in the community (witness) that emerged in the conference data. A project logo was developed (see Figure 1). The logo depicts the goal of wellness (the city at the end of the road), with a bus as the key mechanism to get there; the concept is that people can get on or off the bus as they need to as the project proceeds to wellness, which reflects the inclusive and flexible nature of participation in the project. The participatory principles are represented as the fuel for the bus, and a joint academic-community perspective on the goals of research and program development are represented as the road: listen (to community voice and research evidence), observe (develop data strategies and hypotheses), record (collect data and experience and history), and share (communication, media, and publication).

Based on early findings from the qualitative data from the community discussion groups, thematic areas for work group functions were formulated and represented in the logo as sign posts on the way to wellness: Talking Wellness (reducing stigma and building community strength), Building Wellness (services outreach and quality), and Supporting Wellness (policy support and advocacy for vulnerable populations). The logo was designed by a member of the council who leads a community-based market company with expertise in health messages for communities of color.

The Wellness Council convened the working group orientation meeting to build on the enthusiasm generated at the Kick-Off Conference and plan the working group phase of the project. At the orientation meeting, 75 individuals attended, including many who had attended the Kick-Off Conference. The meeting began with presentations co-led by community members and academics on the results from the conference survey and the qualitative analysis of the roundtable discussions data gleaned from the Kick-Off Conference. Participants at the orientation meeting were then split into three working groups (Talking Wellness, Building Wellness, Supporting Wellness) based on count-off assignment (1, 2, 3). This method resulted in groups that had some participants with relatively little background in the assigned area (for example, providing services or developing policies). This strategy drew new perspectives into the discussion and generated broader community interest, in particular, in each group. The discussion groups considered the goals of their assigned area, discussed what those goals might mean in terms of project action plans, and made recommendations for redefining the working group's focus. Each group reported its recommendations, using one to three community and/or academic participants from the group. The full group then discussed the recommendations.

The three thematic areas received broad support, and preliminary action plans were formulated. The plan called for convening three work groups-Talking Wellness, Building Wellness, and Supporting Wellness. The Talking Wellness group seeks to increase depression awareness, reduce stigma around depression, and celebrate community strengths. The Building Wellness group aims to improve depression services, outreach, and overall service quality. The Supporting Wellness group seeks to stimulate policy support and advocacy for better depression awareness and care.

At the conclusion of the orientation meeting, the group supported forming the working groups, and people were asked to indicate their interest in serving through a sign-up list. Participants in the orientation meeting were given a shirt with the project logo on the front and an image of a quilt made from the logos of participating council organizations on the back.

After the orientation meeting, the Wellness Council issued invitations to sign up for work groups to all Kick-Off Conference and orientation meeting participants, and an acting community co-chair (or two) was identified to convene each group, with ongoing leadership to be discussed in the first few group meetings. The Wellness Council recruited academic co-chairs for each working group, but this process took several months and the academic leadership changed over the course of each working group's development; the project's overall academic chair (Wells) served as interim co-chair of groups as needed. The research committee, with Wellness Council approval, developed a plan to evaluate the progress of the working groups through minutes maintained by the groups (typically recorded by HAAF staff) and by field notes taken by trained research assistants, drawn

from UCLA/RAND NIMH and the Drew/UCLA EXPORT centers.

Work groups started meeting in December 2003/January 2004. Each working group was charged with identifying its community leaders, developing a meeting schedule, and developing an action plan. Action plans include goals, methods, and a timeline for activities to accomplish the mission of the group. Community co-chairs were trained in their roles in a seminar at HAAF; academic co-chairs, who joined the project at different points during the project, were individually trained. These action plans were developed during the first half of 2004 through monthly or biweekly meetings of working group members. Working group members were offered a stipend of \$25 for each two-hour meeting, which also included a commitment of an additional one to two hours of work per month outside of group meeting time. Work group leaders reported back at the monthly Wellness Council meetings. Preliminary action plans were vetted with the community twice, once in March to a group of 60 community-based providers, community members, and academics, and again in July at a larger  $(N \approx 200)$  community consensus meeting. The methods for those consensus meetings are described by Patel et al (in this issue).41

Following this consensus meeting, each working group continued to develop the work to fulfill the endorsed plans, including research evaluations of planned programs. The Wellness Council sponsored the development of a project website to collect and host materials, and meetings and communications were facilitated through an internetbased scheduler and contact lists for each group and the project as a whole. Examples of toolkits and products currently being developed and piloted by the working groups include: 1) (Talking Wellness): poetry readings and other media-based presentations within the community around the

themes of depression and community wellness; 2) (Building Wellness): a webbased toolkit for community social service providers and case workers to screen for depression, provide client education, and facilitate referrals to community providers; 3) (Supporting Wellness): participation in a multistakeholder effort in Los Angeles County to develop plans for use of funds for new mental health programs, through the Mental Health Services Act of California. Groups also hosted their own community conferences, including one on listening skills (Talking Wellness and Wellness Council) and policy and advocacy education (Supporting Wellness and Wellness Council).

### METHODS FOR PROJECT EVALUATION

The Wellness Council and research committee have sponsored the collection of a variety of datasets, including self-administered participant surveys at the Kick-Off Conference (in-person) and working group orientation meeting; minutes and other documents developed during Wellness Council and work group meetings; field notes on roundtable discussions at the Kick-Off Conference; group consensus ratings at the orientation meeting; field notes on working group meetings (starting in December 2003 through December 2004); semi-structured, open-ended, qualitative interviews with Wellness Council members (conducted in Fall/ Winter 2004); and data on audience responses to the working group plans at the community consensus meeting in July 2004. In this paper, we use data from minutes and field notes from the council meetings, the self-administered surveys collected at the Kick-Off Conference and working group Orientation meetings, and field notes from the roundtable discussions at the Kick-Off Conference—all of which were attended by most of the authors of this paper.

Methods/Activities	Self-Administered Quantitative Questionnaire	Field Notes	Qualitative Interviews
Wellness Council members and meetings		On meeting discussions and actions	On process, expectations, and outcomes
Kick-Off Conference	Pre- and post- conference survey	From roundtable discussions on depression	
Working group orientation meeting	At beginning of meeting	On process and interactions	
Working group subcommittee meetings		On process and interactions	
Community consensus- building conference	Modified Delphi expert panel method		

Table 1. Summary of evaluation methods by Witness for Wellness activities

Other manuscripts are under development with other data from this project. Table 1 summarizes how activities in the overall project were assessed during the first year.

Development of the self-administered surveys for the Kick-Off Conference and the working group orientation meeting occurred in the following way. Initial questions were developed by the project's evaluation and research committee. These questions were vetted by the Wellness Council members, and substantial changes in items and item responses were made. For instance, one academic wanted conference participants to rank depression as a community problem relative to other prevalent social and health problems in the African-American and Latino communities in Los Angeles. Other academics and community providers argued that such questions would be difficult to efficiently ask and might be difficult to interpret. Instead, items were asked that sought to locate depression as a component of leading social and health problems in the community. In another case, academics wanted to use five-point Likert scales to assess depression knowledge, beliefs, and information. Here community providers argued that such an approach was needlessly complicated, and so "agree" and "disagree" response options were used. Many other substantive and formatting changes were requested and incorporated into the

ultimate content and form of the surveys. Cultural appropriateness of questions and reading level were major concerns of the Wellness Council and led to substantially shortening the number of items and simplifying wording. In short, survey domains and items reflected the consensus of both academic and community judgments on how best to assess key concepts for the conferences. Table 2 summarizes the domains assessed in the two self-administered surveys.

At the Kick-Off Conference each participant received a pre-and postconference survey that included substantive items on depression knowledge and information, as well as basic demographic information. On the conference agenda, time was set aside to fill out both the pre-conference survey and the post-conference survey. Participants were asked to turn in both surveys as they exited the venue. More than 500 community members, project participants, and conference staff attended some part of the Kick-Off Conference; 370 surveys were returned, of which 265 included pre-conference responses and 274 included post-conference responses. One hundred and sixty-eight surveys included both pre- and postconference responses. Demographic information was collected on a separate form, and 251 participants returned this survey. Tables 3 and 4 summarize results from these surveys.

At the roundtable discussions, participants were asked to respond to four questions: "What does depression look like?"; "Whose business is it anyway?"; "Why is it so hard to talk about?"; and "Who can help?" Volunteers from HAAF, UCLA, Drew, and RAND completed at least one two-hour session in note-taking, lead by a senior anthropologist. Scribe training was consistent with an introduction to qualitative field observation and note-taking. Trainees were instructed on techniques of rapid transcribing as well as methods of identifying crucial moments and exchanges between participants. At the conference, each scribe was assigned to 1 of the 50 roundtable discussions. Notes on participants' responses and reactions to the four questions (each group was asked to address at least three of four questions), as well as ensuing discussion, were taken long hand on a semistructured form or typed into an electronic version of the form if the scribe had a laptop computer. The scribes spent an additional one to three hours completing the notes after the conference. These notes were collected by the evaluation team and transcribed, as needed, into electronic documents for data analysis. Notes varied in length and richness; a few were quite short and others were pages long.

The working group orientation conference focused on expectations, volunteer's skills, support needs, individual and community self-efficacy, as well as brief assessment of depression-care needs. Specific items and results are summarized in Tables 5 and 6; demographics of working group orientation participants are provide in Table 3. Approximately 75 people attended all or part of the working group orientation meeting, of whom 63 completed the survey at the beginning of the meeting and provided the evaluation team with locator information.

Data analyses for this paper consist of descriptive statistics (frequencies, percentages) on the demographic char 
 Table 2.
 Summary of items and domains included in the Kick-Off Conference preand post-surveys and the working group orientation meeting

Domains	Items	Kick-Off Conference	Working Group Orientation Meeting
Demographics	5	Х	Х
Depression knowledge	14	Х	
Self-rate depression knowledge	1	Х	
Depression information	4	Х	
Community's role in addressing depression	10	Х	
Depression's connection to other problems	3	Х	
Skills sets in advocacy, research, leadership	14		Х
Civic participation	8		Х
Individual and community self-efficacy	7		Х
Expectations of wellness project	9		Х
Needs to sustain participation	8		Х
Barriers to treatment depression	9		Х

 Table 3. Demographic characteristics of working group orientation participants

 and Kick-Off conference participants

	Working Group Orientation (N=63) % (n)	Kick-Off (N=262) % (n)
Sex		
Male	19.0% (12)	11.5% (30)
Female	79.4% (50)	88.5% (232)
Age		
<25	9.5% (6)	8.4% (22)
25–34	14.3% (9)	29.0% (76)
35–44	25.4% (16)	23.3% (61)
45–54	28.6% (18)	24.4% (64)
55–64	11.1% (7)	11.8% (31)
≥65	7.9% (5)	3.1% (7)
Education		
<high school<="" td=""><td>1.6% (1)</td><td>0.8% (2)</td></high>	1.6% (1)	0.8% (2)
High school diploma/general equivalency degree	9.5% (6)	16.1% (42)
Associate degree	11.1% (7)	17.6% (46)
Bachelor of Arts degree	25.4% (16)	32.6% (85)
Masters degree	30.2% (19)	26.4% (69)
Doctoral degree	19.0% (12)	6.5% (17)
Race/ethnicity		
Black	55.6% (35)	51.8% (89)
White	20.6% (13)	14.5% (25)
Hispanic/Latino	15.9% (10)	25.0% (43)
Other*	8.0% (5)	8.7% (15)
Community/professional affiliation		
Community-based agency	50.0% (31)	52.4% (132)
Government	11.3% (7)	15.5% (39)
Academic	19.4% (12)	7.1% (18)
Medical	14.5% (9)	18.6% (47)
Community	1.6% (1)	3.6% (9)
Faith-based professional	1.6% (1)	
Volunteer	1.6% (1)	2.8(7)

\* For group orientation, "other" includes Native American (2), Korean (1), and Filipino (2), while for the Kick-Off Conference, "other" includes Asian Indian (1), Japanese (1), Chinese (1), Korean (1), Pacific Islander (1), and other (10).

#### Table 4. Changes in self-reported knowledge, perceptions, and opinions

	( <b>T</b> , <b>F</b> )†	Completed Pre or Post (N=370)		Completed Pre and Post (N=168)			
		Pre- Conference %	Post- Conference %	Pre- Conference %	Post- Conference %	- Statistic*	P Value
Knowledge items (% correct response)							
People of color hardly ever become depressed							
enough to need professional help.	F	93.5%	90.4%	92.2%	90.4%	.31	.578
Feeling tired all the time and having sleep							
problems are common signs of depression.	Т	84.4%	94.5%	86.1%	92.8%	3.46	.063
People should be able to talk themselves out of							
feeling discouraged, down-hearted, and blue.	F	70.2%	75.7%	70.3%	75.4%	1.21	.272
Depression is a medical illness that affects how							
people feel, think, and function.	Т	92.0%	94.9%	91.6%	95.8%	2.58	.108
In general, it's better to keep sad feelings to							
yourself.	F	95.4%	96.3%	95.2%	95.8%	.07	.796
Using drugs and alcohol can be one way							
people try to cope with depression.	Т	67.3%	77.9%	68.1%	79.5%	5.73	.017
Most of the time, medical providers know if							
their patients have depression.	F	72.7%	81.7%	73.7%	82.0%	3.69	.055
Depression can cause someone to have							
trouble finding work or keeping a job.	Т	95.0%	98.9%	95.1%	98.8%	4.50	.034
People with severe depression may need							
medications to help them get back to feeling							
normal.	Т	89.3%	97.4%	88.0%	97.0%	13.24	<.001
For most people, counseling is as effective as							
medication in treating depression.	Т	64.1%	84.4%	61.0%	84.8%	20.63	<.001
Depression caused by severe stress, such as							
being homeless or witnessing violence, does							
not usually improve with treatment.	F	62.6%	66.9%	63.0%	67.0%	.12	.725
Lack of health insurance is one of the most							
important barriers to getting good care in	-			/			
communities of color.	Т	85.0%	93.0%	86.1%	90.9%	1.20	.273
Children rarely get depressed.	F	86.2%	90.0%	86.1%	87.1%	.11	.746
Risk taking can be a sign of depression.	Т	73.2%	89.5%	75.5%	90.8%	10.52	.001
Self-rated knowledge of depression		22.00/	4.6.40/	20 50/	1.5 10/		
-low		32.8%	16.1%	30.5%	16.4%		
-moderate		46.2%	54.8%	48.1%	56.6%	0.40	004
-high		21.0%	29.1%	21.4%	27.0%	9.42	.024
Perceptions and opinions (% agree)							
If I, or a loved one get depressed, I know							
where to go from professional help.		71.6%	88.8%	70.4%	89.6%	18.84	<.001
Someone I know is depressed enough to need		, 110,0	0010/0	, 011,0	031070	10101	
treatment.		62.5%	73.6%	60.0%	76.7%	7.72	.006
Listening to someone else talk about their			, .		, .		
depression makes me depressed.		59.1%	52.6%	61.7%	50.6%	2.58	.108
In our community, it is difficult for people with			,		,		
depression to find professional help.		12.2%	17.5%	11.5%	19.0%	2.78	.096
Depression is a community problem that we							
can do something about.		82.0%	96.0%	78.9%	95.8%	19.60	<.001
I feel hopeful that our community can make							
progress on improving access to care for							
clinical depression.		87.4%	89.0%	86.7%	90.4%	1.20	.273
Compared to other health problems facing our community like cancer or diabetes,							
depression is just not a top priority.		56.3%	53.9%	58.1%	53.7%	.49	.486
Depression is connected to violence		89.3%	93.7%	89.0%	93.3%	1.96	.162
Depression is connected to unemployment		93.8%	97.0%	94.3%	97.0%	1.14	.285
Depression is connected to school drop-out		80.2%	90.2%	81.9%	91.3%	5.16	.023
Depression is connected to malnutrition		72.2%	76.3%	69.4%	77.5%	4.57	.033
Depression is connected to traffic congestion		36.4%	50.6%	35.7%	51.7%	5.06	.024

	( <b>T</b> , <b>F</b> )†	Completed Pre or Post (N=370)		Completed Pre and Post (N=168)			
		Pre- Conference %	Post- Conference %	Pre- Conference %	Post- Conference %	Statistic*	P Value
Depression is connected to low birth weight							
babies		64.6%	74.7%	66.9%	75.8%	2.57	.109
Depression is connected to homelessness		93.8%	95.5%	93.5%	95.0%	.25	.617
Depression is connected to alcohol and drug							
abuse		96.7%	96.6%	96.2%	96.9%	.40	.527
Depression is connected to police brutality		71.5%	81.7%	75.0%	81.7%	1.79	.181
Depression is connected to crime		87.9%	91.4%	88.2%	90.8%	.53	.465

#### Table 4. Continued

\* McNemar statistics for 2×2 tables and Bowker statistics for tables with more than two response categories.

† T=correct response is true; F=correct response is false.

acteristics of Kick-Off conference and working group orientation participants, changes in pre- and post-conference knowledge and attitudes from the Kick-Off Conference, and percentages and frequencies of working group participants who were involved in previous HAAF efforts, civic life in general, and similar social activities. On the knowledge items from the Kick-Off Conference, McNemar statistics for  $2 \times 2$  tables were used for items with two response categories and Bowker statistical test was used for items with more than two response categories.<sup>42,43</sup> Statistical differences with P value  $\leq 0.05$  were considered significant.

We also conducted a thematic analysis of roundtable discussion notes by using an inductive coding technique.<sup>44,45</sup> These data analyses were accomplished in a team fashion; training and oversight was provided by an anthropologist, and most of the coding was conducted by project volunteers. Summaries of findings related to the four questions are presented in the results section.

All research activities were reviewed and approved by the human subject protection committees at Charles R. Drew University of Medicine and Science, RAND, and UCLA. Verbal informed consent, as approved by the review committees, was obtained at the Kick-Off Conference for both the selfadministered surveys and the notes taken from the roundtable discussion. Written informed consent and locating information were collected from working group orientation meeting participants. We encountered no active refusals to participate at either activity, although informal refusal (not completing or turning in self-administered questionnaires) varied from  $\approx 30\%$  at the Kick-Off Conference to 15% at the working group orientation meeting. In terms of response rates on questionnaires, few data were missing except for the race/ethnicity item on the Kick-Off Conference survey; 30% of participants did not answer this item. This same item on the working group orientation survey was completed by all the respondents who returned the survey.

#### RESULTS

### Kick-Off Conference Survey Results

Our approach was to use the Kick-Off Conference surveys to capture data about community knowledge and information about depression and its role in larger community issues. Of those who completed the Kick-Off Conference demographic survey (Table 3), most were female (88.5%), aged 25 to 54 (76.7%), had at least a bachelor'slevel degree (65.5%), were African-American (51.8%), and were affiliated with a community-based service provider (52.4%). These proportions vary little from what was observed among working group orientation participants. In short, both the conference and orientation meeting participants appeared to be well educated and involved in community-service provision.

Table 4 (right four columns) presents results for the cohort (n=168) of conference participants who completed both the pre- and post-conference survey. Results for the complete preand post-conference sample (n=370)are presented in the left two columns. Findings are qualitatively similar whether we consider the full pre- and postsamples or just the cohort sample. Looking at the cohort data, conference participants were significantly more likely to give correct or improved responses on the following knowledge items after the conference: using drugs and alcohol is one way that people cope with depression; depression can cause someone to have trouble keeping or finding work; people with severe depression may need medications to feel normal; for most people, counseling is as effective as medications; risk taking is a sign of depression; and their self-rated knowledge increased. In terms of perceptions, significantly more participants reported knowing where to get help if a loved one had depression, knowing a depressed person, and thinking that depression is a problem that the community can address. Lastly, depression

## Table 5. Leadership background, civic participation, and individual and community efficacy of working group orientation participants (N=63)

	% ( <b>n</b> )
Leadership, advocacy, and research background (yes)	
Leadership training program	39.7% (25)
Leadership position in community	30.2% (19)
Leadership/management position in my job	49.2% (31)
Consumer advocate experience	23.8% (15)
Policy advocate experience	22.2% (14)
Media advocacy experience	17.5% (11)
Management/budget/personnel training	23.8% (15)
Management/budget/personnel experience	33.3% (21)
Self-study	42.9% (27)
Research training/conferences/coursework	55.6% (35)
Investigator in research study	23.8% (15)
Participant in research study	34.9% (22)
Client/patient service provider	57.1% (36)
Community leadership/planning experience	47.6% (30)
Civic Participation (yes, in the last 12 months)	
Have you participated in other HAAF projects?	41.3% (26)
Have you participated in other community-based projects?	60.3% (38)
Have you participated in other research projects?	31.7% (20)
Did you vote in the last election?	88.9% (56)
Have you contacted a political official by mail, phone, or email?	49.2% (31)
Have you signed a petition related to a political cause?	63.5% (40)
Have you campaigned for a political candidate?	15.9% (10)
Have you contacted a public official to report a community or neighborhood	
problem?	41.3% (26)
Have you ever participated in a community or political protest?	46.6% (27)
Individual and community efficacy (strongly or somewhat agree)	
I have control over the decisions that affect my life	96.8% (61)
I am satisfied with the amount of control I have over decisions that affect my life	79.0% (49)
I can influence decisions that affect my community	77.4% (48)
I am satisfied with the amount of influence I have over decisions that affect my	
community	44.3% (27)
My community has influence over decisions that affect my life	71.0% (44)
By working together, people in my community can influence decisions that affect	
the community	98.4% (61)
People in my community work together to influence decisions on the state or	/
national level	70.9% (44)
	. ,

was regarded as connected to many of the most significant community problems. Statistically significant increases in the connection of depression to school dropout, malnutrition, and traffic congestion were found.

# Qualitative Results from the Kick-Off Conference

In response to the first question— "What does depression look like?" participants provided rich descriptions of behaviors and thoughts associated with depression. These descriptions were related to three key themesinvisibility, behaviors, and feelings. Examples of their phrases used to describe depression included, "It's invisible," "It's the quiet monster," "It has no face." Longer statements on this theme included the following:

"Depression is shapeless yet oppressive, colorless yet opaque, weightless yet able to crush, ageless."

"It's like an iceberg that shows very little on the surface, but it's huge underneath."

"Depression looks different. It has no pattern. People can hide and mask this feeling." "Anybody can be depressed and not know it or no one being able to detect it."

Behaviors that conference participants identified as related to depression were varied and sometimes contradictory, including anger, irritability, lack of control, suicidal inclination, lethargy, appetite changes, risk taking, substance abuse, social isolation, crying, and hyperactivity. Disorder was also noted as a behavior associated with depression, as was its cumulative effects on people's lives.

"I had a patient that would not take care of herself and her children. Her place was a mess. Her life was out of order. I realized that maybe this person was depressed."

"Depression is the hardest and easiest thing to pile up. Keep it to yourself; what is said in the house stays in the house."

Feelings that the participants noted as associated with depression were also wide ranging. Participants offered the following characterizations:

"Sadness, quietness, seclusion from others, poor decision making, day dreaming or being in a daze, confusion, a lot of crying, covering up depression by being too emotional." "Loss of memory. Feeling that you have nowhere to go. Caught, like no way out."

These evocative descriptions suggest that from the perspectives of conference participants, depression can be difficult to detect and extremely disabling.

Related to the questions of who is responsible for addressing depression, the key theme was that individuals and the community must take responsibility for "beating" depression. As such, participants stressed the importance of educating the community on available services and increasing their awareness about available helping professionals. Similar to what we found in the quantitative survey, these participants

## Table 6. Expectations, needs to sustain participation, and barriers to depression treatment among working group orientation participants (n=63)

	Percent (n)
Expectations (Agree)	
The community will go forward to develop wellness	85.7% (54)
New relationships will be developed	81.0% (51)
Very little will change	3.2% (2)
I will develop my career/skills	55.6% (35)
My organization will develop an effective program	41.3% (26)
Harm will come to the community	3.2% (2)
My agency will develop new relationships and collaborations	74.6% (47)
It will make me a more effective community advocate	82.5% (52)
It will change the way I do my own work	66.7% (42)
Needs to sustain participation (Yes)	
Money/pay for my time	22.2% (14)
Leadership training	52.4% (33)
Healthcare/depression education	57.1% (36)
Skill development	55.6% (35)
Certification as a health worker	31.7% (20)
My employer agreeing that it is within my job scope to do this	39.7% (25)
Making a difference in people's lives	82.5% (52)
Making a difference for my community	81.0% (51)
Barriers for seeking depression treatment (agree)	
Don't know they are depressed	82.5% (52)
Don't want the stigma of a mental illness	90.5% (57)
Don't want to jeopardize their job	90.5% (57)
Don't have access to treatment	81.0% (51)
Can't get time off from work to get treatment	72.6% (45)
Don't want to worry their family or friends	84.1% (45)
Don't believe treatment will work	74.6% (47)
Don't have the money or insurance to cover treatment	87.3% (55)

felt that personal and community resources and investments are needed for dealing with depression.

"It's a personal concern and a community concern. It's everyone's business." "It takes a village.... We are all in it together. We should all care about the functioning of society.... I think it's everybody's concern."

But, participants acknowledged a lack of information about where to access care.

"I think we don't know where our resources are and we don't use them." "It's important for me to know that there are people who can help me and that I'm not alone."

"We need more services. Los Angeles Unified School District needs to be aware of these issues. The kids need to know that they can go to their teachers for help about their environment, their isolation."

Participants were also asked "Why is it so hard to talk about depression?" Several themes were identified in response to this question, including the normalization of depression, cultural beliefs about what being depressed means, including the stigma of mental illness, and lack of education about depression. Participants indicated that the chronic nature of depression, its invisibility, and links to poverty, environment, behavior, and even racism hindered acknowledging depression separately as its own problem. For example, participants noted that distinguishing depression from general malaise was often difficult because of important and widely acknowledged social, economic, and environmental problems.

"Poverty blots out depression as a significant experience."

"They have been so depressed for so long, folks think it is part of their personality."

"There is a fear of the dominant culture's solution to our problem."

In addition, because of cultural beliefs and norms (among African Americans), participants reported that people did not want to be labeled as depressed because a core cultural value was to "pull yourself up by your bootstraps." Participants noted that one of the reasons their community had difficulty talking about depression was that those living with illness did not want to be labeled as "crazy," "weak," "a burden," "unable to function," or as "not being spiritual enough."

These issues were compounded by concerns about the social stigma of mental illness and potential discrimination. Indeed, as one participant reported,

"[A mother] would rather have her son be seen as a substance abuser and be booked on a crime than be labeled as mentally ill."

Beyond the concern that a diagnosis of depression "goes on your personnel file at work," participants also feared ostracization.

"Someone may be labeled crazy: people may not want to work with them because of their mental problems."

Providing education on depression was seen as an important component to addressing depression problems in the community. People need to learn about the underlying contributors to depression and allow for real discussions and community empowerment. As one participant put it, "We need to demystify depression as a community."

Lastly, participants were asked who could help. Using simple pile-sorting techniques, we counted the instances that participants identified relatives, social intimates, medical professionals,



... a partnership approach to developing and implementing research within the project resulted in the collection of multiple qualitative and quantitative datasets and a partnered approach to data analysis and presentation.

Fig 2. Sources for help identified by participants

mental health professionals, spiritual/ religious professionals, media/advertising, and community as a source of help. Figure 2 summarizes these findings. The most frequently cited source of help was community, followed by social intimates and mental-health professionals. Lower percentages of participants identified relatives, medical professionals, and spiritual/religious figures as sources of assistance for depression. Key attributes of potential sources of help were: trustworthy, nonjudgmental, attentive, rightness, comfortable, open-minded, inviting, closeness, health connection, good listener, heartfelt.

In summary, the Kick-Off Conference attracted a diverse, educated group of service providers, medical professionals, government officials, and academic officials. At the conference, increases in depression knowledge and information related to symptoms (such as risk taking, drug and alcohol use), options for treatment (including counseling), and where to get treatment were observed. In addition, growing certainty was noted in the capacity of community to contribute to treatment of depression. Finally, rich descriptions were provided through the roundtable discussions about how depression is perceived, who is responsible for addressing depression, and what the community and individuals need to address this problem.

#### Working Group Meeting Survey Results

The demographics of the participants in the working group orientation (Table 3) were similar to those from the Kick-Off Conference. Participants possessed a range of service provision, leadership, advocacy, and research experiences and training; more than half had experience as a service provider and some course work and/or training in research (Table 5). Nearly half also had experience as a manager in an agency or in community leadership and planning. Specific civic activities that many group members had been involved in included both HAAF and other communitybased agency projects in the last 12 months. High rates of voting (89%), signing policy related petitions (64%), and contacting public officials (49%) were also reported. In terms of individual and community self-efficacy, high perceived control over individual lives was reported, as was confidence that by working together the community could influence important decision making related to its concerns. However, perceived individual capacity to influence decisions that affect the community was lower.

Regarding expectations and needs to sustain participation (Table 6), high percentages of working group participants thought community health and advocacy and new relationships between individuals and agencies would be formed through the project. Very few (3.2%) felt that little would be changed or that the community might actually be harmed by the project. In terms of sustaining participation, a key motivation for participants was the capacity of the project to affect individuals and communities. In the course of participating, working group orientation members wanted to receive education, leadership training, and skills.

Finally, we assessed barriers to depression care and treatment. All of the barriers listed were endorsed by  $\geq$ 70% of participants. Most regarded stigma and job loss as the most significant barriers to receiving treatment for depression.

## DISCUSSION

We initiated a community capacitydevelopment program on depression and wellness based on a blended approach that used findings and resources from an evidence-based approach to quality improvement and a community participatory partnership research model developed by a lead community agency. Overall, the project can be viewed as a pilot for a public health social movement, which has become an important paradigm for communitybuilding projects in health.<sup>46</sup> Over a six-month period of development of the W4W project, substantial progress was made in developing a planning and governing council, convening a Kick-Off Conference to engage the community, hosting an orientation conference to develop a strategy for working groups, developing those groups, and formulating the project's name, logo, and a strong academic-community partnership across multiple academic and community institutions. Key to the overall project success in pursuing these goals was the leadership, credibility, and cultural expertise of HAAF, coupled with the scientific and clinical credibility and experience of the academic and community-service delivery partners. In addition, a partnership approach to developing and implementing research within the project resulted in the collection of multiple qualitative and quantitative datasets and a partnered approach to data analysis and presentation. In the year after the progress described in this article, for example, joint community-academic presentations occurred at a CBPR conference in Oregon, the annual meetings of Academy Health (2004), the American Association of Public Health (2003 and 2004), the Institute of Medicine (2003), the NIMH/NIDA/NIAA health services research conference (2004), and the Robert Wood Johnson Clinical Scholars Program (2004).

The project identified and excited a cadre of experienced community service providers, academics, and government officials who were committed to the notion that the community was capable of improving depression-related health outcomes. The community component of this project also appeared to be particularly vital; most participants at both conferences were service providers. These participants reported substantial advocacy and political involvement and represent a promising start. Across the various affiliations and for both the conference and the orientation meeting, most participants were African American. A goal of the project was to stimulate such leadership development within this community related to reducing the burden of depression on the community.

The research data from the conferences helped accomplish several goals. The information provided the Wellness Council and interested community members with baseline information on knowledge of depression in the community. In addition, the findings suggest that the Kick-Off Conference improved information and knowledge about depression symptoms, treatment options, treatment access, and confidence that the community can contribute to a solution to depression access and treatment. In addition, qualitative data provided the project with knowledge of community members' framing of depression and with specific language and strategies to be used in developing work group action plans.

The project's development shifted the goals of both the academic and community leaders who initiated the project. The goals of disseminating the Partners in Care findings and approach<sup>18</sup> evolved into goals of enabling community-derived strategies to improve depression care and support wellness, informed as appropriate by the experience and methods of Partners in Care and other evidence-based programs. The goals of HAAF leaders may have shifted less, but the methods used by HAAF have become more consistently integrated with research and evaluation, and the partnership strategies became more explicitly documented, facilitating their use and replication in other projects. For example, HAAF is currently sponsoring a diabetes initiative that uses the partnership agreement documents and the evaluation approaches developed for the W4W Kick-off Conference.

The relatively rapid development of this project was greatly facilitated by HAAF's unique position in the community and the availability of flexible funds to develop the program and research from collaborating NIH research centers. In particular, HAAF is not a traditional community-based health provider and does not regularly compete for federal, state, or local funding to provide healthcare services of any kind. Instead, it operates as a facilitator and technical assistance agency for providers in a wide range of heath areas, including substance abuse, diabetes, asthma, pregnancy, and in this case, depression and mental health. This role as a facilitator permits HAAF to bring together large numbers of community members, service providers, and government officials in a trusting environment. Further, HAAF, which began as a university-based intervention agency, has maintained strong relationships with local universities that has enabled it to easily recruit leading scientists to present at its topical health conferences. In addition, key personnel at HAAF have long histories of participation in key local institutions including the school district and schools, health department, churches, and businesses.

As to the advantages of co-sponsorship across NIH centers, a project of this scope required  $\geq$  \$250,000 in development funds in the first year alone, half of which was transferred to community agencies and members to support their activities. As an action research project with evolving goals, processes, and participants, the scope of funding required could not be fully anticipated at the outset, and resources had to be identified quickly for program development and research as new activities arose. The formation of the Community Health Improvement Collaborative initiative (Wells et al, in this issue)<sup>47</sup> permitted considerable flexibility and responsiveness in terms of pilot funds. The extraordinary generosity of community members, in terms of time

commitments and creativity, also facilitated the project's scope. Community volunteers devoted hours to assembling conference and orientation meeting notebooks that were provided to each participant, for example.

Enabling factors on the academic side included extensive experience of mid-level-to-senior project investigators in working with community groups and conducting research on mental-health and substance-abuse issues.<sup>2,24,29,48–54</sup> Over time, the executive committee and Wellness Council were successful in recruiting diverse clinical and social scientists across the range of stages of academic development (from fellows to full professors), offering stability and scientific diversity to the project. The diversity of participating communityservice agencies, greatly facilitated consideration of community needs and resources within the project and also enabled identification of and response to needs of individual project participants when such needs became apparent during or after group meetings.

The project has used most of the core principles and encountered many of the challenges inherent to the CBPR method, as described by others.<sup>55–59</sup> For example, following the framework of Israel et al,<sup>60</sup> the project recognized the importance of the community as a unit of identity and struggled in its discussions and approaches with various definitions of the target communities. Consistent with a CBPR framework, the project attempted to build on the strengths and resources of the community; over time the academic participants have learned about and directly experienced these strengths. Further, the collaborative partnership approach described by Israel et al<sup>60</sup> is reflected in the project's written partnership agreement as well as in its leadership structure. The CBPR principle of integrating knowledge and action for mutual benefit of all partners has been an important if sometimes elusive goal, given different meanings of knowledge and action for

different participants. Yet the search for common understandings has promoted the co-learning process central to a CBPR approach, and HAAF has provided for the growth of the community's leadership and for consistent attention to social inequities and their role in both the community and the project.

Israel et al<sup>60</sup> also describe a cyclical and iterative process of partnership development and maintenance, assessment, use of data analysis, and dissemination to achieve longer range goals. This project has initiated such a cycle, but the project leaders and in particular the authors of this paper were often both enriched and overwhelmed by attending to the diverse programmatic, interpersonal/social, and scientific implications of different components of this cycle. For example, it can be daunting to attend group meetings, plan programs and research, and find funds to support community and academic infrastructures for a project of this scope developing over the course of a few months. Despite the advantages of the NIH centers for flexible funding, the limited funds given the scope have required consistent attention to balancing multiple priorities.

Israel et al<sup>60</sup> also noted the importance of a strength-based model and of an ecological perspective that addresses multiple stakeholders and layers of influence on health concerns. We have, even through the project title, attempted to instill a strength-based approach and struggled to achieve that focus, given this project's focus on a stigmatized condition in communities already at risk for stigma and discrimination based on race, ethnicity, and often socioeconomic disadvantage. In that regard, the project has relied heavily on the participation of service-provider agencies and consumer advocates from the community who have brought dignity and wisdom to the discussion of these issues.

Despite initial successes in initiating the project, our work to date has limitations. First, we have been more

successful in engaging African Americans than other racial and ethnic groups. Second, the project initially was most successful in engaging relatively highly educated, community-service providers. As the project develops, we wish to incorporate a stronger focus on inclusion of grassroots community members; indeed, the work groups at the time of this writing have made much progress in this regard. Third, our research has largely focused on the process of project development and describing participants and their responses to programs sponsored by the project. As described elsewhere in this issue,<sup>61</sup> we have been developing programs that examine the effects of some action plans developed within the project more broadly in the community, but we have not yet had the resources to develop a rigorous evaluation of the project's overall impact-for example, relative to other communities within Los Angeles-or programs similarly structured for other disparity issues. Finally, the authors of this article cannot claim objectivity from the process, nor do we want to do so; we are all research participants within the project. This lack of objectivity suggests that research reports from the project, even when following rigorous research designs, cannot impart conclusions from the more traditional positivist orientation to knowledge that assumes an impartial perspective. Instead, the project reports are inherently closer to a participatory inquiry or a paradigm that honors and integrates both a traditional research approach and participatory inquiry.<sup>62,63</sup>

In the future, we plan to provide regular updates on the progress of this initiative, which like the relevant articles in this issue, provide a view of the work of the project from multiple perspectives and use a range of paradigms to share the lessons we have learned.

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