

THE BUILDING WELLNESS PROJECT: A CASE HISTORY OF PARTNERSHIP, POWER SHARING, AND COMPROMISE

Introduction: The Institute of Medicine has recommended development of community-focused strategies to alleviate the disproportionate burden of illness on minorities, including depression. So far, limited data exist on the process of developing such partnerships within diverse racial/ethnic environments as they strive to develop community-driven, evidence-based action plans to improve the quality of outreach services. We describe such an effort around depression in south Los Angeles and explore the issues of the process in the hopes of informing future partnership development.

Methods: Community meetings, presentations, feedback, discussion groups, and consensus-based action items were implemented over an 18-month period. A writing subcommittee was designated to develop a description of the group's work and process, as well as the diverse perspectives in the partnership. Data sources included meeting minutes, materials for members and community feedback presentations, scribe notes, and the reflections of the authors.

Results: Development was seen on the formal group level, in the process, and on the realization of three categories of action plans. Designed to assist social service caseworkers in the recognition of and referral for depression, the action plans included developing a website, a tool kit (modified Delphi process), and a one-page depression "fact sheet" with region-specific referrals.

Conclusion: Through the process of developing a means to combat depression in a racially/ethnically diverse population, the community is not only better informed about depression but has become a true partner with the academic element in adapting these programs for local service providers, resulting in improved understanding of the partnership process. (*Ethn Dis.* 2006;16[suppl 1]:S1-54-S1-66)

Key Words: Case Study, Community Partnered Participatory Research (CPPR), Compromise, Depression, Partnership, Power Sharing, Provider Resources

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INTRODUCTION

Although ethnic/racial disparities in health care have existed for as long as we have measured the health of ethnic/racial minority groups, only in recent history has a public outcry of concerns been raised among policymakers, providers, and community leaders about the quality of and access to medical care for ethnic/racial minority populations in the United States. In 2002, the Institute of Medicine (IOM) published a report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, which concluded, through a review of more than 100 studies, that minorities who have the same income, insurance coverage, and medical conditions as White non-Hispanics in the United States receive decidedly poorer care. According to the report, when socio-cultural differences between patient and provider are not appreciated, explored, understood, or communicated in the medical encounter, the result is patient dissatisfaction, poor adherence, poorer health outcomes, and racial/ethnic disparities in care.¹ Three years earlier, a supplement to the Surgeon General's report on mental health had reported that depression is higher in low-income populations across the nation.² The IOM's recommendations called for the development of new, community-focused intervention strategies to alleviate

the disproportionate burden of illness, including the burden of mental health conditions such as depression, on minorities and particularly those with lower incomes.

Data from multisite studies of efforts to improve primary care for depression and address the equity issues outlined by the IOM, such as Partners in Care (PIC) and IMPACT (Improving Mood-Promoting Access to Collaborative Treatment), are promising. Miranda et al found that, with only modest accommodations for minority patients, implementation of quality improvement interventions can improve quality of care for both White non-Hispanics and under-served minorities, with the latter especially likely to benefit clinically.³ Wells et al found that similar quality improvement programs can improve long-term health outcomes and equity even five years after implementation.⁴ Yet while these programs may be encouraging as demonstrations, historically under-served minority groups in US communities remain at high risk for unmet need as depressive disorders continue to be widely underrecognized and undertreated.⁵

The IOM has specified that for quality improvement programs to fully integrate culturally specific needs into services for at-risk communities, efforts should promote partnership and should involve substantial public participation. Broad public health efforts, such as National Depression Screening Day (NDSD), which integrates traditional models for quality services into community settings to improve depression recognition and linkages to treatment, have been instituted. Yet these programs have not explored the role of under-

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Witness for Wellness (W4W) strives to achieve its goal by combining principles from evidence-based research with community expertise and direction⁶ and by executing its collaborative agenda through an increasingly balanced academic-community partnership . . .

served communities in generating, as well as disseminating, programs and research in their own best interests. That is, while many quality improvement programs are located in the community, they are rarely driven or framed by community priorities.

Witness for Wellness (W4W) is a community-led, multistakeholder, academic-community partnership initiative, which aims to address the apparent disconnect between the potential benefits of quality improvement interventions for depression and the actual care that the historically under-served minority communities in Los Angeles receive. Witness for Wellness (W4W) strives to achieve its goal by combining principles from evidence-based research with community expertise and direction⁶ and by executing its collaborative agenda through an increasingly balanced academic-community partnership, referred to by W4W partners as the community-partnered participatory research (CPPR) approach. Perhaps best described as a variation of the more established community-based participatory research (CBPR) model,⁷⁻⁹ CPPR focuses on expanding and clarifying what Minkler and Wallerstein have named a core issue for CBPR advocates today: “the meaning and reality of

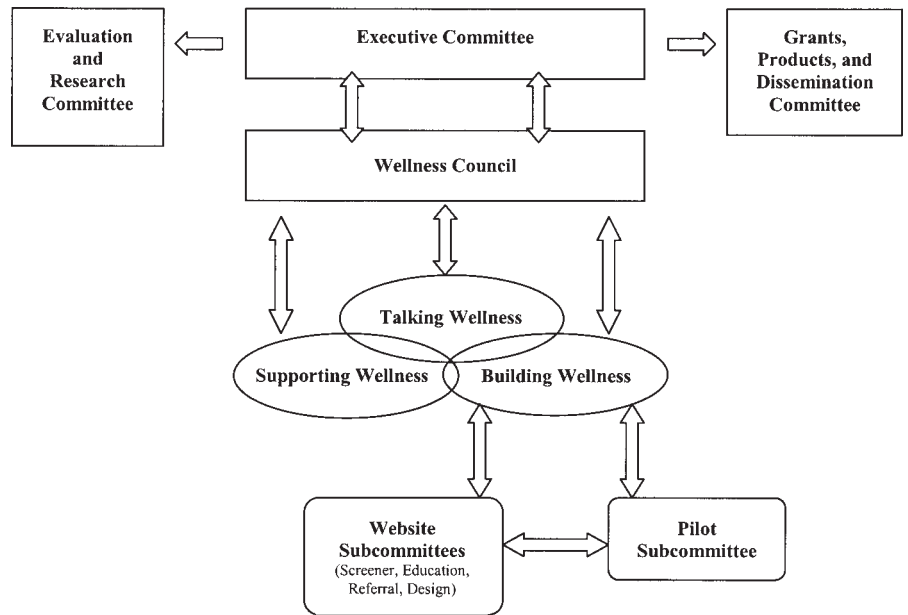


Fig 1. Flowchart diagram of Witness for Wellness and Building Wellness Working Group - August 2005

‘partnership’...[as] partnerships range across a continuum, from those driven by communities to those controlled by universities.”⁸ Within the limits of Minkler and Wallerstein’s continuum, CPPR falls closest to an “equal” relationship where academic and community partners involved in the W4W initiative enjoy a balanced partnership in all aspects of research, including program development, research design, implementation, and analysis, “with impressive participation not just of the leadership of Healthy African-American Families, but also of community members.”²⁷

Within W4W, different working groups focus on specific areas that relate to reducing disparities in appropriate mental health care (for a flowchart diagram of W4W, see Figure 1). These working groups and their areas of focus include improving community awareness of depression and reducing stigma around mental illness (Talking Wellness), improving quality and outreach of services (Building Wellness), and addressing key policy barriers to care while supporting advocacy to protect

vulnerable populations (Supporting Wellness). This paper describes the development and perspectives of the Building Wellness working group, as it aims to develop feasible, community-driven, evidence-based action plans to improve the quality of services and outreach concerning depression in one particularly under-served community of Los Angeles County, south Los Angeles.

Whether minorities in south Los Angeles differ from White non-Hispanics regarding the rate of mental illness cannot be answered simply. Certainly, African and Hispanic Americans in Los Angeles are overrepresented in populations that are particularly at risk for mental illnesses. High-risk populations include the homeless—African Americans make up $\geq 30\%$ of the homeless in Los Angeles County¹⁰; those who are exposed to violence—Hispanic Americans in the City of Los Angeles account for 53% of all the victims of violent crime,¹¹ while African Americans are twice as likely as other ethnic groups to be victims of violent crime¹⁰; and the incarcerated—32% of African-American males and 17% of Hispanic-American

ican males born in Los Angeles in 2001 are likely to go to prison during their lifetime as compared to 6% of White non-Hispanic men.¹⁰

In addition to a higher risk of mental illness, national-level studies like those examined in the IOM report suggest that for most persons living with a mental illness in south Los Angeles, access to appropriate, quality care is limited because of disparities along ethnic/racial and economic lines. For example, studies of African Americans with probable depression or depression/anxiety have consistently shown low rates of appropriate care.¹²⁻¹⁴ One study of alcohol, drug, and mental health (ADM) care, conducted through Healthcare for Communities, a national household survey of >60 communities,¹⁵ showed that among respondents with a probable need for ADM care, non-Hispanic Whites were more likely to receive active treatment (37.6%) than either African Americans (25.0%), or Hispanic Americans (22.4%).¹⁶ Active treatment was defined as any medication, counseling, or referral to specialty care. Ethnic differences in access to care, quality of care, and unmet need for ADM care paralleled these disparities for Hispanic Americans and African Americans compared to non-Hispanic Whites. For African Americans, the pattern included less access to and greater perceived need for ADM care, plus a lower rate of active treatment than non-Hispanic Whites. For Hispanics, the pattern included more delays in receiving care, lower satisfaction with care, and lower rates of active care among those in need as compared to non-Hispanic Whites.¹⁶

South Los Angeles (both city and county territory including zip codes 90001-03, 90044, 90047, and 90059) is primarily populated by African Americans (40.1%) and Hispanic Americans (57.7%).¹⁷ Moreover, 66.7% of the people living in this area earn <200% of the poverty threshold. Translating these percentages into estimated in-

come, for a single person <65 years of age with no children, more than two thirds earn <\$18,000. Or for a family of four, two adults and two children, more than two thirds earn a total family income <\$34,000. Some people (36.7%) in south Los Angeles earn less than half of these figures.¹⁷ Given these figures and the W4W agenda, south Los Angeles was perceived to be an appropriate starting place in this effort to improve equity in care for minority communities with great levels of unmet need.

Recognizing that people in south Los Angeles with unmet need often seek and receive social services through community-based systems, Building Wellness' initial priority was to improve the ability of community agencies to recognize need (depression) and provide links to appropriate care. Working toward this goal, the action plans developed out of this partnership began with the premise that programs such as the tool kits from Partners in Care, Youth Partners in Care, and IMPACT can be, with some effort, modified for use by the public-sector clinics that are most available to underserved communities in South Los Angeles.¹⁸⁻²⁰ To begin the modification process, community members who had direct experience with such agencies (as providers or clients) offered invaluable guidance in the development of innovative programs, aimed to reach beyond currently available, evidence-based quality improvement programs for depression, which have chiefly focused on primary care. As both a contribution to the literature and an exercise in academic-community partnership, this paper describes the progress made by Building Wellness, through the more balanced CPPR approach. It also explores the issues and challenges that have surfaced during this collaborative process in the hopes of informing the development of future partnership initiatives as well as the continuation of our own.

METHODS

The members of the Building Wellness working group designated a writing subcommittee composed of academic and community representatives to develop a description of the group's work process, as well as lessons learned from the diverse community and academic perspectives in the partnership. Data sources in writing this paper included minutes from monthly working group meetings, materials for members, materials used during community feedback presentations, scribe notes (coded in formal qualitative analyses by academic-community coding teams), and the memories and reflections of the community and academic authors.

The W4W initiative, as a whole, has trained scribes to document working group progress and the overall collaborative process. Most scribes are research assistants from the partnering National Institutes of Mental Health Advanced Services Research Center. They have been trained by an anthropologist from RAND to record key themes, emotional tone, and nonverbal behavior related to key themes, with short quotations for the comments that best illustrate tone and themes. However, for this particular working group, scribe notes were quite limited because of scheduling conflicts for the assigned scribe; only two sessions from December 2003 to the present were available. To compensate for the limited scribe notes, a key data source was developed, consisting of a thorough review of all written materials and the development of a summary by one academic and one community member of the W4W project. In addition, academic and community members of the writing group convened on 10 occasions to discuss minutes, summaries, data from Building Wellness presentations, the group's progress from its inception to August 2005, and themes that came up during the writing process. For those meetings, one of the project's trained scribes served as the group's

writing assistant, recording themes and follow-up items, which were then modified through circulation to group members.

Summary of W4W Development

The W4W academic-community partnership initiative addresses a set of broad goals relating to the development of feasible, potentially replicable strategies to reduce burden of depression on under-served communities in Los Angeles. As a starting point for community dialogue and program development, W4W partners used findings and resources, developed through rigorous searches on the impact of improving quality of care for depression in primary care settings, as conducted in different regions of the country and across a range of ages and diverse cultural groups. Studies that led to these approaches include the Medical Outcomes Study, Partners in Care and Youth Partners in Care (YPIC), We Care, and IMPACT.¹⁸⁻²² These studies developed ways to improve medical care for depression, or ways to help low-income women obtain care, and then evaluated the impact of those intervention approaches on depressed adults and in YPIC, youth. The combined findings from these studies suggest that feasible approaches to improving access to appropriate treatment for depression improves health and quality-of-life outcomes of depressed individuals, including under-served ethnic minority groups, and may also reduce existing health outcome disparities.^{3,23}

The lead community organization in this enterprise is Healthy African-American Families (HAAF). Academic project leaders represent UCLA, the RAND Corporation, and Charles R. Drew University. A series of preliminary meetings between HAAF's community-based organizational partners, community members and consumers from south Los Angeles, academic partners, and representatives of the Los Angeles County Departments of Health and

Mental Health, led to the formation of a Wellness Council in March 2003 to support the development of the W4W initiative.⁶ The first activities of the Wellness Council included: 1) developing a collaborative partnership agreement to outline responsibilities and expectations of W4W members and co-leads; 2) forming an executive committee of project leaders from HAAF, Drew, UCLA, and RAND; and 3) organizing a community conference both to provide information about depression, treatments, barriers to treatment, approaches to improve services delivery, and the impact of depression on individuals and the community, as well as to gather feedback from participants about these issues and their ideas for addressing depression in the community setting.

In addition to clinical and research-based representation, >500 community members from south Los Angeles attended the first W4W "kick-off" community conference in July 2003. Using feedback from the conference, the Wellness Council and executive committee convened a working group orientation and planning meeting in November 2003. This orientation meeting resulted in the formation of three primary working groups for the W4W initiative: Talking Wellness, which focuses on consumer outreach and wellness education; Supporting Wellness, which focuses on wellness advocacy through interactions with policy makers; and Building Wellness, which focuses on providing intervention resources for improving quality of care services and outreach for people with unmet needs.

An open invitation went out to all attendees to join a W4W working group during the November orientation. The HAAF invitation was sent through a mass email to recruit people from south Los Angeles, who may not have participated in the initial conference. During the orientation, members signed a contract, committing to attend regular

working group meetings and to be responsible for two hours of "home-work" per month in exchange for a \$25 stipend per two-hour meeting as well as refreshments and possible transportation, when needed. Each group was asked to formulate action plans (feasible steps or programs, methods, and time frame), specify resource requests to the Wellness Council/executive committee and facilitate community member feedback and input into the action plans, for potential approval at a follow-up feedback conference.

Building Wellness Development

Based on feedback from the kick-off conference, the Wellness Council formulated 14 potential action items for Building Wellness members to consider (Table) at the first Building Wellness meeting on December 3, 2003. By group consensus, each member of Building Wellness volunteered to study and think about one action item. Each member committed to present options for addressing their item at the following meeting.

Not everyone from the first Building Wellness meeting returned to fulfill his or her presentation assignments. Still, over the next few meetings, though some items were not presented by the original volunteer, those who were present at subsequent meetings discussed each action item extensively.

In the midst of these discussions, as a short-term goal, the group decided to clarify and narrow its action plan in preparation for a first round of community feedback sessions, scheduled for March 2004. Members divided the various action items into categories addressing the following three questions: 1) How can communities get access to quality help? 2) Who needs help? and 3) How do community service providers outreach effectively and in a manner that is culturally responsive?

To facilitate communication about these categories, members developed

Original 11 action items for the Building Wellness Working Group

ACTION PLAN	METHOD	TIMELINE	PARTICIPANTS
Reach Out			
Develop guidelines for responsible, confidential outreach.*	Review existing guidelines	2 years	Researchers and Building Wellness group
Train teams of community service providers (social services, home health leaders, case managers) to screen for depression and link to services.*	Identify trainers and trainees Access their needs and knowledge Develop a curriculum Evaluate	3 years	Identify source to develop and conduct trainings
Recruit and train volunteers to provide support services (eg, transportation, childcare for health visits, and provide medication reminders or help with therapy tasks [social activity]).	Identify and recruit sources Develop recruitment strategies Contract child care services Contract transportation service Develop medication reminder plan	Not Applicable	Refer to Supporting Wellness group with assistance from qualified contractor
Train case managers to coordinate care and social services with special knowledge of issues for the depressed.	Develop curriculum Implement trainings Offer continuing education units Evaluate	Not Applicable	Refer to Talking Wellness group working with institutions
Develop consumer/family self-help guide (eg, modify "Beating Depression" tool kit).	Contact professional to develop Provide sensitivity information	2 years	Identify source and Building Wellness group
Provide Quality Services			
Develop and adapt training and support materials for primary care practices (eg, Partners in Care) to ensure culturally appropriate depression care.*	Identify source to develop materials Identify agencies to offer training Provide culturally sensitive information	2 years	Contracted service Working with a steering committee, representative from each group
Develop, adapt, or implement programs for depression or depression/violence in schools.	Identify existing school programs Develop a program, implement and compare	Not Applicable	Referred to Talking Wellness with contracted services
Develop capacity to provide brief therapy in alternative settings (eg, workplace, faith-based settings, schools).	Unable to provide services	Not Applicable	Committee to develop a referral list
Develop strategies for the community to monitor the quality of care they receive for depression.	Identify strategies Focus community groups to develop strategies Design and implement strategies	Not Applicable	Refer to Supporting and Talking Wellness groups
Integrate depression care improvement strategies into other care improvement programs in healthcare and other service sectors.	Develop and evaluate process Identify existing and evaluate Design improvement care plan Integrate Evaluate and update	Not Applicable	Refer to Supporting Wellness group and partnering agencies
Monitor the quality and implementation/outreach of new programs to ensure access and appropriateness for special populations (eg, elderly, HIV, children, substance abuse, homeless).*	Develop a monitoring system Partner with existing programs Evaluate and update	3 years	Researchers and Building Wellness group

* Action items presented at the March 2004 community conference.

their own terms: training, identification, and development. The concept of training arose as a potential solution to the looming reality of trying to take on an existing, flawed healthcare system. It referred to what would be needed to train community service providers and health professionals in depression recognition and referral as well as how to deliver appropriate care in a sensitive

manner, learning to be aware of the stigma that is often associated with depression and mental illness in the south Los Angeles community. The term identification referred to assessing what providers currently know about depression and referral options, identifying and modifying an appropriate curriculum to train providers and identifying trainers and trainees. The

term development referred to developing tool kits and/or programs to care for persons with depression through various community venues as well as developing community capacities and resources for future action items around decreasing disparities in health and quality of care. Development also referred to developing guidelines for ethically responsible and confidential outreach, given con-

cerns about societal stigma towards depression and seeking mental health care.

Eventually, the short-term agenda narrowed further, focusing on the development of a Building Wellness website to support these three broad categories of action. During this process, the group's terms also narrowed in scope to become: provider training, resource development, and care identification. Provider training is currently used by the group to denote promoting the Building Wellness website throughout provider networks and referring providers to the website listings for training in service quality improvement. Resource development refers to determining the steps and resources needed to develop the website. Care identification refers to identifying quality care programs and training as well as identifying specific consumer populations, providers, and other potential partners, who might be interested in or in need of care-improvement practices. (As the interests or group agenda shift again, these terms may take on new meanings.)

The process of narrowing and focusing the action plan was demanding for group members because of competing priorities, a diverse set of action items, and limited time, relative to the preexisting expectations for participation in the project. The clear preference of community partners to focus on supporting outreach through community service providers made developing a website to support providers in identifying depression as well as educating and referring depressed clients to specialty services in the community a central organizing point for the group. There was also a strong fit between this proposed unifying action item and the capabilities and resources of the academic partners, given some comparable website development activities in other programs.^{24,25} As this focus evolved, other action items were deferred for later development.

Initial Building Wellness discussions also regularly returned to debate about potential target community groups. Community members, in particular, had a strong interest in youth, while academic representatives suggested focusing initially on adults but also then having a planning group for youth. With some reluctance, the larger group agreed to this strategy, although a youth planning subcommittee was not formed for some time because of the group members' limited time and the need to accomplish multiple, simultaneous tasks. Strong representation of community members from south Los Angeles and local neighborhoods near the HAAF headquarters highlighted these areas as obvious target neighborhoods. Although several Building Wellness members had stronger interests in neighboring communities with greater African-American representation, the group ultimately decided to maintain a broad, multicultural focus in its products and agreed to develop materials for its planned website in English, Spanish, and Korean, the three main languages spoken by populations in selected target areas.

Composition of the Group

From its inception, the Building Wellness membership and its diverse representation have been in flux. During the first three months alone, Building Wellness members included case workers from the juvenile justice system, Planned Parenthood staff, medical doctors (family physicians, psychiatrists, and general medicine), anthropologists, community advocates, HAAF employees, representatives of the church, administrators from the Los Angeles Unified School District (LAUSD), prison administrators, workers from youth development organizations, social psychologists, consumers, and community artists. While membership is always changing, on average, more than half of Building Wellness comprises representatives of the south Los Angeles

community, and though Building Wellness membership is open to stakeholders of any ethnic/racial background with an interest in improving services quality and outreach in south Los Angeles, of the 15–20 attending members, African-American women usually compose approximately half of the total group and two thirds of the community representation; academic representatives are more often smaller in number as are non-African-American males. African-American men from the community, females from partnered academic institutions, and Latinos have consistently been the least represented groups at the table, although one community co-chair and co-chair of a subcommittee on youth is an African American male and one academic co-lead is Hispanic-American.

Leadership

The leadership structure in working groups parallels the balanced partnered leadership structure of the Wellness Council. Aiming to support a strong community voice in this CPPR partnership, working groups should have two community co-leads and one academic co-lead. This helps assure attention to evidence basis and evaluation while remaining true to community perspectives and tying the project goals to priorities of the community. During the first Building Wellness meeting in December 2003, group members selected two community co-leads. The executive committee searched for and nominated an academic co-lead. Soon after the first meeting, in January 2004, one of the community co-leads resigned from that role. The group voted in a new community representative from the Building Wellness membership; this woman is still one of the Building Wellness co-leads today, while others have resigned over time. In addition, the identified academic co-lead resigned from this role after six months, just after the main community feedback session. The overall project academic co-chair served as interim co-chair until

a replacement academic co-chair was recruited, which took seven months of active searching.

The first group of community leaders went through a leadership training course to review leadership and listening skills, strategies for facilitating group communication and for modeling W4W principles like respect, responsibility, and accountability. Newer community leaders have not yet experienced this training, though the expectation is that they, like all participants, will develop the leadership skills necessary to take on the co-lead position through observation of and interactions with leaders during meetings as well as attending optional workshops throughout the year (eg, “How to Listen” conducted by the Office of the City Attorney, “Policy 101” conducted by Cheryl Branch, local community advocate and leader). Overall project co-chairs trained academic co-chairs individually, as they were recruited after the initial leadership training.

RESULTS: DEVELOPMENT AND PROGRESS OF THE GROUP IN DEVELOPING ACTION PLANS

Incorporating Community Input

To keep the Building Wellness mission and its interventions aligned with community priorities and needs, the group’s first goal was to present its three categories of action at the March 2004 community conference.²⁶ The action items marked with an asterisk in the Table indicate presented items. To explain how the items would fit into the working group’s larger timeline (see Figure 2), one community representative likened Building Wellness to building a house. She told the audience that she thought of the partnership, both between academics and community in the formation of Building Wellness as well as between Building Wellness and community services providers, as the

Mar 2003	Jul 2003	Nov 2003	Dec 2003	Feb 2004	Mar 2004	Jul 2004	May 2005	Aug 2005
Formation of Wellness Council	Kick-Off Community Conference	Working Group Orientation and Planning Meeting	First Building Wellness Meeting	Small Group Begins to Explore Website Feasibility	Community Feedback I	Community Feedback II	Web Designer Begins Website Layout	Slideshow Presentation of Website to Working Group

Fig 2. Timeline for Building Wellness Working Group development: March 2003 – August 2005

foundation of the building. The frame of the house represented the group’s mission statement, research hypotheses, and plan of action. The bricks represented Building Wellness tool kits and educational materials and trainings. Each room in the house represented a different special interest group that could be specifically accommodated with evidence-based, culturally responsive outreach and services. The kitchen is built last because that is where families get together for evaluation; the presenters emphasized the importance of evaluation in this process so that Building Wellness can go out the front door and build another house, with valuable information for its next project. This metaphor was well-received by the audience. Presenters also explained that, in addition to considering what would most improve public outreach and services quality, Building Wellness also had practical concerns, like feasibility. Preliminary feedback from the community on this presentation was positive. Out of a total 50-point score, the Building Wellness presentation received a 41 with respect to clarity of the project, feasibility, impact, and reach. In discussion, the community audience’s main concern was about feasibility; they encouraged a more focused action plan.

The April 23, 2004, Building Wellness meeting began with open discussion about the tasks outlined in the work plan presented during the March conference. Members discussed taking advantage of the resources offered by partnered individuals and organizations such as the Department of Mental Health, Los Angeles Best Babies Collaborative, and primary care providers

who regularly see postpartum and prenatal patients. The group also talked about available funding mechanisms such as First 5 Los Angeles and the rationale for considering paths that could take advantage of existing resources. This led to a discussion around how to prioritize the needs of specific populations. Many community representatives expressed concerns about the mental and physical health of teens in South Los Angeles. Others raised questions about limiting the required level of depression to severe, believing that unmet need in the community is greatest for those with mild-to-moderate depression because of its stigma. Again the question of capacity and available resources arose: SPA-6 (the south Los Angeles region) needs were thought to outweigh agency capacities. Members recognized the need for strategies to develop future planning capacities. In face of these difficulties, the group decided to maintain its focus on assisting social service case workers in facilitating recognition and referral for depression, as an overarching goal that honored community priorities and infrastructure while attempting to bridge the gap between available programs and the community’s unmet need. The group decided to bring these issues to the next community feedback session in July 2004.

The July 2004 feedback conference took place at the Magic Johnson Theatres in the Baldwin Hills section of south Los Angeles, a well-known location in the community around HAAF. At this community conference, each W4W working group presented final action plans to ≈200 community

members, who then voted on action plans through use of computerized, hand-held voting devices.²⁶ The presentation centered on increasing access to care through social service agency case workers, for those suffering depression in south Los Angeles. This action item was presented by two community members who danced and made entertaining comments to help community members relate to and consider action items that otherwise touched upon a sober subject (unmet need).

Building Wellness reviewed community feedback and research findings from the July conference at the following working group meeting on July 23, 2004. One academic founder of W4W reviewed the research questions and provided the group with findings from the community ratings of the action plans. Overall, the group believed that community had strongly supported the proposed plan. With this support, the Building Wellness group developed a detailed work plan over the subsequent 9–10 months. This extended period was necessary because the action plan (focusing on community service providers) required insights from community members, who were not accustomed to considering the needs and operations of provider agencies. Further, while the academic partners were more familiar with supporting programs on depression for primary care or specialty care actions concerning depression, they were less familiar with the issues around supporting programs for community caseworkers, particularly in south Los Angeles. These issues, combined with an almost personal sense of responsibility for assuring a useful and ethical program to support access to real services for the local community, placed a burden of work on the group that had not been fully anticipated.

Building a Website

After the July feedback session, work group meetings centered on putting the presented action items into play. Building Wellness planned to incorporate its

categories of action, provider training, resource development, and care identification, into the development of its website to facilitate social service agency identification of depression among their clients, with supports for client education and referral to specialty services or primary care.

In considering how to best organize the operational plan, Building Wellness members reviewed articles and materials from existing websites on depression and consulted both an experienced web programmer and web designer. Given project resources and the established target audience (social service and community case workers), the group considered its program options. A subcommittee was delegated to make initial recommendations. Based on the subcommittee's recommendations and suggestions from the larger, group discussion, Building Wellness divided into three additional subcommittees, each of which would be responsible for one component of the total product. To collaboratively develop the tool kit, each subcommittee planned to employ a modified Delphi process to review the characteristics of existing depression screeners, client education materials, and referral lists.

Finally, one subcommittee was formed to plan and execute a research pilot demonstration to evaluate implementation of the website, as a provider tool kit and resource, by tracking use of the website by a handful of small provider agencies. Subcommittees planned to work simultaneously, each developing its own strategies for progress and development. Outlines of subcommittee activities and plans were presented to the whole working group during monthly meetings.

The first new subcommittee, responsible for identifying a depression screener instrument, was co-lead by the interim academic co-chair and a community organization leader, who was developing depression screener recommendations for a larger initiative on the health of pregnant women in Los

Angeles. The committee planned to research, review, and evaluate the cultural responsiveness, user friendliness, and scientific qualifications (such as reliability and validity) of existing depression screeners.

The second new subcommittee, responsible for developing resources for client education about depression and depression treatment, was co-lead by a community member and a public-sector mental health services provider. This group reviewed existing community-based websites and publicly available materials for youths and adults, including the NIMH website, materials from Depression and Bipolar Alliance, and brochures from depression research studies like Partners in Care, and then created Building Wellness materials and stories about depression as needed.

The third new subcommittee was responsible for developing resources to facilitate a reliable referrals process for clients identified as having probable depression. Examples of issues addressed by this committee include the complexities of getting updated referral information in real time, securing information about insurance policies, services and resources offered, and locating hotlines with live contacts. A referral specialist from the Los Angeles County Department of Mental Health Services visited Building Wellness and briefed the full working group on some of the barriers to providing reliable referrals as well as possible strategies. After his presentation, the working group decided to focus on developing strategies and resources, such as draft referral letters, to facilitate the process. While the group also wanted to develop an extensive list of clinics and agencies that offer services to persons with depression and/or other psychological illnesses, many expressed concern that the information could become easily outdated or not reflect the realities of obtaining access in the community. As the subcommittee worked on this problem, they decided to couple the more general

referral resources with a referral list that concentrated on agencies, which previously had agreed to partner with the group in providing their information through the website.

Over a 9- to 10-month period, each subcommittee developed components of its plans. The screener subcommittee identified four potential screening instruments, provided copies of those instruments to the full working group, and summarized published information on reliability, validity, sensitivity, and specificity. The screener subcommittee also obtained overall ratings of the perceived scientific quality, cultural/community appropriateness, and feasibility of using the screeners in community settings from the Building Wellness group. A modified Delphi process was used to reach consensus.²⁶

While all four screeners (Partners in Care screener, PHQ-9, National Depression Screening Day Screener, CES-D) were positively evaluated, three screeners (Partners in Care, PHQ-9, and National Depression Day) were especially liked, but for different reasons. The Partners in Care screener was viewed as having a more complicated format but simpler language and capable of capturing need over a broader period of time, while the PHQ-9 was appreciated for its simple format and scoring. The National Depression Day screener was viewed as having language most appropriate to the target community and was Building Wellness' first-choice screener for this reason. However, use of the screener is associated with an annual fee, which this project could not afford in terms of sustainability. As a result, the second-choice (PHQ-9) was selected as the main screener. This negotiation was based on a trade-off between community preference and cost, and led to some tensions between the executive committee, which is responsible for cost decisions, and the community members and leaders, given efforts in the consensus-building process to encourage community voice in selection.

The main concern raised about the PHQ-9 was the wording of an item about loss of pleasure in usual activities, which was viewed as requiring too high of an education level for this community. At the suggestion of the overall project community co-chair, a compromise was reached in which a community-generated item was added to the scale, while still preserving the initial item and scoring, to permit a study of responses to the original and reworded item. The process of reviewing the screeners in detail was thus a mixed, and potentially minimizing, experience for the community, both familiarizing them with the research process but also introducing a source of tension over the decision-making process, given the project structure and resources.

The client educational resources subcommittee similarly reviewed several alternative sets of educational materials with the full working group. The choices were discussed, and the subcommittee offered a set of recommendations. The group selected two materials: the Partners in Care patient brochure (available in English and Spanish) and a set of PowerPoint slides, which had been modified for presentation to a Head Start parents' group (in Spanish and English). Building Wellness members were particularly interested in the PowerPoint slides, which discussed 11 leading points about depression and treatment. The group shared stories about their own experiences (or family members' or friends' experience) with seeking care, depression, etc and used that discussion to revise and shape the set of talking points. The group then decided to use the voice and face of different group members to brief each point about depression, a strategy referred to as "talking heads." Options for comic-book style stories about depression were also discussed, but as the main strategy for the website was to support case-workers, not to educate clients directly, this strategy was dropped. The sub-

committee then nominated one of its clinician members from the Los Angeles County Department of Mental Health Services to modify the Partners in Care patient brochure into a simple, one-page "fact sheet" about depression, to use as the main resource for providers to give their clients. Building Wellness members discussed various drafts of the fact sheet extensively and finalized it according to the group's input.

The client referral resources committee developed a draft list of referral agencies through contacts of the Wellness Council, group members' personal experiences, information provided by local clinics, and by searching a master directory of service agencies in Los Angeles. Names and locations of clinics, with characteristics of services and eligibility requirements (such as insurance or service area), were listed in a spreadsheet, which was circulated for comments to all group members and the Wellness Council. Subsequently, after much discussion about the difficulty of assuring that individuals given an evaluation could actually receive only a referral list, a decision was made to contact all agencies on the list, obtain their permission to provide them as a referral, update the information, and also determine the agency's interest in partnering in other activities of either Building Wellness or the larger W4W project (for example, participating in a mental health fair). Given the large number of potential agencies (≈ 50) and the time required for each contact, the completion of this component in the near future has become a priority.

As the subcommittees developed their respective web resources, the larger working group decided to develop a separate committee on the visual design of the website. This group evolved from an initial planning group, which had explored the feasibility of a website plan during February 2004. At that time, this group first recommended that the overall W4W project develop a website that could be the basis for

further development of work group web pages and presentations of products. That website was developed by a UCLA NIMH Center web designer working collaboratively with the Wellness Council and executive committee (www.witness4wellness.org).

In its most recent configuration, the web-design committee sought consultation from the UCLA NIMH Center web programmer, a RAND-based NIMH Center web designer, and subsequently (ongoing) from the initial web programmer designing the overall W4W website. The web design committee has drafted a slogan, images, conceptual models, and a sitemap. Each member of the subcommittee contributed something significant to the draft design of the site.

The last subcommittee to be activated, as the extensive preliminary phases of developing the action plan neared completion, was the subcommittee to design the pilot of the website-based tool kit. This committee included the overall W4W academic co-principal investigator and one of the newly recruited community co-chairs of the Building Wellness group. In addition, a newly recruited academic co-chair (a graduate student and experienced mental health clinician) was included. The group's focus was to consider options for a pilot design and to work with the executive council to secure funds for the pilot. The executive council recommended a randomized design (at the provider level) for the pilot study. Building Wellness reviewed and accepted a preliminary outline of the pilot design. The group submitted a proposal for a one-year pilot to a competitive "internal" funding program at UCLA, the UCLA-in-LA initiative through the vice-chancellor for community affairs. The pilot was funded in June of 2005. Additional funds are being set aside in the NIMH center's budget to support the community partner's costs in the pilot study.

As of August 1, 2005, the Building Wellness working group is finalizing its website and tool kits. The pilot sub-

committee has developed an operations plan, measures, and procedures for its pilot study and is in the process of contacting potential sites. This study, which will be the subject of a subsequent article, also will follow the CPPR model, in which community members will co-lead through balanced partnership in all aspects of the program and evaluation processes.

DISCUSSION: LESSONS LEARNED AND PERSPECTIVES

The Building Wellness working group case study, using the CPPR focus on balanced power-sharing, illustrates that a diverse, community-academic partnership can develop action plans concerning building services outreach and quality for depression while incorporating the input of community members and community service providers in the process. With regular community input, groups can develop an operational plan for an intervention initiative over a subsequent period, though the process is not without its expected tensions and complications. To generate a successful, community-tailored product, moreover, for a sustainable partnership to flourish and grow, these tensions and complications must be identified and resolved.

Maintaining Focus Over Time

The extended duration of the group's work before it was able to take concrete action (18 months) presented some challenges to sustaining the interests of community members and academic participants alike in Building Wellness. The lead agency's model of flexible community engagement, with its focus on inclusiveness and openness to either participation or disengagement, as individual needs occur, has supported the overall sustainability of the process but has also posed challenges to continuity in group work, given individual-level changes in leadership

and membership and the associated shifts in priorities or attention to prior group-level decisions.

In part, this particular working group sustained its focus and efforts by securing funding for an initial pilot trial, with a rigorous design, of its central action item: a case worker tool kit to facilitate depression identification, education, and referral. However, the success of this product to accomplish its goals, and the implied necessity to improve services, ability, and/or quality, awaits the results of the pilot and subsequent main trials, as well as the acceptability and utility in community locations and cultural acceptability to community members using the services. Hopefully, the extensive community engagement in designing the program will help with its cultural validity.

The sustained attention to addressing a real-world problem related to service provision was perceived by the group as a serious and important task. This perception also may have helped hold the group's attention to the process and sustained it through the various tensions that arose. At the same time, the weight and reality of taking on an existing system contributed to the complexity of the task. Considering how best to improve routing people with unmet needs in community-based agencies to appropriate depression care was a serious matter; not an easy accomplishment for those less familiar with such agencies or with the necessary clinical and screening processes required. The process of attending to such complex issues within a community-academic partnership sometimes meant yielding to the tendency of academics to bring an academic rigor to such factors as developing community consensus, as well as the necessity for joint efforts at funding for academic and community sides of programs and evaluations. Perhaps inherent to such partnership work, within which community members largely represent under-served minority groups and aca-

demics are primarily White, is that such developments and conflicts can translate into power conflicts either between community and academic perspectives and resources and constraints, or as racial/ethnic group differences, conflicts, or discrimination. How, given this context, did the group arrive at a point of developing its programs after sustained effort? And what have we learned to pass on? This writing group decided to jointly identify a set of issues and themes to help flesh out the lessons learned from the first cycle of partnership process (for Building Wellness community members' own voices about the lessons learned, see Figure 3).

Compromise: Opportunities and Challenges

The Benefits of Compromise

As the group flushed out the definition of "special needs populations," the diverse affiliations of Building Wellness members made consensus a major challenge. The range of targeted special interest groups included foster care children, African-American women, African-American men, case managers, primary care providers, specialty providers, and consumers. The challenge was to figure out how to serve all these groups at one time or, at least, find a way for all partners to rally around one goal in the short term. This challenge related both to diverse interests within community members (particularly over special populations) and between community members and academics (over strategies to build on existing evidence-based programs that have focused on providers). After extensive discussion, Building Wellness found a compromise by selecting providers of greater relevance to the broader south Los Angeles community, the social service providers most likely to encounter community members in need, who might not be receiving health services. In doing so, the group maximized impact for every interest group.

- Everyone on the bus must have a value in the process and/or the outcomes for the project to be successful.
- As a co-chair, the challenge is not that there are competing priorities within the group; rather it is weaving individual priorities into the fabric of the overall strategy, goals, and objectives of the group. This process for us acted as a catalyst for synergy fostering goodwill and cooperation allowing Building Wellness (BW) to move forward.
- Only when working group members acknowledge that they are each unique and bring with them valuable input will we move the project forward.

Fig 3. Lessons learned, through the voices of community members

Even this compromise, however, created conflict over time, as such a long-sustained effort around providers delayed achieving other priorities. Of particular difficulty in the group was the decision to delay focusing on youth, given this very strong priority of the group. For this reason, group morale has required instituting the youth planning subcommittee as soon as possible. Fortunately, the recent publication of a youth study comparable to the adult Partners in Care has increased the feasibility of developing a focus on youth, perhaps even within the pilot project period for the current website.¹⁹ In negotiating this compromise through a CPPR collaboration, where community contributes to the planning stages of the research more heavily, the academic co-chairs had to provide as much information as possible on the status of the intervention literature for children as well as adults to keep all members of the partnership informed.

Identifying and Dealing with Conflict

One of the most difficult aspects of the group development for community members was the process of deliberation

around selecting the PHQ-9 screener for the website tool kit. The decision to include grassroots community members in the early phases and to share the decision-making process and discovery of pros and cons was a pilot experience for the project as a whole and followed the W4W approach to developing action plans with community input.²⁶ However, during the several weeks required to do the review, respond to community questions and feedback, and conduct more research on the screeners in a collaborative process, the group learned information that presented a conflict for the executive committee regarding the community's favorite screener (costs for an alternative screener). This finding led to concerns for some members that their opinions were not valued or were ignored or concerns that the preliminary work on the screeners should have been completed before the first presentation to the community members of the working group, to save their time and effort.

Academic members of the group had not anticipated this outcome, initially thinking that the shared process of discovery was its own important

learning experience for the group process. Of interest, some of the discussion of this conflict took place not within the group meeting, but during the sessions to prepare this manuscript, in which community leaders revealed their perceptions of the group's reactions, which had not previously been openly expressed. This discussion itself provided insights for the academic leaders into the unspoken group process and emphasized the importance of more extensive discussions after shared, innovative events of how the event played out and the experiences of members. Similarly, this conflict emphasized the importance of orienting the group within events to its scope of responsibility in relationships to the overall project and the executive committee.

While this process engendered some tensions in the group, it was an important event for providing a more open forum within the group and particularly among the group leaders for discussing conflicts and sharing perceptions of the process, to allow the work of the group to move forward. For example, these tensions served as a catalyst to provide the community-generated alternative of one item, and this event was followed by a very lively discussion of the educational materials with excellent community input, including more open acknowledgment of likes and dislikes by community members.

Power Sharing and Resource Differences

One hallmark of the CPPR approach followed in W4W is equal value for community and academic perspectives and contributions. Community members provide their ideas, time, knowledge of the community, connections, and in-kind resources, and academics provide their technical knowledge, access to research resources, connections, and in-kind resources. Despite this philosophy and the acknowledgment of the value of all of these contributions within the program, in

One hallmark of the CPPR approach followed in W4W is equal value for community and academic perspectives and contributions.

the pilot phase of W4W initiative, the source of money for many of the pilot programs or technical research expertise needed to develop programs (such as the websites) derives from academic resources, especially the NIMH Center and its partner NIH centers within CHIC and RAND Health. In discussions of many potential action plans for the Building Wellness group, community members often raised issues of feasibility first and gently questioned academic partners about the potential availability of resources or fits with academic programs. For example, at the time a website was suggested (by a community member) the NIMH center's lead web programmer happened to have time available for planning purposes. Undoubtedly, the availability of this resource may have helped shape the group's consistent focus on the website strategy as the main initial action plan. Similarly, the resources for funding the pilot study of the website were from an internal academic source, partnered with NIMH center funds. In partnering in the use of these funds, community members must also contend with the academic leaders' adjusting to shared control of their resources and any resulting tensions or conflicts entailed in that adjustment.

The implications are that real differences in power and conflicts over the sharing of power affect the work selected, how group members relate, and the sources of conflict in the work. These power-related issues can also interact with cultural differences in communication style or exacerbate trust concerns either between community

and academic partners, regardless of cultural background, or between different cultural groups within and across community members. As was the case for our writing group, these issues may fall to the leaders to identify and resolve and then as appropriate bring back to the working groups.

The larger W4W project is assuming a long-term strategy to addressing these power issues. In particular, the project is seeking to develop direct funding for community partners and to increase the knowledge and control of community members over the research process and funds. These changes are being negotiated with some of the funders for the academic initiatives supporting the project and the CHIC collaborative.²⁶

In the short run, we have adopted several processes to help modify the potential for power conflicts. First, the overall W4W community co-chair has coached her academic colleague to adopt a "lead from behind" style, supporting others in taking on a leadership role as training for the future. Second, the council decided to add a community member to the executive committee. Third, community co-leads are being funded as co-investigators for the new Building Wellness pilot study. Fourth, the current academic co-chair for Building Wellness is a social worker with extensive experience in the south Los Angeles community. However, members must continue to identify, acknowledge, and resolve their appropriate sources of conflict.

CONCLUSION AND FUTURE DIRECTION

The authors are encouraged that a diverse community-academic partnership work group was able to successfully struggle through 18 months to review a broad agenda of potential action items, select a target goal, develop it, and develop the resources for a pilot program that may hold promise for improving

outreach related to unmet needs for depression care through social service agencies in south Los Angeles. The authors also realize that accomplishing this goal within a CPPR model is challenging and requires committed, flexible leadership and strategies to identify conflict, including conflict around sensitive power sharing issues as well as developing compromises or strategies, such as exercises and celebrations, to resolve conflict and dispel tensions.

This working group has been on a steep learning curve, complicated by the fact that the members, academic and community members alike, are subjects in a process evaluation of this approach. The group is being observed as it works to develop its program and identify and overcome the challenges inherent in this work. Finding the common causes for concern and the hope that the group may be able to provide real strategies to the community it serves, lives in, and works with, keeps the group going, as acknowledged by all community co-chairs.

The community and academic co-chairs also acknowledge the leading challenges for this group as it proceeds to fulfill its mission. One challenge is to sufficiently address the great cultural diversity of the south Los Angeles area and to effectively recruit participants and modify strategies for the range of major cultures. Another challenge is to follow our efforts on case-finding with a matching effort on services quality for the main providers in the area. For this challenge, we have available models developed in other demonstrations and hopefully by now a community better informed about depression to partner in adapting these programs for local service providers, with an improved understanding of, and experience with, the partnership process.

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