



California Reducing Disparities Project
(CRDP) Phase 2

Best Practices in Community Based Participatory Practice 2018



Psychology Applied Research Center
@ Loyola Marymount University

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PARC@LMU would also like to thank the 24 key informant interviewees who provided critical insights and examples of the philosophy of community based participatory practices (CBPP), how CBPP can be implemented, ways that CBPP contributes immensely to community change, and the challenges and obstacles often encountered while implementing CBPP. Although the names of the contributors remain confidential, the participants represent various stakeholder roles and have a variety of experiences in conducting community-based work. Specifically, they reflect the following roles and knowledge:

Roles

- Academic/University Researchers
- Community Members
- Elected Officials
- Mental Health Professionals
- Mental Health Consumer Advocate
- Participant in CRDP Phase 1
- Program Evaluators

Knowledge

- Cultural Competency
- Equity/Disparities
- Community Based Participatory Research
- CRDP Priority Population Specialists
 - African American
 - Asian and Pacific Islander (API)
 - Latino
 - Lesbian, Gay, Bisexual, Transgender, Queer/Questioning (LGBTQ)
 - American Indian/Alaskan Native

Acronyms

| | |
|-----------------|---|
| API | Asian and Pacific Islander |
| CAB | Community Advisory Board |
| CBPP | Community Based Participatory Practice |
| CMHPC | California Mental Health Planning Council |
| CBPR | Community Based Participatory Research |
| CDEP | Community Defined Evidence Based Programs and/or Practices |
| CDPH-OHE | California Department of Public Health-Office of Health Equity |
| CRDP | California Reducing Disparities Project |
| EOA | Education, Outreach, & Awareness |
| EBP | Evidence Based Practice |
| IPP | Implementation Pilot Project |
| LGBTQ | Lesbian, Gay, Bisexual, Transgender, and Queer/Questioning |
| MHSA | Mental Health Services Act |
| MHSOAC | Mental Health Services Oversight & Accountability Commission |
| PARC@LMU | Psychology Applied Research Center at Loyola Marymount University |
| PEI | Prevention & Early Intervention |
| SOGI | Sexual Orientation and Gender Identity |
| SPW | Strategic Planning Workgroup |
| SWE | Statewide Evaluator/Statewide Evaluation |
| TA | Technical Assistance |
| TAP | Technical Assistance Provider |



Preface

The Goal of this Document. This Best Practice document is intended to provide an overview of Community Based Participatory Practice (CBPP), including its basic elements and applications in order to serve as an ongoing reference point for the California Reducing Disparities Project (CRDP) Phase 2. It will:

- Provide a definition of Community Based Participatory Practice (CBPP) (The term CBPP rather than Community Based Participatory Research (CBPR) is proposed to reflect a broader application of CBPR activities and can also be referred to as community engagement),
- Establish a basis for shared meaning and language related to CBPP for CRDP Phase 2 partners,
- Explain how CBPP undergirds CRDP Phase 1 and 2,
- Describe CBPP essential elements and best practices, including examples for different priority populations,
- Highlight the benefits of and challenges associated with CBPP,
- Provide tips and strategies to guide your use of or assessment of CBPP in action, and
- Note ethical considerations in the use of CBPP.

Purpose and Scope. The intended audience of this review of CBPP includes CRDP grantees, local evaluators, technical assistance providers, state officials and other potential funders of community-based mental health programs, and California State Legislature. It is also intended for other key stakeholders, such as the Mental Health Services Oversight & Accountability Commission (MHSOAC), the California Mental Health Planning Council (CMHPC), the California Department of Public Health Office of Health Equity (CDPH-OHE) Advisory Committee, the County Behavioral Health Director's Association, and the Cultural Competence, Equity & Social Justice Committee. While strategies for engaging in CBPP are our primary focus, we also present a case for why CBPP is important for planning, provision, and program evaluation of mental health services, particularly within the CRDP priority communities. Examples of successful practices as well as current thinking about CBPP to fully engage community members in their work will be provided.

Our hope is that this document will assist CRDP partners in the fulfillment of their respective roles, support the CDEPs and their local evaluations, and move the needle in the reduction of mental health disparities in the five priority populations through culturally and contextually-grounded strategies that represent the experience and wisdom of various communities.

Our Methods. This Best Practices document reflects information compiled from two sources. First, we completed a review of scholarly literature on community-based evaluation and research, program development, and policy change, as well as reports and summaries of local and national CBPP efforts. Second, we conducted 22 key informant interviews with 24 individuals who have experience and expertise in a broad range of CBPP activities. Key informants were identified by CDPH-OHE and PARC@LMU (the CRDP Phase 2 Statewide Evaluator). They reflect a convenience sample of subject matter experts who agreed to be interviewed. Several were contributors to CRDP Phase 1. Others represent and/or work closely with the CRDP Phase 2 organizations serving the five priority populations (African American, API, Latino, LGBTQ, American Indian/Alaskan Native). Key informants reflected a cross-section of perspectives including community members-at-large, mental health professionals, experts in mental health disparities, policy makers/elected officials, and subject-matter experts related to cultural/linguistic competency, research/program evaluation, equity/disparities, and CBPR/CBPP. Most informants reside within California, with some exceptions made for individuals with national reputations regarding community-based participatory practices.

Disclaimer:

This document is not intended to be an exhaustive and complete reference or review of the social science and public health literature on CBPP, community engagement, or CBPR. Rather, it is intended to provide an overview of key concepts, principles, and applications of CBPP to inform its utility in CRDP Phase 1 and Phase 2.

Introduction

“The most effective collaborations include representation from various sectors—businesses, clinicians, schools, academia, government, and the faith-based community.” (Benjamin, R., Vice Admiral, Surgeon General, US Public Health Service, 2011, p.xi)

The Backstory. In November 2004, the people of California passed Proposition 63, the Mental Health Services Act (MHSA), that funded California Reducing Disparities Project (CRDP) Phases 1 and 2 to improve mental health access and outcomes among historically unserved, underserved, and/or inappropriately served communities by offering Prevention Early Intervention (PEI) Direct and Indirect Programs. CRDP Phase 2 must demonstrate the extent to which the \$60 million investment administered by California Department of Public Health-Office of Health Equity (CDPH-OHE) contributed to:

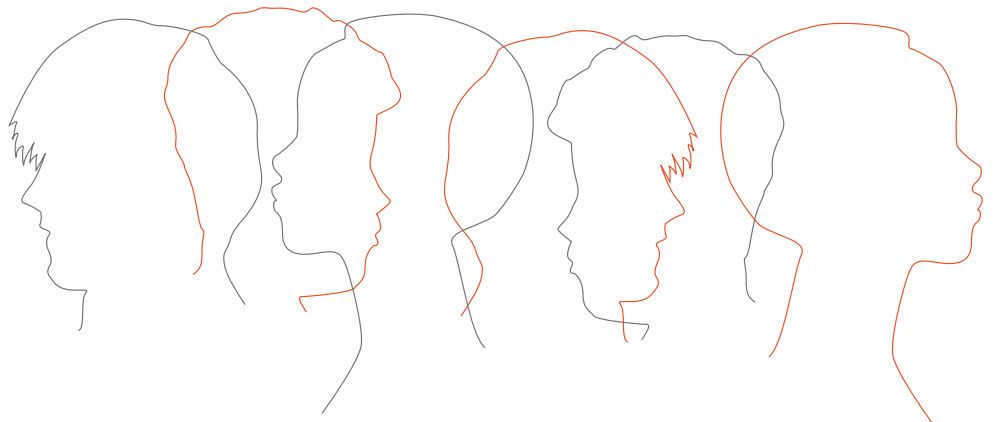
- Reductions in the severity of mental illness for five priority populations;
- Systems changes in county PEI level operations;
- A return on investment (the business case); and
- Changes in state and county mental health policies and practices.

MHSA establishes an accountability mandate that must be addressed by all recipients of this \$60 million investment. A central feature of CRDP Phase 1 and 2 is its grounding in (CBPP), which will be described in greater detail later.

CRDP Phase 2 is a collective effort involving multiple partners—each with an important role to play in the project’s overall success. The **Implementation Pilot Projects** (IPPs) design, implement, and evaluate their local community defined evidence practices (CDEPs). The **Technical Assistance Providers** (TAPs) provide technical support to the IPPs and coordinate efforts with **CDPH-OHE** and the **Statewide Evaluator** (SWE). The SWE evaluates the overall initiative and its various components and provides evaluation guidelines and technical support to the IPPs and TAPs. CDPH-OHE manages the overall initiative and maintains communication with key stakeholders across the state. **The Education, Outreach, and Awareness** (EOA) keep the public updated on this new innovation—advertising, marketing, alerts, and possible directions for mass production.

CBPP is incorporated in all facets of the initiative to varying degrees. The SWE serves as a cross-site evaluation, collecting implementation and outcome data about Phase 2 as a whole and each component (i.e., IPPs, TAPs, SWE, EOA, and CDPH-OHE). Prior to Phase 2, CDPH-OHE established guidelines for the SWE, which included 3 objectives, 7 evaluation questions, and 15 deliverables, which the statewide evaluation plan is required to address. Thus, the SWE's use of CBPP came with institutional constraints. On the other hand, the IPP local evaluations were focused on establishing the effectiveness of their CDEPs. They have more flexibility in the design of their local evaluations to develop evidence for intervention strategies that are culturally and contextually grounded. They also have more latitude than the SWE to incorporate CBPP into their CDEPs and local evaluations. However, local evaluation plans had to be in alignment with the SWE evaluation guidelines, which provided information on the basic content to be shared about their plan (e.g., the evaluation questions, the methodology, data analysis and dissemination plan, etc.). Further, because the SWE was required to demonstrate effectiveness of Phase 2, IPPs were required to include the SWE pre and post-test core measure items into their local evaluation protocols. Finally, IPP evaluation plans required final approval by CDPH-OHE. To support this requirement, the SWE reviewed all IPP local evaluation plans to ensure that they met these guidelines and that they provided the necessary detail and rationale so that their proposed plan would meet CDPH-OHE approval.

CRDP Phase 2 is rich with opportunity to move the needle for California's unserved, underserved, and/or inappropriately served populations. Its success will rest in large measure on the partners' collective ability to amass credible, convincing, and diverse sources of evidence of effectiveness—from the local IPP (CDEP level), to each priority population, and CRDP as a whole. CBPP can augment systems change, community change, and the indigenization of evaluation practices that can result from CRDP Phase 1 and 2.



What Is Community Based Participatory Practice?

Definitions

There are many terms used to describe community-based participation. Most people are familiar with and adopt the phrase Community Based Participatory Research (CBPR). While CBPR is primarily anchored in a research process, we are choosing to use the term—Community Based Participatory Practice (CBPP)—that reflects a broader array of practices related to participatory activities that include and extend beyond research. In its broader application, CBPP, like CBPR, offers a set of principles for engagement and participation—typically between communities and entities external to the community (e.g., government agencies such as County Departments of Mental Health, policy makers such as elected officials, institutions, researchers/program evaluators). It inspires attention to culture, context, trust building, shared meaning, consensus, and equity.

CBPP. CBPP encompasses several types of activities that include the active engagement of community members in identifying, defining, addressing, solving and evaluating issues in their own community. As a broad umbrella term, CBPP can be employed in a cross-section of activities including program implementation, program evaluation, research, and systems and policy change. The participatory components and the principles of CBPR as articulated by Minkler and Wallerstein (2008) are present across these activities.

“Creating healthy environments for people of all ages will require their active involvement in grassroots efforts. Private citizens, community leaders, health professionals, and researchers will need to work together to make the changes that will allow such environments to flourish.”

(Benjamin, R., Vice Admiral, Surgeon General, US Public Health Service, 2011, p. xi)

VOICES FROM THE FIELD

Mental Health; Equity/Disparities; Program Evaluation

“I would say that community-based best practices are practices that are rooted in the community and rooted in culture. They’re practices that might be long time, long standing practices that have been going on in the community, but don’t have wide recognition because they are focused on a very specific population. They’re practices that might not necessarily be recognized by others as having a strong evidence base or having a strong results-based orientation and that might just be because they have not been evaluated in what we see as the traditional, Western-based evaluation that the people rely on, and particularly government agencies or other funders might not necessarily see it that way. I think just by the very nature of these kinds of projects, they are very firmly rooted in equity. So they are very concerned with making sure that those folks that are most impacted by the...in this case mental health, are at the center of the project.”



A number of participatory models could fall under the umbrella of participatory practices. They include but are not limited to:

- Community Based Research (CBR)
- Community Based Participatory Action Research (CBPAR)
- Community Based Participatory Evaluation Research (CBPER)
- Participatory Action Research (PAR)
- Participatory Learning and Action (PLA)
- Feminist Participatory Action Research (FPAR)
- Empowerment Evaluation (EE)
- Participatory Evaluation (PE)
- Community Engaged Research (CER)
- Community Based Participatory Interventions (CBPI)
- Youth (-led) Participatory Action Research (YPAR)
- Transformative Action Research (TAR)

VOICES FROM THE FIELD

African American Priority Population Specialist

"...I think I would characterize PAR as the community doing the research from start to finish. Like...coming up with the questions, coming up with the methods, it's really being community driven, whereas CBPP or CBPR, the community is participating alongside the researchers. The intent behind PAR is that the researcher steps aside and is there as a trainer and a guide, whereas in CBPP, researchers and community members are equal partners. There's a partnership, whereas in PAR it's more of like empowerment for community to do it. I don't know if that's kind of splitting hairs but that's how I would see the difference between [the two]. PAR is you have a group of community members who are there being guided and being trained to do it, but they are the ones going out and doing all of the work whereas in CBPP you have everyone around the table doing it collectively together.... so having community participation of agencies or grantees in funding decisions, policy decisions, program decisions, you know, there's multiple levels. Anytime you have the people who are participating, really truly participating as equal partners, it throws the power structure up. So when we think about CBPP there's multiple levels."

The participatory features of these activities are similar. Implicit and explicit is the inclusion of equitable voices from all parts of a community, and an emphasis on culture and context. But who is the community, and what constitutes community engagement?

VOICES FROM THE FIELD

Equity/Disparities; Mental Health; API Priority Population Specialist

"...to me, it's always been community driven, community based, community informed, but I think it means somewhat different things depending on the community and what you're talking about. I think that our research methods are so diverse and complex now that CBPR has to, in some way, keep up with that as well."

Community. Community can be defined or described in a variety of ways (e.g., people located in a particular geographic space; people with a shared identity and/or history; etc.). Macqueen and colleagues (2001) identified the following five categories that reflect how community is conceptualized: 1) locus—a sense of place, 2) sharing—common interests and perspectives, 3) joint action—a source of cohesion and identity, 4) social ties—interpersonal relationships, and 5) diversity—social complexity within communities. For example, the African American Priority Population Report (2012) (from CRDP Phase 1) defines community as: “Any group having interest in common or working together for mutual benefit.”

Community has also been understood from distinct points of view—a systems perspective, a social perspective, and an individual perspective (NIH, 2011).

The *systems perspective* describes community as a living organism with multiple parts, activities, and interests that must work in collaboration to effectively meet community needs. The parts of the living organism include such things as businesses, social service agencies, nonprofits, or other types of organizations. When operating in a cohesive fashion, they are able to meet the needs of the community (e.g., employment, education, mental health, recreation, and other factors).

“...successfully addressing a community’s complex problems requires integration, collaboration, and coordination of resources from all parts.” (Thompson et al, 1990)

One of the limitations of this perspective is that the community is perceived from the vantage point of organizations, in which existing power structures may be reproduced, with little to no voice from individual constituents or representatives of the community.

The *social perspective* looks at community by focusing on existing social and political networks that link individuals to community organizations and community leaders. It focuses less on organizations that address specific needs and more on how political and social power operates within a particular context. Social networks comprised of community groups or organizations, individuals, and the relations or linkages among them are central and an important way to engage communities.

“People should not make assumptions about identity based on appearance, language, or cultural origin; nor should they make assumptions about an individual’s perspective based on his or her identity.” (James, 1890)

In the *individual perspective*, people create community by living and articulating aspects of their identity that are salient and connect them to others. It emphasizes factors such as race (e.g., Native American), community geography (e.g., South Los Angeles), ethnicity (e.g., people of Hmong descent), or gender identity/sexual orientation (e.g., LGBTQ). The meaning and salience of these identities will vary from person to person and among members of the community at large, and include other factors important to how individuals view themselves (e.g., issues related to intersectionality). Understanding how individuals perceive themselves and other members of their community is important.

CBPP Tip

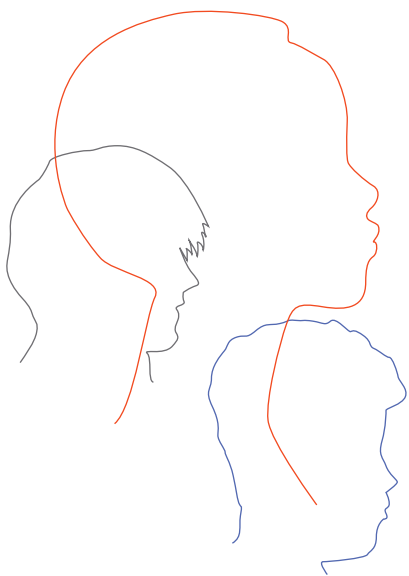
In an ideal CBPP, communities have self-determination to clarify the characteristics that define their community.

“Today, the multiple communities that might be relevant for any individual — including families, workplace, and social, religious, and political associations — suggest that individuals are thinking about themselves in more complex ways than was the norm in years past. The eligibility criteria that scientists, policy makers, and others develop for social programs and research projects reflect one way that people perceive a group of proposed participants, but how much those criteria reflect the participants’ actual view of themselves is uncertain. Practitioners of community engagement need to learn how individuals understand their identity and connections, enter into relationships, and form communities.”
(NIH, 2011, p.6-7)

VOICES FROM THE FIELD

Mental Health; Equity/Disparities; Program Evaluation

“...I think some of the key challenges are trying to fit them into a Western paradigm that might not be the most appropriate, trying to get the community based practices to follow...the same kind of path of getting them to be evaluated the same way that strategies that were created for the more dominant culture, it’s not going to work. Making sure that you’re not trying to fit into, for example if you’re working with the LGBTQ population, making sure that you’re looking at the gender spectrum and not having them fill out forms that have male, female, and other, that’s not going to work and you’re going to get a lot of pushback from the community when you try to do that. So I think those challenges of trying to fit into a structure that’s been established by funders [and] the government is something we need to look out for...”



Understand how community is defined for your priority population from both an intersectional framework and from their local context. It may not be enough to simply say “the Latino community” or “the Asian American community”. CRDP Phase 1 Priority Population Reports offer some important insights. Here are a few examples.

LGBTQ *is also not a single community but rather represents many diverse communities and populations.....What LGBTQ individuals have in common is they are seen as living outside the norm of expected heterosexual and assigned gender behavior, and therefore may and do experience stigma, discrimination and oppression from government, health systems, school systems, religious institutions, employers, family members and society-at-large. (First, Do No Harm: Reducing Disparities for Lesbian, Gay, Bisexual, Transgender, Queer and Questioning Populations in California, p. 19)*

The report also notes that [one] should focus on the distinctiveness of each sector of the LGBTQ community—lesbians, gay men, bisexual, transgender, queer and questioning—within an overarching approach to mental health throughout the lifespan for the racial, ethnic and cultural diversity of LGBTQ communities. (First, Do No Harm: Reducing Disparities for Lesbian, Gay, Bisexual, Transgender, Queer and Questioning Populations in California, p. 15)

API *“Who are the Asians, Native Hawaiians, and Pacific Islanders [AANHPI]? ...it is important not to assume that the AANHPI community is one homogeneous group.” (In Our Own Words, p16).....Given the diversity of the AANHPI populations, there were many differences among various subgroups. These differences could be observed in terms of language, culture, history, immigration patterns, religion, spirituality, traditions, acculturation, education level, and socioeconomic status, just to name a few. These differences may be even more pronounced when comparing information on recent immigrant populations.” (In Our Own Words, p.22)*

Latino *“The term Latino often is used in reference to a variety of backgrounds (e.g., people from Cuba, Mexico, Puerto Rico, South or Central America, or other Spanish culture or origin) and includes variance in immigration histories and other factors such as generational and socioeconomic status (SES) differences. (Community-Defined Solutions For Latino Mental Health Care Disparities, p.2) “Despite many commonalities across the various Latino groups, the existence of cultural, linguistic, educational, and sociopolitical differences sometimes requires classification of Latinos into subpopulations for investigative purposes. Distinguishing among Latino subgroups from different regions and examination of their demography, history, culture, and views on mental health are important for future research. Researchers should not attempt to characterize all Latinos as one homogenous group and ignore between and within-group heterogeneity.” (Community-Defined Solutions For Latino Mental Health Care Disparities, p.59)*

“...the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices.” (CDC, 1997, p 9)

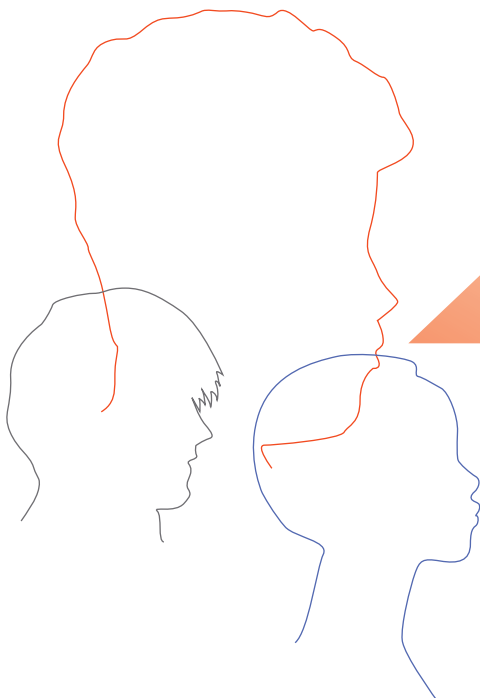
Community Engagement. Community engagement refers to the inclusion of community members and their perspectives in deliberation, decision-making, and projects affecting them and their community. In the context of CBPP, it means there is collaboration between the community and researchers, institutions and/or policy makers. Community members are aware of the strengths and challenges of their communities. They know and understand their historical, cultural, political, and current context. They also have the relationships and connections to social networks to help create lasting changes in regard to the social issue (See: Agency for Toxic Substances and Disease Registry, 2011, Ch. 2).

While engagement implies the incorporation of community views and partnership, how this is defined can look very different from one engagement process to another. Engagement occurs on a continuum (see Figure 1 below adapted from NIH figure 1.1 Community Engagement Continuum, 2011 p.8).

VOICES FROM THE FIELD

Mental Health; Equity/Disparities; Program Evaluation

“The [priority] population has been engaged in the identification of needs, the identification of the prioritization of strategies, concept mapping activities to, like, identify the concepts that define mental health and well-being and now the members of the population of focus are going to be trained to be able to go out and administer surveys and ask people the questions that they need to ask to find out if the strategies that are being implemented are actually having an impact. So that’s an example of how this works, how this population itself, the community itself has been engaged in all steps of this process to really make sure that it’s the strongest product possible.”



Levels of Community Engagement

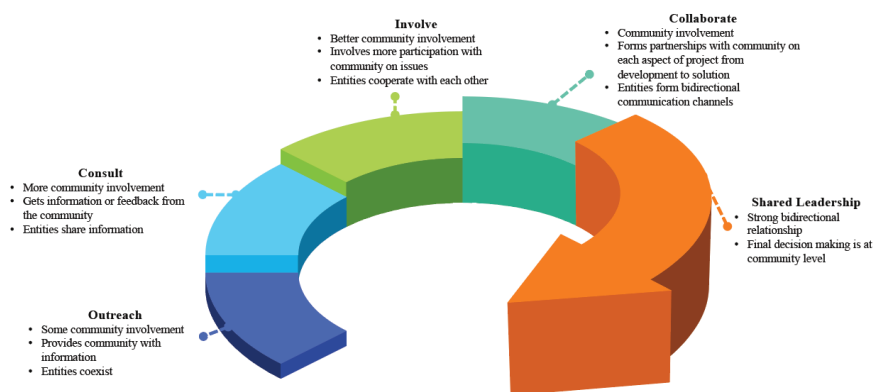


Figure 1 adapted from NIH (2018)

Figure 1: Levels of Community Engagement

Figure 1 illustrates a continuum of how community engagement could be employed. While the farthest end is considered ideal, it is not always feasible given the work at hand.

- **Outreach:** at the lowest level of community involvement, the community is simply informed of the work that is taking place.
- **Consult:** community feedback is sought, but is not actively a part of the project design. Feedback is obtained through community meetings, key informant interviews, focus groups, etc. Minor changes might result from the feedback but the fundamental approach is not altered. At this level of engagement, there is little room for shared development or responsiveness to community concerns.
- **Involve:** more information is shared. The community enters into active problem solving to inform what is developed or implemented. This may entail negotiating shared meaning and methods related to an issue. Dialogue is pursued to ensure that the community's perspective, concerns and aspirations are heard, considered and understood and the tasks, perspective and goals of the external entity are also understood.
- **Collaborate:** the community is in a partnership role where input is more than advisory. It is bidirectional. Community members are invested in the project and play a role at every stage of development and implementation. Communication is more regular and trust has been established.
- **Shared leadership:** what many consider the gold standard of engagement, the community co-creates or drives the agenda. Their voice is amplified in ultimate decision-making. The most engagement and potentially impactful work is done when communities and outside entities (researchers, policy makers, governmental agencies etc.) engage on an equal level (Minkler, et. al, 2012; Israel, 2001) (https://depts.washington.edu/ccph/pdf_files/CBPR_final.pdf., https://www.hud.gov/offices/lead/library/hhts/NIEHS_Successful_Models.pdf).

(Collaborate: An Example)

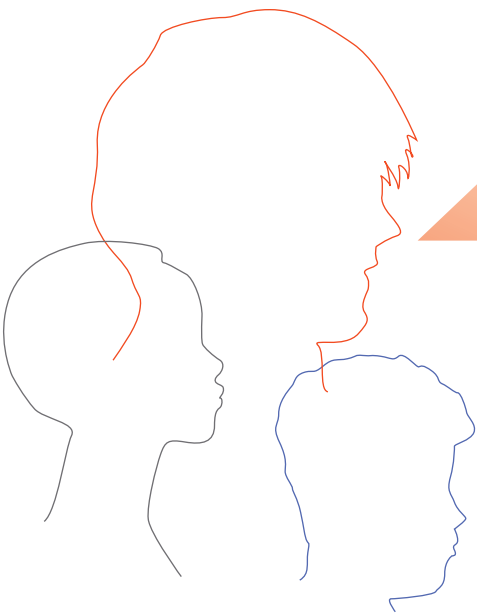
The African American Health Initiative (AAHI) presents a success story of a local, Black, San Bernardino County, CA community's willingness to engage in health planning through a CBPR process to identify problems and recommend solutions. Using a mixed-method sequential exploratory design, researchers employed a social ecological approach within a CBPR framework to focus on engagement strategies for health assessment, decision-making, and planning for improved health outcomes related to a variety of diseases. Upon selecting a planning project director, two groups were identified. The first group was the AAHI Community Advisory Committee or the planning participants (n=194) which consisted of community stakeholders, educators, community advocates, business owners, public officials, health professionals, physicians, nurses, attorneys, retirees, civic and social organizations, corrections and parole, social workers, substance abuse counselors, religious groups, public health, academicians, and researchers. The second group were the self-identified Americans of African ancestry living in SBC (N=1,078) and included key informants, focus group interviewees, residents surveyed, public forum attendees, and health providers. The recruitment plan targeted 345 participants from the general Black population and 155 participants from the poor and near-poor population. The community decided what information needed to be collected, how to collect, what instruments were appropriate, and how to analyze and interpret the data. A 147-page comprehensive report called *Voices of the People: An Afrocentric Plan for Better Health* (Woods, 2004) was created detailing project results. In this report, nine major recommendations were identified: 1) develop capacity of Blacks for health decision-making, 2) mobilize health care providers, 3) develop accountable collaborative of Blacks, 4) County Department of Public Health develop a strategic plan to care for residents, 5) education to empower and advocate, 6) action for individual behavior changes toward healthy lifestyles, 7) leadership in African-centered research, 8) improve economics, and 9) guidance in natural remedies. The release of the comprehensive report led to the selection of a 13-member committee to translate findings into practical solutions resulting in the incorporation of a new nonprofit established to decrease health disparities and obtain funding to implement the nine recommendations. The success of this initiative led to the adaption of this model [for African Americans] to form the Latino Health Collaborative (Woods, 2009).

In CRDP Phase 1, Priority Population Reports expand on the idea of community engagement by defining engagement from their priority population's perspective. For example, the Native American Population Report (2012) states that Native Americans should be included in all components of the CRDP—that is, a shared leadership level of engagement (p. 26).

VOICES FROM THE FIELD

(Program Evaluation; CBPR)

“One key informant, who leads a CBPR evaluation firm, emphasized that the field has become focused on techniques of engagement, and has lost focus on the fundamental purpose of CBPR i.e., to change the balance of power in research projects and communities at large. Communities must have control over their information and the ability to use it in ways that support their own goals. Often the collaborative projects offer opportunities for representation at various levels, but the real goal is that they are the controlling bodies for the determination, collection and representation of the data about their communities. This critique argues that there are too few projects that engage in shared leadership in the context of CBPP in a research application.”



CBPP Tip

First, determine what level of community engagement you are employing, why, and the pros and cons associated with that level of engagement.

Second, operationalize what you mean by “community engagement.” Who gets selected to participate, how, and why? Are they “representative” of your priority community? Do you have adequate representation of diverse perspectives in the engagement process?

This CBPP tip introduces another important element of engagement—intentionality, which refers to the extent to which it is inclusive of individuals across relevant cultures, language, origin, age, and religion. This helps to create a holistic understanding of and inclusion of diverse perspectives, issues, strategies, and challenges.

Intentional inclusion of the members of diverse groups often requires attention to the constituents who are members of the community of focus and determination of the extent to which all voices, not just privileged voices, are heard. Unheard voices in a community may undermine the success of an effort because their needs go unmet. Often, it is a smaller population or subgroup that experiences the most challenges, yet has the least voice in decision-making. It is also not enough solely to include individuals (a numbers game), while sidelining their cultures’ and communities’ worldviews. Intentionality includes meaningfully engaging individuals from various groups in the community, inclusive of their culture and perspectives.

Principles and Application

Minkler and Wallerstein (2008) (elaborating on Israel and colleagues, 1998 and 2005) suggest the following 11 principles of CBPR, which are equally relevant to CBPP:

1. Recognizes community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research [and practice], involving an empowering and power-sharing process that attends to social inequalities.
4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involves them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.
10. Openly addresses issues of race, ethnicity, racism, and social class, and embodies “cultural humility.”
11. Works to ensure research rigor and validity but also seeks to “broaden the bandwidth of validity” with respect to research relevance

Expanding on this list, Lucero and colleagues (2018) noted the importance of shared values and agreements so that multiple theories of knowledge, methods, validity, scope, and flexibility are reflected. In a community-academic partnership, the 11 principles operate within a continuous feedback loop that must be able to respond to events that emerge both within and external to the community.

Minkler, Garcia, Rubin, & Wallerstein (2012) note that what is unique about the CBPR perspective is “the way in which the research is conceptualized and carried out; the heavy accent placed on genuine community engagement throughout the process; and the use of findings to help bring about change” (p 10). While this is true—and applicable to CBPP—one might consider these as “aspirational”. In other words, all principles may not be fully usable in a specific CBPP project for any of a variety of reasons, but the principles continue to serve as guideposts to promote engagement and foster evolution toward the effective realization of all 11 principles. Even when there is a sincere effort to collaborate or partner with communities for the purposes of research, practice, or policy, the reality is CBPP requires: 1) time to build the

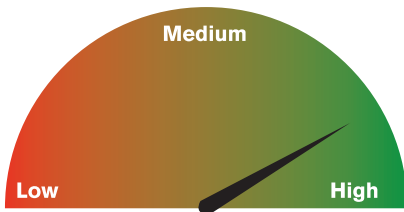
essential relationships, 2) resources to fully actualize all 11 principles to their fullest intent, and 3) a context that does not have pre-existing or superimposed constrictions that limit the ability to express certain principles. That said, it is nonetheless important to not throw the baby out with the bath water. We can still engage and collaborate with community, recognizing which principles are in fact working, being developed, or difficult to implement in a given context.

One might, therefore, consider the Minkler and Wallerstein (2008) principles as “aspirational” in the sense that the practice of CBPP (and CBPR) always occurs within a context that will impact the extent to which they are employed in any given project. One can think about this using the analogy of a dashboard, with the far-left quadrant reflecting lower levels of aspirational attainment and the far-right quadrants approximating the aspirational ideal. In the following section, we apply the dashboard analogy to examples of CBPP in the field with a particular context.



The Apsaálooke (Crow) people of Montana Crow Environmental Health

Steering Committee (CEHSC) initiated collaboration among local organizations, the Tribe, and academic partners, resulting in a closer to ideal form of CBPR to address environmental hazards. They also noted the importance of “...clear, unbiased and empowering...” communication between their partners to the success of their efforts. Capacity was also built as tribal members and researchers learned how to collaboratively work together to address a community-defined issue. Why is this closer to ideal? The community initiated the issue and solicited the participation of the partners. They effectively engaged in bi-directional communication and were not beholden to funding directives or governmental prescriptions. (Cummings, C. et al. Community-Based Participatory Research in Indian Country: Improving Health through Water Quality Research and Awareness, Unpublished article).

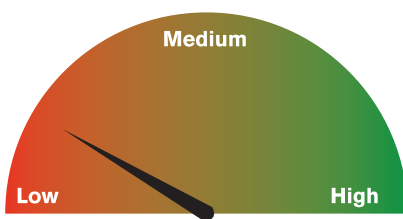


The Community Coalition, a social justice organization in South Los Angeles

The Community Coalition, a social justice organization in South Los Angeles, had a vision that Black and Latino residents and youth in this community could and should flourish. By reclaiming public dollars, generating justice and opportunity, and elevating a thriving community, South Los Angeles could become a place of opportunity for Black and Latino residents who have been locked out of their dreams for years. Guided by that vision, they initiated a CBPP process to gauge progress in the 25 years since the 1992 South Los Angeles Civil Unrest. Building on a 27-year partnership with PARC@LMU, with already established high levels of trust, a collaborative process was launched. Together, they developed and implemented a community poll to gain widespread community input, ensure a cross-section of community perspectives, and obtain the perspective of typically unheard voices. In total, 4,287 adult residents and high school students were polled (spanning 15 ZIP codes and 6 public high schools)

through door-to-door outreach and personal contacts with adult residents at their homes, parks, and other areas where community members gather (e.g., barber shops, churches, community centers, etc.). After the poll data was analyzed, over 125 community stakeholders were identified and recruited to participate in focus group sessions to interpret and nuance the meaning of the poll findings. A total of 75 participants representing key sectors of the South LA community (high school students, LGBTQ+ youth, social service providers, residents who were formerly incarcerated, English and Spanish speaking adult residents, and gang interventionists) participated in 9 focus groups. Based on this broad community input, Community Coalition is positioned to advance a justice reinvestment and safety platform (“People First”) to involve thousands of everyday residents in local and state policy campaigns.

Why is this even closer to the ideal? Essentially, all of the principles were present. The community initiated the process. The community was central to and guided all phases of the research process—from the research questions to the methods and instrument development through to the interpretation, dissemination, and application of findings. Co-learning and capacity building occurred for both the Coalition and PARC@LMU. The project was completely aligned with the local public health and ecological concerns of the South Los Angeles community. Issues of racism, culture, and classism were openly addressed and reflected in all aspects of the process held up by cultural humility. Trust and collaboration were high given that they were grounded in a 27-year community-research relationship. The process was not tied up by external restrictions and expectations.



In less than ideal CBPP situations, communities are often brought into projects once they are designed and key decisions and research questions have been made. In other instances, members of the community are brought in to be on advisory committees, but in ways that do not reflect bi-directional engagement. These would be considered on the low end of the dashboard because the community does not initiate, define, or control, in any meaningful way, any part of the process. The issue(s) may not have immediate relevance or be a priority for the local community. Culture, context, or cultural humility are not likely to be evident or practiced. Community perspective and input are cursory at best. The community often does not know the impact of their contribution and may or may not be included in the dissemination of results or changes. Nevertheless, even in this context, projects can succeed with making lasting change if community members are able to voice their needs, identify and/or develop strategies and select outcomes to inform the project.

VOICES FROM THE FIELD

(Mental Health Consumer Advocate)

“If you get funding, particularly from... some federal agency, you’re always required to have your advisory board, so sadly in many of those I know I’m the token community person or I’m the token family person or member. When those boards meet annually, the respondent wondered, ‘...then how am I really influencing or contributing to your research?’ the respondent felt as though you’re just going through the motions...but the point is how much does my opinion or ideas really matter?”

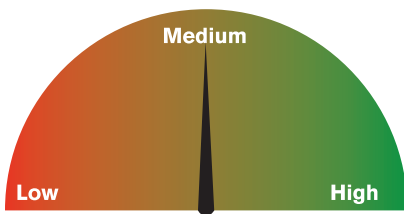
“So [CBPP] is about [being] invited to the table at every stage, but beyond just being at the table its adapting the meaning, the language, everything, so the community can understand, doesn’t feel overwhelmed or you know...I have no clue what they are talking about, they feel I have something to contribute here, my opinion is valid.”



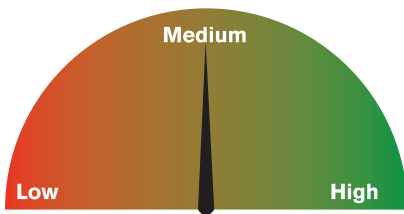
CBPP in CRDP

Phase 1 and Phase 2

CRDP is a state funded project with legally mandated accountability expectations for the California Department of Public Health’s Office of Health Equity. In such complex initiatives as CRDP Phase 2, communities are often brought into the process once the initiative has already been designed and key decisions about programmatic methods, research questions, policy changes, or systems practices have already been made. Nonetheless, even within this context, the principles of CBPP can still be found at moderate to high levels in various elements of CRDP Phase 1 and Phase 2, such as its strategic planning process, the design and implementation of CDEPs, the state-wide evaluation, and the local program evaluations.



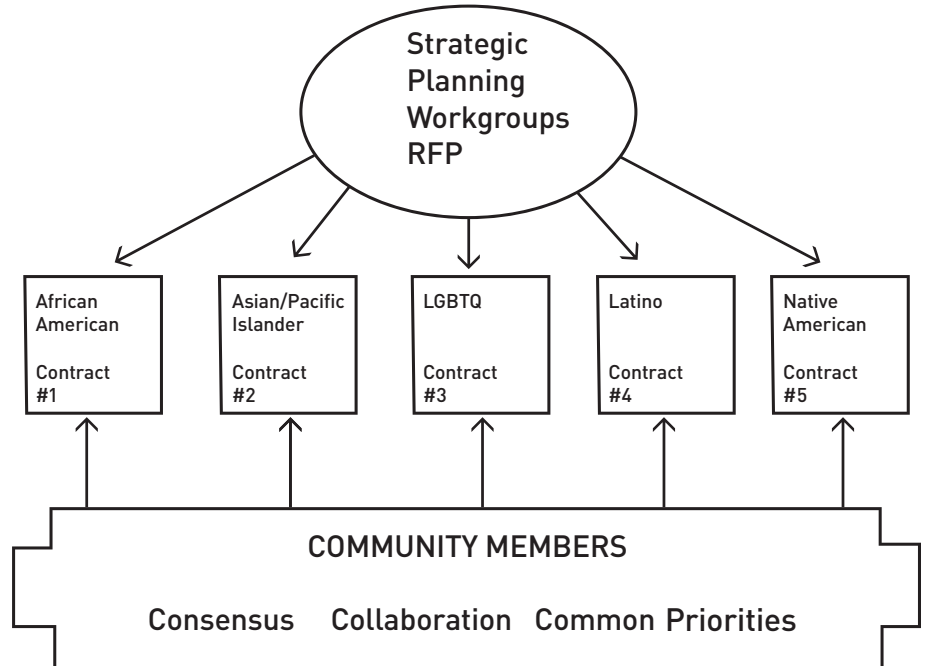
CRDP— In General: Using the dashboard, one can discern when, where, and to what extent principles of CBPP were applied in CRDP. This initiative launched in response to the will of California voters who, in November 2004, passed Proposition 63, the Mental Health Services Act or MHSA, that funded California Reducing Disparities Project (CRDP) Phase 1 and 2. (General CBPR Principle: *The community-of California voters—initiated the process.*) The goal of CRDP is to improve mental health access and outcomes among five historically unserved, underserved, and/or inappropriately served communities by offering Prevention and Early Intervention (PEI) direct and indirect programs (Principle 10: *Openly addresses issues of race, ethnicity, racism, and social class, and embodies “cultural humility”*). The initiative gives credence to and promotes the development of community defined evidence practice (rather than evidence based practices) within each priority population (Principle 10: *Embodies “cultural humility”*) Each of the thirty-five grantees or Implementation Pilot Projects, however, were not necessarily involved in the early defining moments of Phase 1 making this perhaps a less than “ideal” application of CBPP. As a result, one could argue that CRDP, in general, might be somewhere in the center of the dashboard.



CRDP—Phase 1: From its inception, CRDP incorporated CBPP. For example, in its Phase 1 solicitation, the then, California Department of Public Health, Office of Health Equity (CDPH-OHE), funded five entities “to develop recommendations from their respective communities towards the development of a comprehensive California

Reducing Disparities (CRD) Strategic Plan on how to design a statewide project to eliminate barriers and reduce mental health disparities”. Figure 2 presents CDPH-OHE’s request for proposals structure and philosophy for community engagement.

Figure 2: RFP#09-79158-000
CA Reducing Disparities Project Prevention Early Intervention MHA – Request for Proposals (2009)

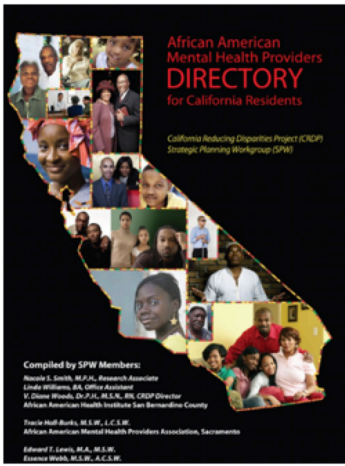


The wisdom, experience and context of each priority population were articulated from the community’s perspective using culturally and linguistic appropriate forms of community engagement. This led to the development of guidelines for each population about how to address mental health disparities through Community Defined Evidence Practices (CDEPs).

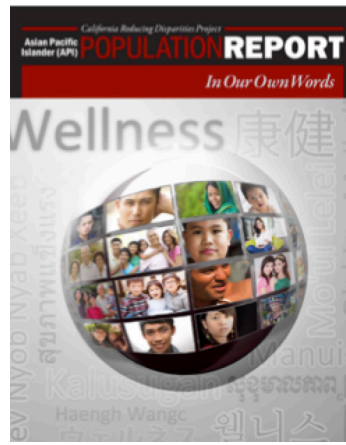
Phase 1: Population Report Community Engagement Methods

Five Strategic Planning Workgroups were formed to work with community members and community leaders to identify the most effective practices for each priority population: African American; API; Latino, LGBTQ; and Native American.

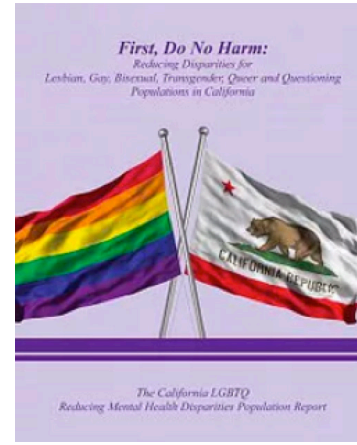
Described below are the community engagement methods developed by each workgroup and used with each priority population. The CRDP Phase 2 framework and expectations were designed based on this community input.



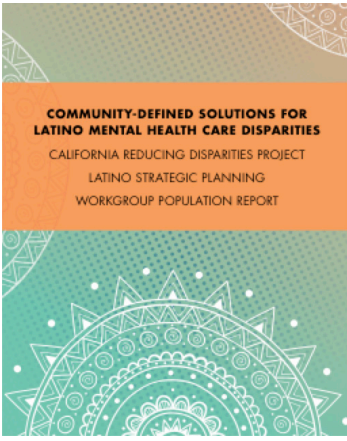
CRDP Phase 1 African American Priority Population Process—A mixed method approach was used to collect data on the status of mental health in the Black community. Survey tools (four distinct surveys distributed by **phone, e-mail, focus group, and at meetings with consumers, client family member, practitioners**) and interviews (**key informants, focus groups, small group meetings, in-depth/ case studies, and public forums**), was used to obtain a comprehensive community sample that sought to accurately represent the diverse backgrounds and experiences of those of African descent in the state of California. This diversity included: age, location, occupation, ethnic identity, sexual orientation, and gender.



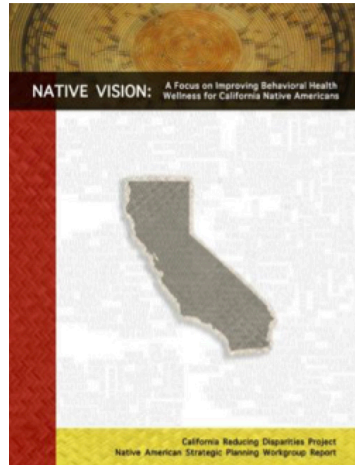
CRDP Phase 1 API Priority Population Process—The Steering Committee recruited a wide range of representatives from various Asian American, Native Hawaiian, and Pacific Islander (AANHPI) communities to form the API-Strategic Planning Workgroup. Under the guidance of the Steering Committee, a focus group protocol was developed to include voices directly from community members. Focus groups were conducted regionally to capture a cross-section of API experiences of disparity (i.e. urban, rural, etc.). A **total of 23 focus groups** were held with **198 participants** held in different regions of California.



CRDP Phase 1 LGBTQ Priority Population Process—The Strategic Planning Workgroup (SPW) was developed to serve as the decision-making body of the LGBTQ Reducing Disparities Project. SPWs were comprised of community leaders, mental health providers, clients/consumers and family members. A multi-method approach was used which included **Community Dialogue meetings**, consulting with Strategic Planning Workgroup and Advisory Group members, collecting promising practices information from providers and interviewing subject matter experts (key informants). The SPW sponsored **12 Community Dialogue meetings** across California, launched an **online community survey**—developed with community members—and administered to over 3,000 California-residents.



CRDP Phase 1 Latino Priority Population Process—“Mesas de Trabajo” (forum meetings), were used to offer community perspectives on mental health services and strategies to reduce disparities among Latinos in California. At each of the 13 **forum meetings**, participants were divided into six to eight workgroups or work tables, with each work table consisting of six to 10 participants. Each workgroup designated one participant to lead the discussion, one participant to document the key points of the discussion, another participant to chart key recommendations that emerged from the discussions, and one participant to report the group’s priorities. A total of **553 participants** took part in the forums.

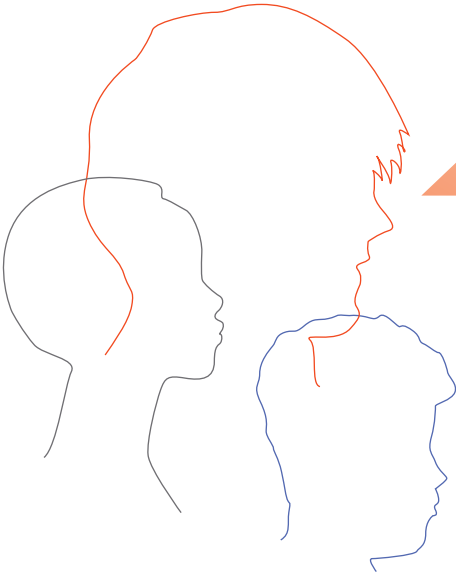


CRDP Phase 1 Native American Priority Population process— Eleven regional focus group gatherings took place throughout the state to gather input from 314 community members and tribal staff to complete the Native American California Reducing Disparities Project report between May 2010 through October 2011. Important recommendations, including numerous interpretations of community-based participatory practices were outlined. These included requiring the use of CBPR methods with each community using mixed-methods evaluations; gathering consent from the communities (**elders, council members, community members, etc.**); developing strict criteria for evaluating cultural and traditional practices; using consultants who are experienced in evaluation work with Native American communities; ensuring the evaluation reflects the community served; and assembling a **community advisory board** to oversee the integration of culturally appropriate community involvement.

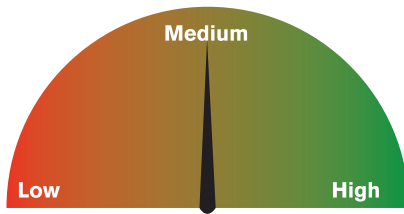
VOICES FROM THE FIELD

Equity/Disparities; African American Priority Population Specialist

"We're looking at how we can address the needs of individual families and communities by giving them what they need when they need it and in the amount that they need it. And as researchers, practitioners, health policy advocates, we have to make sure that we're not of the mindset of going into various communities, diverse communities, suggesting that we know exactly what they want and what they should receive. But, it truly starts, from my perspective, with listening to community members and engaging stakeholders and those who are in leadership positions or decision making positions within the community; in many ways they may be gatekeepers of those who are part of the community."



Emerging out of the Phase 1 process was a Strategic Plan with five goals and 27 strategies (<https://www.cdph.ca.gov/Programs/OHE/Pages/CRDP.aspx>), and a set of priority population specific guidelines which included important insights about what should be reflected in the following Phase 2 components: 1) the CDEPs, 2) the community engagement strategies, and 3) the local evaluation. Essentially, this Phase 1 statewide community engagement and feedback process informed the Phase 2 framework for each priority population. This is CBPP but not without limitations because the local communities selected as Phase 2 grantees may not have been present at the table to provide input on what became the Phase 2 guidelines that they had to adhere to for their CDEPs and their local evaluation. Hence, a midpoint rating is given on the dashboard for Phase 1 "in general" and Phase 2 "in general".

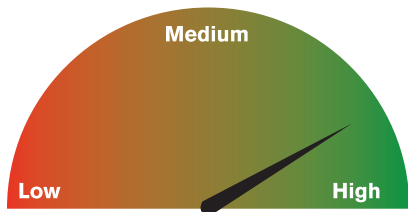


CRDP—Phase 2 In General:

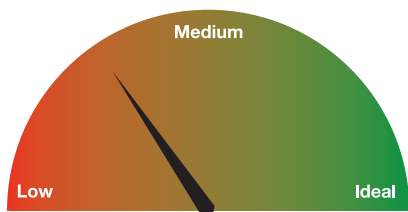
Processes in CRDP Phase 1, along with accountability mandates from MHSA, contributed to the requirements for each CRDP Phase 2 component (implementation of community defined evidence practices; the statewide evaluation; the provision of technical assistance; and the provision of education, outreach, and awareness). Although not all of Minkler and Wallerstein's (2008) 11 elements of CBPR are present at all times and equally in all components of Phase 2, it has continued to build on the CBPP elements established in Phase 1. In Phase 2, community organizations could apply for funding to implement and evaluate a local priority population specific CDEP. Evidence of the principles of CBPR (and CBPP) can be found in a brief perusal of the IPP solicitation for CRDP Phase 2. Consider the following excerpts below in comparison to the Minkler and Wallerstein (2008) list of CBPR principles.

- “Applicants for this grant program must currently be providing services to prevent mental health from becoming severe and disabling within the California African American population through an existing Community-Defined Evidence Practice (CDEP). CDEPs must be acknowledged by the community as effectively meeting its mental health needs in a culturally and linguistically competent manner.” (Minkler and Wallerstein principles # 1,2)
- “Doing business differently has been a focus of CRDP from the start. Doing business differently involves attentive listening and genuine consideration of community and CRDP partner input in order to be responsive to community needs. Doing business as usual has contributed to disparities; therefore, reducing disparities will need to involve doing business differently.” (Minkler and Wallerstein principles # 2,3,4,5)
- “a CDEP is defined as a set of bottom-up practices derived from a community’s ideas of illness and healing or positive attributes of culture or traditional practices.” (Minkler and Wallerstein principles # 1,2,6,10)
- “Evaluation Approach: This describes specific details in regards to how the Grantee would implement a program evaluation that is both culturally and linguistically competent and addresses the needs of the community that it is serving or intends to serve. The approach must describe in detail the plan for gathering qualitative and quantitative data and must detail how community stakeholders would be engaged throughout the evaluation process, resulting in an analysis of the business case for this CDEP.” (p.10) (Minkler and Wallerstein principles # 2,4,7,8,11)

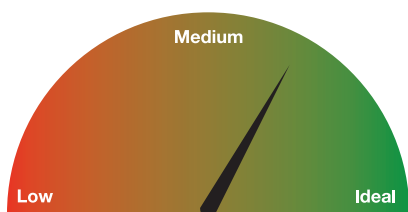
- “Continuous Quality Improvement Plan: The Grantee must provide a detailed plan describing ongoing program monitoring activity that ensures program integrity and continuous quality improvement. This should include:
 - Which stakeholders will be involved and in what setting? (Stakeholders include any persons interested in or impacted by the CDEP, including clients, family members and other community members.)
 - How will stakeholder feedback be incorporated?” (p.11) (Minkler and Wallerstein principles # 3,5,9,11)
 - How will stakeholder feedback be incorporated?” (p.11) (Minkler and Wallerstein principles # 3,5,9,11)



The CDPH-OHE IPP solicitation announcement offered more latitude in the development and implementation of both the CDEP and the local evaluation but there were still some external expectations and approval processes required and the evaluation plans were to reflect the guidance offered in the Phase 1 Priority Population Reports. Otherwise, projects were given greater latitude in Phase 2.



The statewide evaluation solicitation did not have the same latitude that has often led to the question: “Where’s the CBPR?” CBPR within the SWE is in fact a moving target depending on what particular aspect of the statewide evaluation is in question. CBPR in the SWE is first evident in its reliance on the Phase 1 illustrations previously described. PARC@LMU relied heavily on the insights and direction provided in Phase 1 in the development of the SWE Core Measures and overall evaluation design. At the same time, the SWE is also accountable to the CDPH-OHE guidelines set forth by the MHSA that delineated 3 program objectives, 7 evaluation questions, and 15 deliverables. This, too, heavily influenced the development of the statewide evaluation plan. Overall, however, one could place the SWE on the left center of the dashboard.

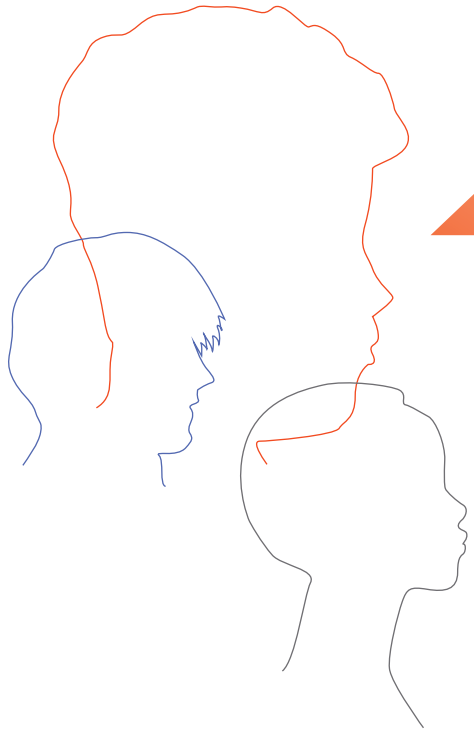


Within these parameters, the SWE engaged in CBPR processes when feasible. For example, after receiving direct feedback and input from Phase 2 stakeholders (e.g., IPPs, TAPs) modifications were made to the SWE Core Measure Questionnaire items that included changes in language, inclusion of additional IPP or TAP generated items, re-ordering of the items, etc. CBPR has been used to a much greater degree when working with individual IPPs or with a priority population to address cultural, contextual, or linguistic considerations in their implementation of the SWE (i.e., translation and conceptual meaning, response scales, administration strategies with the items, etc.). The SWE worked closely with CDPH-OHE, the TAPs and the IPPs to provide responsive feedback and technical assistance on the IPP local evaluation plans and developed a process to assist IPPs with articulating the cultural and contextual features of their CDEPs. Where feasible, the SWE incorporates as many elements of CBPR as possible.

VOICES FROM THE FIELD

CRDP Phase 1; Cultural Competency; LGBTQ Priority Population Specialist

“We had to tweak [CBPR] because, of course, just like with Phase 2, in Phase 1, we were given some of the questions that had to be answered. We had to! We had a goal that we were supposed to reach. So, we couldn’t just leave it all up to the community because we were being paid money to do a certain thing. And Phase 2 is also being paid money to do a certain thing, so the community might think that the most important thing is something completely different than what the IPP has to be evaluating.”



In CRDP Phase 2, not all elements of CBPP are present at every stage, or for every partner. This doesn’t mean that CBPP is not present in Phase 2. In fact, CRDP Phase 2 stands as an example of how to embody core principles of CBPP within the context of a process that has built-in requirements and external pressures that shape how CBPP can be applied.

What is the value added of CBPP?

Successful CBPP partnerships can yield well-grounded benefits to all of the partners involved (Hartwig, Calleson, & Williams, 2006). It brings a set of advantages and benefits that can strengthen and deepen program development, research and evaluation, and policy/systems change (NIEHS, 2000). It makes front and center local knowledge and perceptions (Israel et al, 2001); empowers the community as agents who can investigate their own situations (Stevens and Hall, 1998); increases the credibility of a project, enhancing its usefulness by aligning it with what the community prioritizes as goals (Holkup et al., 2009); provides resources for the community (Israel et al, 2003); provides a forum to bridge cultural differences among the participants (Israel et al, 2001); and builds trust with communities (Webb, 1990).

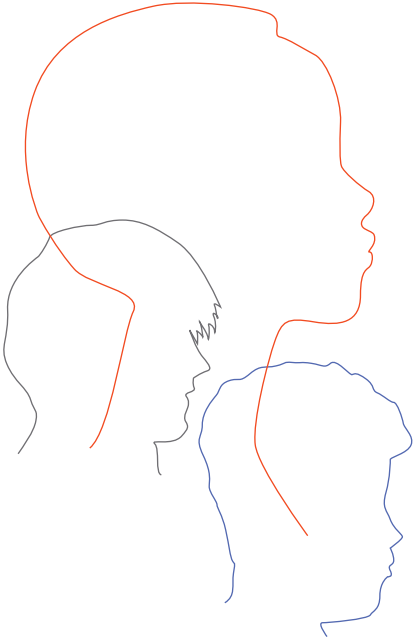
CBPP also seeks to build capacity and resources in under-resourced communities and ensure that government agencies, policy makers, and academic institutions are better able to understand and incorporate community concerns into a shared agenda. It is a process that is used from beginning to end. Research findings, systems change effects, or policy impacts are communicated to the broader community—including residents, the media, and other policymakers—so they may be utilized by the community for continued efforts to improve existing conditions. In summary, CBPP can:

- Improve Validity
- Enable Culture and Context to Determine Practice
- Expand the Evidence Base
- Develop Alternative (Indigenous) Methodologies
- Address Inequalities
- Enhance Language and Understanding
- Facilitate Capacity Building & Sustainability
- Build and Maintain Trust, Stakeholder Buy-In, and Ownership
- Transition Faster from Data Collection to Sustainable Action
- Improve Health and Mental Health Practice and Outcomes

Each of these is described below with examples and voices from the field.

Improve Validity

CBPP explicitly rejects a “one size fits all” approach to research, policy and practice. In CBPP, community members can raise vital questions to determine whether an intervention strategy, research question, policy, or practice, is valid for a community’s culture and context. In other words, is it acceptable, usable, and appropriate? Does it do what is in the best interests of a community? Is it aligned with a community’s sociohistorical and political context? Does it have legitimacy and accurately reflect the lived experience of a particular community and/or constituency? In CBPP, something is valid if it accurately reflects what it intends to portray or address or explain. Was something done right? Did it have the intended effect? And, while something may be right for one situation, is it right (does it fit) another community’s situation? For CRDP, concerns related to questions of validity are most relevant when importing research and evaluation methods, intervention programs and practices, system practices and public policies from other communities, counties or the State.



VOICES FROM THE FIELD

Equity/Disparities; Mental Health; API Priority Population Specialist

“Research that focuses on a specific, underserved population may trickle up to all populations. Research that focuses on primarily a mainstream population does not always trickle down to underserved populations. So, I think it has to do with the methodology, whether it’s strong CBPR, and also where we start in the particular population of analysis. So CBPR research, if you don’t have inclusion [of members of the underserved community] in the trials, it doesn’t necessarily generalize to underserved populations.”

Example

Using a CBPR approach that incorporated Native American social networks, a lead policy agenda was launched across multiple Tribal groups. The TEAL (Tribal Efforts Against Lead) project included a partnership of nine tribes and nations, academic partners, community organizations and local governmental agencies. Each tribe recruited local lay health advisors to implement project elements at the local level. A 15-member community advisory board conducted research on the status of lead in their communities and alternative policies to begin to alleviate it. They engaged the “clan Mothers and Fathers” in making the final decision about the best policies to put forward and ultimately contributed to the Ottawa County Health departments and IHS’s new policies related to blood lead screening and parental notification for young children. (Petersen et al, 2007)

This policy-focused CBPP project presents a good example of validity. They intentionally rejected a “one size fits all” assumption and paid attention to whether the approach remained sound across tribal groups. Tribal community context and culture, including local knowledge of environmental problems guided the policy advocacy and strategies to address environmental health problems in rural communities.

Enable Culture and Context to Determine Practice

CBPP allows communities and institutions to do business differently. Understanding how communities function and the perspectives of community members is key to successful interventions, research, and policy development (Langdon, et. al. 2016; Wallerstein and Duran, 2010). Priority Populations ensure that their lived experience is reflected in whatever is developed or implemented (for example, CBPP with Native Americans—see Ferreira and Gendron (2011); with African Americans Mance—see Cummins, et. al. (2010); Langdon, et. al (2016); with Latinos—see Baumann, Rodriguez, & Parra-Cardona, 2011; Perez et al, 2016; Sanchez-Johnson, et al 2015; Stacciarini, 2009), with Asian Americans—see Katigbak, Foley, & Hutchinson, 2016 and Ma, Toubbeh, Su, and Edwards, 2004); with LGBTQ communities—see Travers, et al., (2013); Northridge, McGrath, & Krueger, (2007).

All partners involved can use CBPP to direct resources and influence policies to benefit the community.

VOICES FROM THE FIELD

African American Priority Population Specialist

“I think that’s one of the benefits of this CRDP is that the IPPs are very much basing their efforts in culture. I can think of examples across the African American IPPs where they are instilling cultural elements to help build trust and maintain trust. When they do a focus group or when they do any kind of gathering of community, they ask the eldest woman in the room for permission to proceed and the eldest woman may be nineteen and a half, but whoever is the eldest gives permission for the rest of the group. I do agree. I think [culture] plays a huge role.”

The following journal abstract provides a good example of how participatory practice can shape an intervention. In particular, the abstract illustrates how understanding the cultural context, connecting with critical stakeholders, combined with trauma mental health knowledge, allowed the mental health team to effectively address the trauma needs of this community.



Example

The partnership of professionals and community is essential to contribute to the wellbeing of the people. This understanding assumed critical significance the day the Army Public School Peshawar came under attack. On 16th December 2014, 151 people, including 135 boys, 10 school staff members, and 3 soldiers were killed in the worst terrorist attack in the history. An estimated total of 1,099 pupils and teaching staff were present on the school premises, of which responding forces were successful in rescuing approximately 960, though 121 were injured. This gruesome attack rendered scores of people traumatized. There was a dire need to respond to the psychological trauma of the injured and surviving students, teachers and their grieving families. The students who survived the ordeal and lost their friends and classmates were in shock and were showing signs of distress. The parents expressed their anguish and grief over the brutality of the attack and loss of lives. There was an influx of emotions that required timely intervention. Responding to this challenge, a culture-sensitive participatory approach was adopted to chalk out a plan to deal with the crisis. The mental health team consulted with the stakeholders and was mindful of the local cultural sensitivities and the societal norm in reaching out to the affected. The tasks undertaken were providing Psychological First Aid, assessment of the trauma, preparing informational leaflets and facilitating grief work to stabilize the affected community. The paper documents the experience of participative approach in designing trauma intervention plans in times of crisis and explores other dimensions of this partnership for better outcomes, for both individual and the community (Siddiqui & Qayyum, 2016).

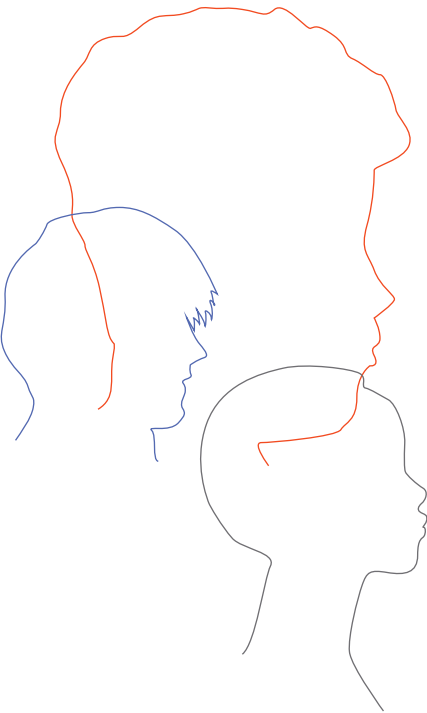
Expand the Evidence Base

Often the evidence base is solely informed by empirical research (e.g., EBPs) that is not designed or reviewed by the communities forced to adopt or use them. CBPP creates space for community-defined knowledge or wisdom (e.g., indigenous theories), as well as methods, measures and evidence to emerge.

VOICES FROM THE FIELD

Mental Health Consumer Advocate

“CBPP is not only about engaging local community members, but also a variety of members. Of particular note was the importance of not “going to the same people” each time. Community members can get so used to the research process that one risks losing the creativity of new community members. Additionally, continually engaging new and diverse community members and partners for different projects ensures that a diversity of community perspectives is represented in the research studies, which reflect the changing cultures of the community.”

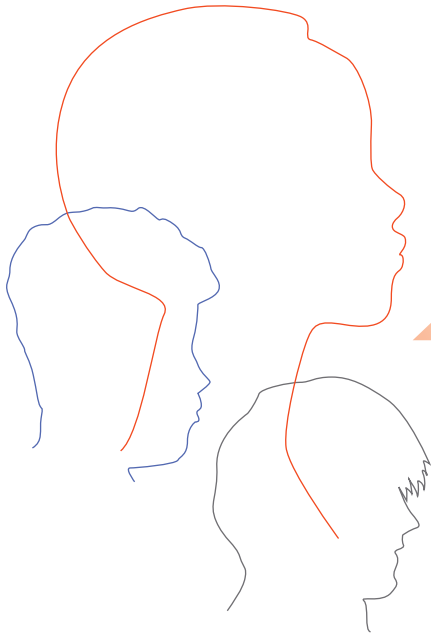


CBPP Tip

There are some cultural, linguistic, and contextual situations where conventional research methods won't work. For example, focus groups, interviews, direct observations, and cultural adaptations of existing measurement tools, can be alienating and insensitive to certain communities. Recognizing this, research methods have been expanded to include alternative and innovative methods. These include ethnography, community narratives, storytelling/re-storying, photo voice (photoethnography), sharing circle, photo elicitation, audio/video diaries, etc.

The Development and Utilization of Alternative (Indigenous) Methodologies

CRDP Phase 2 allowed IPPs to design and implement their CDEP programs and evaluations using their own community and culturally informed strategies. Because community members are the only ones who have the subject-matter expertise and/or information needed to make the case, a participatory approach is required. The application of CBPP principles and values ensures that all activities are in harmony with the local wisdom (or knowledge) and methods (i.e., epistemology), as well as the customs of the community. CBPP therefore not only establishes credible evidence, but also uncovers and recovers culturally valid methods, measures and outcomes. The cultural lens and indigenous methods guide the process to ensure the right questions are asked, useful hypotheses are posed, appropriate and culturally tailored methods are used, relevant data is obtained, and contextually-informed interpretations emerge.



VOICES FROM THE FIELD

Program Evaluation; Mental Health; LGBTQ Priority Population Specialist

"I think the name 'community-based participatory research' is a very good indicator of what they're trying to do in terms of process. [This] has methodological implications... and basically entails respect, a type of humility to be able to work with individuals who may or may not share your ideological or methodological frame of reference."

Academic/University Researcher

"The challenge is being credible with the community. Understanding or study-up and understand what you're getting yourself into with the population needs. With the credibility line, some will think it's a good idea and some will be suspicious. There may be challenges around methodology. Some people may want to do things differently. You'll have to figure out how to manage that. And you'll have to be open to talking about it to come to a collective consensus. The researcher's role is knowing the process but not being rigid."

Address Inequalities

With the inclusion and prominence of community voice, analysis, and critique, CBPP can challenge power and resource inequities. Addressing these inequalities and power imbalances requires constant emphasis on sharing knowledge, decision-making, and resources and support among all research partners (Darrow et al., 2004; Williams et al., 2006; Gibbs et al., 2008).

As an empowering process, CBPP “seeks to actively involve marginalized and disadvantaged communities in understanding and addressing issues which have an impact on their health and well-being (Israel et al., 1998).” In doing so, positive changes in the social determinants of health are more likely. It is also important that, within the practice of CBPP, the privileged perspective of researchers, policy makers, and decision-makers do not tip the balance of equity and power away from the community.

Finally, CBPR can facilitate a faster transition from data collection to sustainable action. Knowledge generated through the collaborative data collection process can be applied immediately to inform interventions, policy or service changes for improved health (Wallerstein, 2006; Chiu, 2004; Viswanathan, 2004).

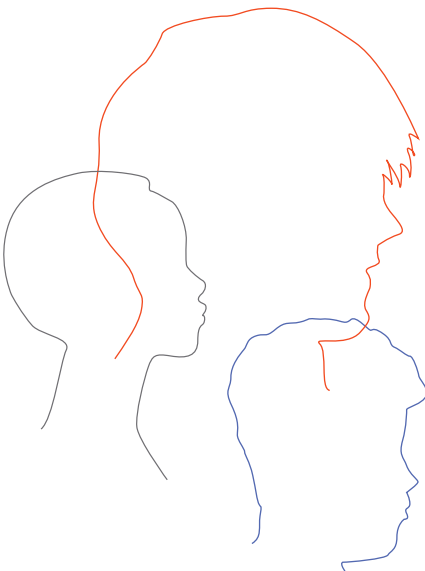
Example

CBPR actually improves the 3 Rs of science—rigor, relevance, and reach (Balazs and Morello-Frosch, 2013). In their Northern California household exposure to environmental toxins research, the scientific rigor of the research was strengthened as a result of their community partner’s influence on the study design choosing relevant sampling units, recruitment methods, and selecting the list of chemicals for analysis. In this example, because the perspective of the researcher was not privileged over that of the community, the research rigor was strengthened. Research relevance was enhanced because the study’s data was directly tied to issues of concern to the community. The community partner was able to use the research findings in testimony before the local planning commission to protest a conditional use permit that would have added to toxins in the neighborhood (Balazs and Morello-Frosch, 2013).

Enhance Language and Understanding

CBPP gives space to negotiate what is often a broad divide in the conversation between academia and community and arrive at shared meaning. Unfounded assumptions, if unchecked, can compromise the integrity and value of a process. The development of tools to survey or assess issues in various communities is important to not assume conceptual equivalence or linguistic equivalence. For example, conceptual equivalence of a questionnaire means an item measures the same concept in all languages into which this questionnaire has been translated (Preedy & Watson, 2010). Conceptual equivalence also means the instruments and observed behaviors have the same meanings across cultures (e.g., is a belch offensive in all cultures in question?). This is different from linguistic equivalence, also known as translation equivalence, which means an instrument has been translated and back translated successfully (Tanzer, 2013). In other instances, seemingly nonthreatening terms, phrases, or non-verbal messages can trigger negative reactions for partner communities. Knowing the history and culture of a given community can increase awareness and sensitivity to these issues. These are both different from metric equivalence that assumes that scores on a measure are comparable across cultures. For example, would the amount of time spent in caregiving for an ill, elderly family member be an equal “burden” across cultural groups? In one group, it may be a burden. In another it may be an honor (Rubin & Babbie, 2009).

CBPP encourages all stakeholders to work together to ensure shared meaning and understanding with respect to language, terms, tools, and metrics.



VOICES FROM THE FIELD

CBPR

One interviewer who served as an evaluator with Native American/Tribal communities stated:

“Culture’s Everything. It impacts anything that you do. Some things that you might think are benign have a total negative reaction to tribal meeting.”

She later states... “If you ask how long you have lived in the United States, that triggers trauma in people. Because they were there before the United States, and it really makes people angry.”

“These things that we think are really benign from our own worldview, when we apply it to another people, with a different history and a different collective knowledge we don’t know what kind of harm, things that we think are benign, might do to that community.”

Example

One size may not fit all when asking sexual orientation and gender identity (SOGI) questions. In the process of refining their local evaluation plans, the LGBTQ IPPs expressed concerns that the SWE Core SOGI items did not reflect the best practices for asking questions related to SOGI or accurately capture the experiences and identities of LGBTQ individuals, or the translation and meaning of terms. Moreover, the IPPs indicated an overall lack of cultural/linguistic appropriateness and/or relevance for their priority population. Collecting valid cross-site SOGI data represented an important step in assessing whether CDEPs are effective with LGBTQ people in intersectional settings.

To ensure cultural, contextual and linguistic appropriateness, the SWE engaged in an extensive number of consultations with the CRDP Phase 2 technical assistance providers (TAPs), the IPPs, and OHE. In a highly collaborative process with the SWE, the 7 LGBTQ IPPs in partnership with their TAP, helped refine the set of essential SWE Core SOGI items to be administered across all 35 IPP sites. Intersecting identities and cultural realities revealed that what emerged as best practice for inquiring about SOGI did not always align with cultural and linguistic realities.

In some instances, the instructions were rearranged to increase cultural sensitivity. In other instances, some items were changed to be open-ended. At other times, when English terms used in the SOGI questions lacked adequate conceptual or language equivalence (e.g., in Hmong, Korean, and Vietnamese, terms such as transgender/trans, intersex), a modification was made to include the use of open-ended responses in these items. This important modification allowed the items to be asked in a way that is respectful to specific cultural and linguistic considerations, but still collects quality SOGI data.

Facilitate Capacity Building and Sustainability

A goal of CBPP is to bring together expertise and resources from different groups that have unique assets to offer and allow each group to learn from the other. For example, community members don't always have research skills, but through a partnership with researchers they may have the opportunity to learn some of the tools of evaluation and research for other uses that can benefit their community. For academics, developing knowledge of the culture and context of communities allows them to build and maintain research and practice agendas that are grounded, valid and responsive to the needs of communities. It gives them a space to reflect upon assumptions in their theories, methods, and practice. For county departments and policy makers, it presents an opportunity to vet assumptions and examine decisions in the context of a more informed understanding of local impact. Community members learn more about systems change and mechanisms for accountability.

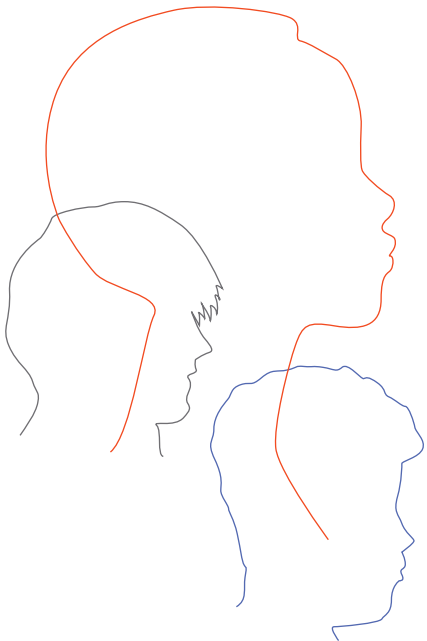
VOICES FROM THE FIELD

Community Member

“For members of the community, gaining research knowledge and skills, presentation and writing opportunities, and receiving mentoring may be valuable and even empowering. One community member stated that she was able to add her involvement in a community-based research project on her resume, and therefore, the experience was of personal benefit to her.”

Example

A six-year collaboration was formed to advance environmental justice in New York using CBPR between a) West Harlem Environmental Action (WE ACT), an environmental justice organization; b) the Harlem Health Promotion Center (Harlem HPC), an academic center dedicated to advancing the science and scholarship of CBPR; and c) the NIEHS Center for Environmental Health in Northern Manhattan at the Mailman School of Public Health to advance environmental justice in New York. The partnership resulted in a variety of environmental justice achievements: air monitoring studies published in peer-reviewed journals, training courses for community leaders on environmental health topics, educational forums for community residents on environmental justice issues, and meaningful input into policy decisions that have addressed diesel exhaust exposure in northern Manhattan. The collaboration was also expanded to include Columbia University, and more broadly, other community-based organizations, government agencies, academic research centers, and health institutions in northern Manhattan and the South Bronx (Shepard, Northridge, Prakash, & Stover, 2002).



Build and Maintain Trust, Stakeholder Buy-In, and Ownership

CBPP is based on the fundamental goal of building partnerships. Ideal partnerships practice mutual responsibility and create trust between partners that may have similar goals, but different values, perspectives and responsibilities. Trust is built over time and through shared action and work. This also requires acknowledgement of very real violations of trust that have occurred with historically underrepresented and marginalized communities. To support this trust, formal agreements are often established to create a shared understanding of expectations, roles and responsibilities.

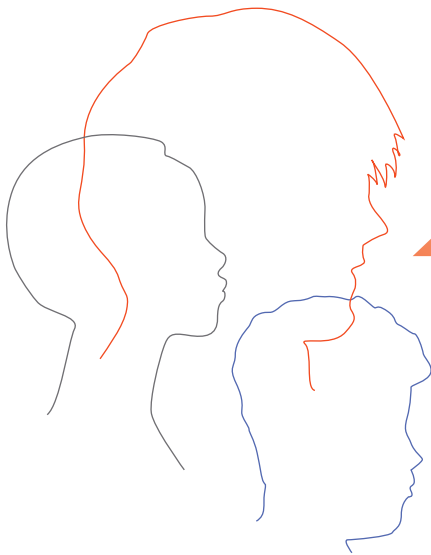
Closely related to trust is stakeholder buy-in. The more involvement a community has in the process, the more buy-in and ownership they are likely to feel. Ideally, this means the community is a driver in the design and implementation of system procedures and practices, policy development, programs, and evaluation and research studies. Trust and buy-in are enhanced when the community can see immediate and tangible benefits, for instance in research or in policy.

VOICES FROM THE FIELD

Mental Health; Equity/Disparities

Cultural Competency; LGBTQ Priority Population Specialist

“A recurring theme in the interviews with researchers, policy makers and community members was that true engagement needs to be a partnership sustained over the course of the project. Engagement by community members must be sustained and significant or the value of the engagement is limited or may fuel greater community distrust.”



VOICES FROM THE FIELD

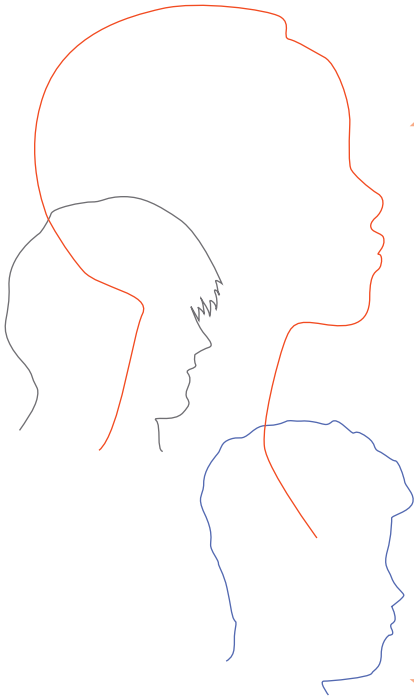
Program Evaluation; CBPR

“I also think a best practice for me...is being very conscious of my own and anyone’s and the team’s positionality in terms of power, privilege, and identities of gender, race, degree, education.”

VOICES FROM THE FIELD

*Mental Health; Equity/Disparities; Cultural Competency;
LGBTQ Priority Population Specialist*

“Researchers tend to come in to a marginalized community, kind of like a tourist, and they get their information, and then they go away and you never hear from them again...leaving people feeling very hurt and used and also leaving them feeling as if they had no say about what was written about them.”



Improve Health and Mental Health Practice and Outcomes

CBPP can address the six challenges of translational research (external validity, evidence, language, business as usual, sustainability, and lack of trust) (Wallerstein and Duran, 2011). Particularly in the case of CRDP, the practice of CBPP can allow strategies, systems and policies to better reflect and therefore meet the needs of unserved, underserved, and inappropriately served populations because the process will de facto reflect the culture, context, and perspective of these communities. It creates space for community-defined concepts of health and illness as well as practice to emerge, for more diverse health and mental intervention strategies to surface, and for more culturally appropriate outcomes and metrics to be used.

VOICES FROM THE FIELD

API Priority Population Specialist

“If it doesn’t take into consideration the key-defining cultural variables in a community, it may not be accessible to that community, it may not be appropriate to the community, and it might be a lot of investment of resources with no significant, meaningful outcome. So, I think those contextual variables along with other kinds of social determinants of justice, of well-being, of equity, probably account for more of the variance in health outcomes than the actual interventions.”

Example

Reducing Farmworker Family Pesticide Exposure was the five-year (2001-2005) continuation of a project known as PACE. ¡La Familia! Extended the collaboration between the North Carolina Farmworkers' Project (NCFP) and researchers at Wake Forest School of Medicine to evaluate a Lay Health Advisor (LHA) model to reduce pesticide exposure among farmworker families. With ¡La Familia!, the PACE geographic and priority population focus expanded beyond North Carolina farmworker community, particularly children, to the inclusion of Latino Christmas tree workers in the western region of the state. ¡La Familia! (1) documented farmworker knowledge, beliefs and perceptions of pesticide exposure of all family members, particularly as they relate to exposure of children; (2) identified pathways for environmental exposure of farmworker children to pesticides; (3) developed, implemented, and evaluated a culturally appropriate LHA intervention to reduce pesticide exposure of children (aged 18-48 months) in farmworker homes; and (4) compiled and disseminated the final intervention program to other farmworker communities and farmworker service providers.

A model of community participation was implemented throughout the project's 5 project that positively impacted community health.

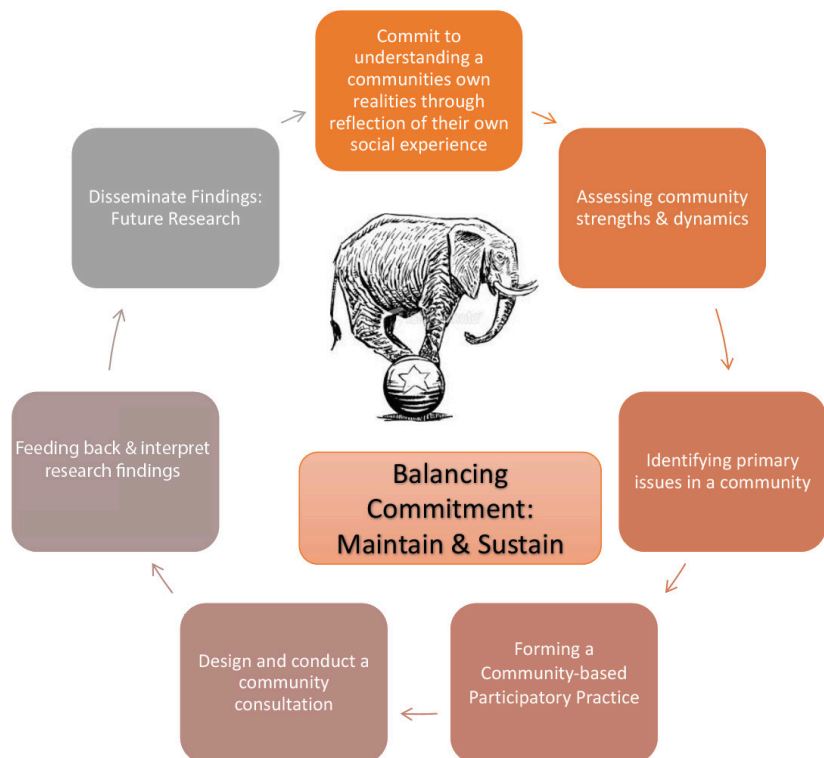
<http://www.wakehealth.edu/Research/Family-Medicine/La-Familia.htm>

Tips and Strategies for CBPP

In closing, a set of specific and actionable tips and strategies are offered to prepare for, participate in, and assess CBPP. While most of the literature and practice focuses on applications to research, CRDP offers a much broader context of community engagement that extends beyond research to include project/program design and implementation, systems practice, and policy development. These tips reflect both best practice from the literature and the thoughts and insights the 24 stakeholder interviewees. They cover issues related to how to engage in mutually respectful partnerships, discourse, understanding, and effectiveness. They also can be useful in gauging where on the dashboard a particular partnership is located to inform expectations, enhance trust, and build for longer-term engagement that may extend beyond the immediate project. Finally, they provide methods to apply the 11 aspirational principles of CBPR.

#1

CBPP is best understood as a circular process with a continual feedback loop as illustrated below.



VOICES FROM THE FIELD

Community Defined Evidence; Cultural Competency; CRDP Phase I; LGBTQ Priority Population Specialist

“As far as thinking about the key component of community-based research, it can be hard to define and say, ‘It’s Step 1, 2, 3, 4, 5’ because Step 1 is getting the community in the room and having from their words ‘what should this look like?’ And, so, each experience is defined by the community and the steps along the way are supposed to be largely community-run. And yet the researchers are in the background and are of the community. But the priority is to make sure that this is a community-owned process. And, therefore, saying the Step 1, 2, 3, 4, 5 is like a nice pretty framework to start out with, but not something to be married to because that first meeting, you’re talking to them and saying, ‘What are the questions?’ ‘What are the concerns?’ ‘What are the potential solutions?’ ‘What are the potential ways of looking at it?’ ‘How can we be involved in a long-term relationship in this project?’”

#2

Build in time for dialogue and create shared understanding among community members and external partners. Communities need time to identify the critical issues and create shared meaning with research partners. It is also helpful to confirm each other’s sense of what is being said, what is being agreed to, and how the quality of the communication is flowing. Don’t assume anything. Understand the meaning and significance of well-being to the community.

VOICES FROM THE FIELD

Mental Health Consumer Advocate

“One interviewer shared an example of a cultural gap that emerged at a community meeting between the community partner and the researcher who was not part of the community but responsible for facilitation of the dialogue. The researcher left the meeting with the erroneous impression that the community was in favor of the research as it had been proposed. The researcher misread the dialog as positive when in fact the community was utilizing a “polite” cultural style to reject the proposal. A community member who had a connection to the researcher was able to help bridge this cultural gap between the community and the researcher, and work towards a shared understanding. “

#3

Collaboration should facilitate a bi-directional exchange of skills that lead to knowledge creation; everyone brings something to the table and there is something to learn from each partner. Also, remember and accept that collective self-determination is the responsibility and right of all people in a community. No external entity should assume it could bestow on a community the power to act in its own self-interest. And when engaging a community, external entities must be prepared to release control of actions or interventions to the community and be flexible enough to meet its changing needs.

#4

Become familiar with the community's history, culture, norms and values, economic conditions, social networks, political and power structures, demographic trends, and negative and positive experience with external entities like researchers, government agencies, and policy makers. This includes learning their history of mental health intervention, prevention and research as well.

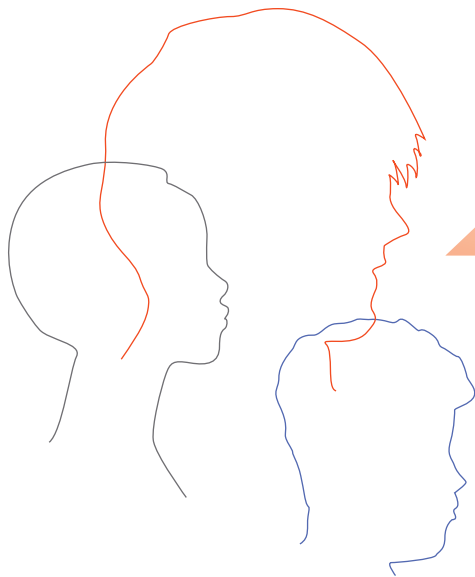
VOICES FROM THE FIELD

Program Evaluation; Latino Priority Population Specialist

“View community partners as knowledgeable and important contributors. Acknowledge that community partners bring their own values can be recognized and worked with. It should not be outsiders looking in, but insiders looking in.”

#5

Spend time in the community, build trust, establish relationships, collaboratively work with the formal and informal leadership, and seek commitment from community organizations and leaders on projects that are meaningful to the community and not just for self-gain or to meet an external agenda. Community collaboration that is closer to the far-right end of the dashboard often requires long-term commitment between partners. Are you able to be “in it” for the long haul to move the needle of engagement?



VOICES FROM THE FIELD

Program Evaluation; CBPR; Native American Priority Population Specialist

“You can’t expect people to come to you, you got to be out in the community...I have 8 different coalitions I’m working with and just expecting people all the time to meet YOU is a power dynamic, and people then stop believing that you really care about their community.”

#6

Be clear about how CBPP will be implemented in a specific setting and if it is feasible. What benefits and what burdens or inconveniences might result for the community? What are the expectations of the community? What can the community expect of the external partner? Are the multiple stakeholders in agreement about the approaches to be used? Is there consensus on the most critical issues to tackle? Are stakeholders communicating with a shared understanding of basic definitions and their significance in a specific community?

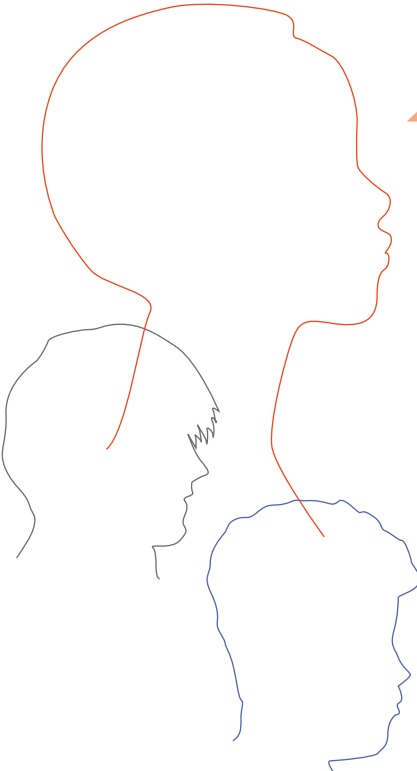
An assessment of capacity is critical. Do community representatives and organizations have the human capital to spare, the technical resources on hand, relevant skills and knowledge base to make needed contributions? If needed, is there an ability or willingness to make a long-term commitment to the work? If policy change is sought, are the necessary elements in place to maximize a policy win? The partners may need to understand the fiscal implications of the change work, how it will continue to be funded and the fiscal landscape for sustainability. In addition, do the organization(s) involved have appropriate staffing to effectively participate?

Finally, be clear about the purposes or goals of the engagement and the populations and/or communities you want to engage. This is an appropriate time to include a memorandum of understanding or community contract that articulates the clear vision of the project, methods to be used, and an agreed upon set of goals and roles.

VOICES FROM THE FIELD

*Equity/Disparities; CRDP Phase I;
API Priority Population Specialist*

“Having a contract and a shared understanding of what the expectations are prior, during, and after the work is being done or being conducted so there is no confusion or misunderstanding with regards to how and what the accountabilities are for the different parties.”



#7

Many partnerships have a limited number of community representatives engaged in the process, which limits community perspectives. One must first determine “what constitutes adequate community representation.” Recognize and respect the diversity of the community in all aspects of community engagement. Awareness of the various cultures within a community and other factors affecting diversity must be paramount in planning, designing, and implementing approaches to engagement. These diverse voices include children, youth, and elders where relevant, appropriate, and feasible.

Some methods to help maximize representation of diverse voices are to 1) hold large community forums to share information about communities, 2) conduct key informant interviews, and 3) do community surveys. Tools such as online polling and Wordle can be used in large group settings.

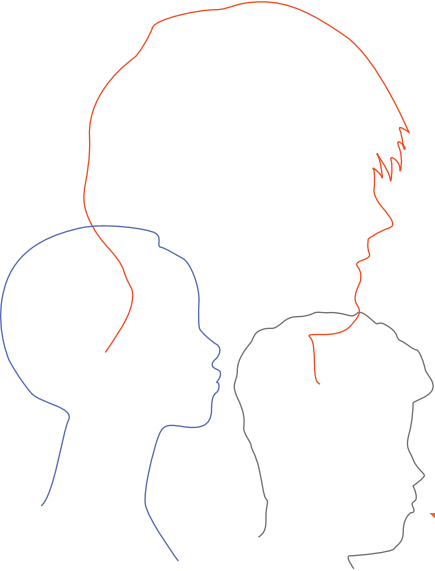
VOICES FROM THE FIELD

CRDP Phase 1; LGBTQ Priority Population Specialist

“Meeting these communities where they spend their time and being critical and thoughtful about what that means. There’s research project after research project that says we’re going to engage with black, African American populations by going to churches...a lot of black people in the United States spend a significant amount of their time in their religious communities, but the problem is that not all of them do. And so how do we make sure that we’re reaching representative samples of populations and meeting them where they’re at? So finding out what other spaces black people who are experiencing mental health challenges or consumers in mental health services—where are they spending their time? And reaching out to those spaces.”

#8

Don't forget the importance of asset identification. Every community has resources/assets that give it identity and meaning. Yet often in low-income communities of color or LGBTQ communities, researchers and practitioners focus primarily on the problems faced by the community and do not acknowledge or even seek to identify the resources that have developed indigenously to address those challenges. For instance, in a low-income community in Washington, DC, one community member teaches chess skills to local children. He is an asset to the young people and their parents and other community members. Assets can be people and they can also be services, organizations, institutions, and cultural practices that are present in a community. In seeking out assets, engage individuals who are bi-cultural—those who know local community and the language and frames of reference of external partners. For example, Los Angeles County Department of Children and Family Services (DCFS) launched a process (i.e., Cultural Brokers) to bridge the divide between DCFS and local African American community residents to mitigate the high rates of disproportionality in the child welfare system. These cultural brokers translate community norms and values for DCFS workers to lessen unnecessary child removals and they translate DCFS procedures to correct misperceptions of intent and reduce friction that may contribute to unnecessary removal of children from their homes.



VOICES FROM THE FIELD

Cultural Competency

“You need cultural brokers. You need people who are of that particular community to be the bridge. And it doesn’t necessarily mean that the cultural broker has to run the show. What the cultural broker has to do is help build that trust and help you cross over that bridge so that you can come into that community and they trust that it’s okay to answer your questions.”

#9

When the community is engaged for systems and policy change remember to:

- a. Demystify the policy making process
- b. Engage systems and policy makers
- c. Engage children and youth
- d. Incorporate and build allies in the policy world
- e. Consider doing a power analysis (SCOPE, 2003)
- f. Think on a regional level as well as local level – there may be important linkages

VOICES FROM THE FIELD

Elected Official

"I think the best way to do policy is from a community-based standpoint, because the best solutions come from the people with the most at stake. Also, when you get ready to implement a solution if the community that you're implementing in has buy in you have a much better shot at achieving successful implementation than you do if you're imposing something on people who weren't involved in the process of creating it. There are any number of examples ... like the development of a swimming pool at a local park. You can build a state of the art great pool at 'park A' with no community participation, and you can build the same exact pool with community participation. The pool that got community participation will get used a lot more. It will be much more a part of the community, it will be much more successful pool than the one that was done without participation... because people know about it, people feel like it's something that they created, people feel ownership, and people understand the contradictions."



Also, remember this is an iterative, circular process. Once the desired policy has been passed, has it been implemented in the spirit with which it was intended? Relationships between partners should not necessarily end once the desired policy is adopted. CBPP in policy implementation can involve ongoing assessment of implementation and determination of the extent to which desired outcomes from that policy are achieved.

#10

While the 11 principles presented by Minkler and Wallerstein (2008) are often cited as the “Gold Standard” when partnering with the community, additional cultural and contextual factors should be considered. The CRDP Phase 2 TAP Priority Population Evaluation Guidelines offer CBPP recommendations specific to their priority population’s values, perspectives, and experiences. The following examples and considerations are offered.

- “Include community involvement in the research process to best ensure that the research is culturally appropriate and scientifically valid.” This quote speaks to the already mentioned “*Mesas de Trabajo*” and community forum data collection approaches. Data collection scenarios where the participants drive the conversation, take notes, and prioritize which thematic areas are priorities to them and the community-at-large. This approach also ensures that the group facilitator not only speaks the appropriate language, but also has similar life experiences that the rest of the group can identify with and trust the data collection process (Latino TAP Guidelines).
- Tools such as the Community Readiness Model can help evaluators to determine community health concerns and “climate” regarding possible program or policy changes (Native American TAP Guidelines).
- It is important to be aware of and to accommodate the need of some CAB members to protect them from exposure to anti-LGBTQ stigma. This begins by ensuring the confidentiality of CAB participants not comfortable publicly disclosing their gender identity or sexual orientation (LGBTQ TAP Guidelines).
- It’s helpful to understand what each stakeholder needs to be able to best participate in the evaluation process. Often, some planning to address these needs can ensure more equitable participation. Some needs to consider include:
 - Language: Consider holding meetings in-language and having interpretation for English speakers at least periodically. Plan for interpretation/translation of materials in advance.
 - Literacy: Consider ways to reduce reliance on written materials by incorporating images or verbal discussions.
 - Transportation: Consider rotating locations and/or offering alternative ways for people to participate. If budget allows, consider providing bus passes or paid parking.
 - Childcare: Consider meeting when children are in school and/or providing childcare during meetings, if possible.
 - Religion/Spirituality: Consider obtaining a list of prayer times, religious holidays, or other customs to be observed.

- Disabilities: Inquire with stakeholders about whether there are specific needs related to a disability or lived experience as a mental health consumer (API TAP).
- While the California Reducing Disparities Project is divided into five priority population groups, these groups are not monolithic. Implementation Pilot Projects will work with individuals who may represent multiple racial/ethnic groups, such as people who identify as Afro-Latinx (African and Latino/a ancestry), Blasian (African and Asian ancestry), and/or represent the LGBTQ population (African American TAP Guidelines).

Finally, in the engagement with the community, reframing or restating the commonly cited principles of CBPR may be helpful to increase the cultural alignment of CBPR principles with the culture and context of a particular community. For example, using CBPR, Smith et al. (2015) developed a set of CBPR principles intended to resonate with the African-American community arguing that existing CBPR principles tend to be written in a language that is familiar to academics and other research professionals and not to communities. The resulting seven guiding principles of CBPR they developed are: 1) we are family, 2) it takes a village, 3) come as you are, 4) just stand, 5) health, wholeness and healing, 6) go tell it on the mountain, and 7) we shall overcome, some day. Each of these principles is operationally defined to guide CBPR engagement with African American communities. For example, Smith et al. explain principle 1, “We are Family”, in the following way. *“This is the title and refrain of a 1977 hit song recorded by the group Sister Sledge. The song is a classic in the pop music world, perhaps because it is a kind of theme song for community solidarity. It thus represents research that is community-based (not community-placed) and supported by the community as a whole. This resonates with the historical context of the Black community. This principle is similar to Principle #1 of Israel, et al. (1998) “Recognizes community as a unit of identity” (p. 53). Smith et al. (2015) provide a comparative analysis of their seven principles showing how they 1) correspond to existing CBPR principles as defined by Israel (1998), the National Black Leadership Initiative on Cancer CBPR principles, the Community-Campus Partnerships for Health and others but 2) use language and principles that are familiar to African Americans.*

#11

Community engagement with Native American populations requires a special set of procedures. As noted in the Native American Priority Population Guidelines:

“Tribal sovereignty is an important issue to take into consideration when addressing American Indian mental health and well-being. California is home to the largest population of Native Americans in the United States, with well over 100 federally recognized and unrecognized tribes within the state (U.S. Census 2010). For delivery of services to be culturally competent, it is important that outside entities have clarity about objectives and expectations within tribal and urban American Indian health policy. The state and counties need to accept that federally recognized tribes have the authority to govern themselves and make their own laws protecting the health and welfare of their citizens. Tribal sovereignty is a unique legal relationship between the federal government and federally recognized American Indian tribes. This sovereignty of tribes is based on the U.S. Constitution (Article 1 Section 8, and Article 6), treaties, Supreme Court decisions, federal laws, and executive orders. Tribal governments have “Nation within a Nation” status, which allows the right to hold elections, determine their own citizenship (enrollment), and interact with the U.S. government on policy, regulations, legislation, and funding. Tribal governments can create and enforce laws in which state laws cannot be applied where they interfere with the right of a tribe (SAMHSA).” (p.5)

LaVeaux and Christopher (2009) examined CBPR in the context of tribal communities. They shared specific considerations to guide community engagement that have relevance not just for research but also for participatory practice as understood and used in CRDP Phase 1 and 2.

Contextualizing CBPR: Key Principles of CBPR — the Indigenous Research Context

Below is an extract from LaVeaux and Christopher (2009) who offer some useful points to consider in the application of CBPR with Indigenous populations:

1. Acknowledge historical experience with research and with health issues and work to overcome the negative image of research

- a. Many tribes have established oversight committees, IRB committees, protocols and codes of research for projects conducted within their tribal jurisdictions (Christopher, 2005; Crazy Bull, 1997a; Davis and Reid, 1999; Freeman, 1993; Strickland, 2006; Trimble, 1977; Wax, 1991).

2. Recognize tribal sovereignty

- a. Most tribes in the US are federally recognized, with the right to govern their own members and control most activities on their own reservations (Freeman, 1993). They have established government-to-government relationships with the federal and some state governments. This means that researchers deal directly with the tribal government to work on the reservation and with tribal members.

3. Differentiate between tribal and community membership

- a. Because Native Americans are the only race or ethnic group in the United States that must prove their membership through enrollment, defining who is a member of a tribal community is more complicated than for other minority groups (Freeman, 1993; Norton and Manson, 1996; Trimble, 1977; Wax, 1991; Yellow Bird, 2005).
- b. Tribal governments establish their requirements for membership in the tribe, but the Census Bureau, federal and state agencies and programs, and state governments may have different criteria. Within the communities, cultural values and traditions may accept or reject some individuals based on moral or cultural standards and norms (Dempsey

and Gesse, 1995; Red Horse et al., 1989; Weiner, 1993). These differences become important when researchers wish to use census or tribal enrollment data, or when they begin to approach community members for participation and leadership roles in projects.

4. Understand tribal diversity and its implications

- a. There are over 500 federally recognized tribes in the United States, each with its own unique cultural identity. This tremendous diversity makes it difficult to generalize across tribes, and necessitates individual attention to tribe-specific characteristics, strengths, and resources (Salsberg et al., 2008). Belief systems, access to care, and cultural norms are also vastly different among tribes.

5. Plan for extended timelines. For several reasons, timelines are often extended by months when working with Native communities

- a. Researchers can expect attendance at community meetings to fluctuate due to ceremonies, celebrations, or harvest. These considerations must apply to each step of planning, development, implementation, data gathering and analysis, dissemination of results, and evaluation of the project to ensure full community participation

6. Recognize key gatekeepers

- a. Gatekeepers may be tribal Elders, respected community members, or tribal government officials. More importantly, they influence others, have contacts within the tribe, and are able to maintain communications when turnover within the tribal government and health care systems occur (Burhansstipanov et al., 2006; Letiecq and Bailey, 2004; Strickland, 2006).

7. Prepare for leadership turnover

- a. Some tribes choose to re-elect tribal government officials annually, others less frequently. However, any change in tribal government may change research priorities.
- b. It has been recommended that research partnerships acquire legal documentation of approval such as a tribal resolution, tribal health, or Indian Health Service approval

that will identify the research as a community project independent of the political leadership (Burhansstipanov et al., 2006; Christopher, 2005; Wallerstein and Duran, 2006).

8. Interpret data within the cultural context

- a. Not only should the community be involved in data interpretation, community members must have a say in what information is appropriate to release to others, and what data could be detrimental to the tribe if released (Wax, 1991). Their position of sovereignty gives tribes the right to deny publication of any or all data that is considered sacred or culturally inappropriate (Fisher and Ball, 2003; Freeman, 1993; Mihesuah, 1993; Strickland, 2006).

9. Utilize indigenous ways of knowing

- a. Incorporating indigenous methodologies into research projects may increase community participation and result in more appropriate and accurate assessment and interventions. Application of indigenous methods may avoid repetition of past research mistakes that have resulted in resentment, anger, and negative views of researchers (Weaver, 1997).

See: LaVeaux and Christopher (2009) pp. 13-17

Ethical Considerations in CBPP

When involving the community in a participatory process there are ethical, legal, social and political issues to consider. Generally, in the context of conducting research, a number of professions follow a set of ethical principles to which ethical dilemmas are analyzed. The Advancement Project (2011) offers the following considerations.

Respect autonomy

Humans have the right to exercise free thought and/or choice. People can decide how they live their lives as long as it does not negatively impact the lives of others.

Non-maleficence

We should not engage in any activities that run the risk of harming others.

Beneficence

Our actions should promote the health and well-being of others.

Justice

Being just assumes 3 standards. They are impartiality, equality, and reciprocity. In other words, treat others how you wish to be treated.

Fidelity

Related to the treatment of autonomous people, fidelity involves loyalty, truthfulness, promise keeping, and respect.

Accessibility of Findings

Are the findings presented in ways that community members can understand, access, or find meaningful?

Benefits to the Participants

How will you ensure that the participants from your priority community are not harmed during the participatory activity and process and gain as much benefit as possible through their participation?

Community Voice

Who is the community? Who represents the community? Who speaks for the community? Do participants come from only some of the area you are working in? Do they represent only some of the social identities in the community? Are there institutional, organizational or other social dynamics that privilege some voices over others? Will some portions of the community benefit more than others as a result?

Credit

How are the CBPP findings represented? Whose voice(s) are heard and represented? Who receives credit for the work?

Data, Knowledge Generation, & Ownership

Once data is collected, who owns it? Where is it stored? How will you responsibly make the data available to the priority community and other stakeholders?

Division of Labor

Is the work divided equitably among partners?

Justice

Do all members of your priority community have equal opportunity to participate? Are some participants who are or feel unfairly impacted as a result of CBPP?

Privacy

Will the outcome of your CBPP do any harm to your priority community and its constituency? How can you protect privacy in the data/information collection and sharing process? Did you get adequate permission from your priority community and participants and/or those that represent them? Do they understand and agree with the agreed upon CBPP plan and process?

Representation of the Priority Communities

Are results/findings in any way reinforcing negative social ills and stereotypes when representing the community?

Respect

How do you maintain respect for an individual's ability to engage or not engage in CBPP without coercion or force?

CBPR and IRB Considerations

Federal regulations mandate independent review and approval by an institutional review board (IRB) before research and in some cases program evaluation studies that involve human subjects may begin. There is a growing literature (Brown et al., 2010; Cross, Pickering, & Hickey, 2015; Malone et al., 2006; Morlares & Norcross, 2010; Shore, 2007) on the process and challenges of IRB approval for projects that use CBPR that it warrants some mention here.

IRBs are generally unfamiliar with CBPR, reluctant to oversee community partners, and resistant to ongoing researcher-participant interaction (Brown et al., 2010). They are grounded in a set of ethics that do not neatly map onto a CBPR process. In fact:

“Promulgation of international codes of medical ethics in the middle of the 20th century, most notably the Nuremberg Code (1947), and the Declaration of Helsinki (originally published in 1964) have, for nearly 60 years, provided an ethical framework for the conduct of human subjects research, with special reference to clinical and biomedical research (Annas, 1992).” (Cross et al, 2015, p.1010)

The Belmont Report (United States, 1978) established principles for the use of human subjects in scientific research. Three basic principles were defined to govern the ethical use of participants in studies: 1) respect for persons (a decision to become a participant must be voluntary), 2) beneficence (the research should maximize the benefits while reducing risk to the subject as much as possible), and 3) justice (fair distribution of risks and benefits, select subjects only “for reasons directly related to the problem being studied” and avoid the selection of subjects for “their easy availability, their compromised position, or their manipulability” among other things).

Projects and community partners must often educate IRB staff and board members about the objectives, ethical frameworks, and research methods of CBPR. This is in part due to the unfortunate reality that at present, there are no clear or routine review guidelines that respect the unique qualities of CBPR. In fact, “CBPR may challenge

institutionalized academic practices and the understandings that inform institutional review board deliberations and, indirectly, prioritize particular kinds of research (Malone et al., 2006, p.1914). As a result, in some instances, obtaining IRB approval for CBPR projects may meet with many challenges (Brown et al., 2010).

CBPR may require an expansion of ethical deliberations beyond procedural, principle-based approaches that are grounded in individual autonomy and biomedical research paradigm. But we are not there yet, so it is helpful to understand some of the issues emerging in the field. This is especially true given concerns that the current ethics culture of academia and administrative agencies (county, state and federal) may maintain and protect institutional power at the expense of community engagement and community empowerment (Chapman, 1997).

Below are some of the challenges experienced in gaining IRB approval in the context of the practice of CBPR. It will be helpful to know these in advance as you prepare an IRB application or to understand feedback received from an IRB committee seeking more clarification or denying approval.

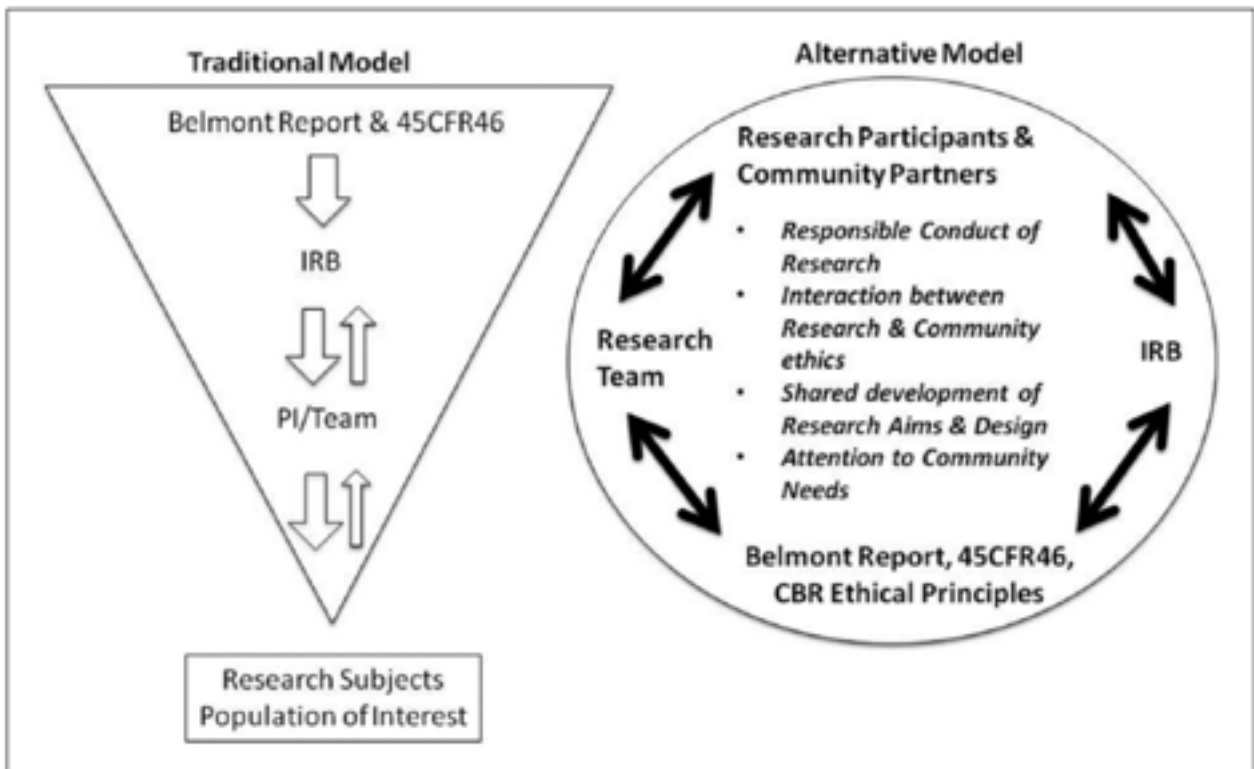


Figure 1. Communication relationships between IRBs, researchers, and research participants.

- There are epistemological differences between traditional biomedical research paradigms, positivist research assumptions, and CBPR that are difficult for IRB committees to take into account. The traditional IRB review model expects a 'top down' model of research.

(This is illustrated in Cross et al., 2015, Figure 1, p. 1011)

- IRB Committees are unfamiliar with the CBPR collaborative process of ongoing engagement of communities in research from development to dissemination (Cross et al., 2015). This process can lead to changes in protocol, methods, participants, etc.—something that violates the expectations of an IRB approval that is based on the assumptions of a clinical trial environment and approach to investigative processes. This is in direct conflict with the spirit of CBPR which adopts and subscribes to a bi-directional process of communication; an interactive approach where researchers, community groups, participants, and IRBs are in collective dialogue about the design of the study, community needs, and the ethical principles that undergird responsible conduct of research (Cross et al. (2015).
- In one project, the objective of the CBPR study was to assess institutional practices within a community, not the responses of individuals within those institutions—a distinction the IRB dismissed as irrelevant but that the project team believed was worthy of further consideration because of the increasing interest in CBPR and the increasing influence of global institutions on local communities (Malone et al., 2006). In CBPR, the actual process defines the role of the community. Their role is not grounded in an assumption based on an individual biomedical model of research. Participants are sometimes seen as research subjects versus research participants by the IRB and therefore the committee expects the same IRB principles to be applied to them. IRBs may not always appreciate the need for these more flexible ways of characterizing the various entities involved in a CBPR study. In any IRB submission take extra time specifying and clarifying the nature of and the roles of those involved in your research partnership.
- Academics and legal analysts often are socially positioned in advantageous ways that may obscure their appreciation of the power dynamics embedded in their ethical decision-making. This raises the question about whether their decisions about an unfamiliar method that shifts the power dynamic in research represent an institutional conflict of interest because the decision about whether the study is ethical or not is influenced by concerns associated with institutional self-protection (Malone et al., 2006). In such circumstances, it may not always be clear whose rights are being protected by the IRB's decision-making process. This is the classic concern related to 'rules of policy' designed to protect an institution from risk, rather than ethical 'first principles' designed to protect participants from potential harm (Flicker and Guta, 2008; Solomon and Piechowski, 2011).

- Those engaged in CBPR have noted that IRB processes can be inconsistent with the ethical guidelines developed by CBPR groups, and that IRB policies can place CBPR teams into ethical conflict with IRBs (Cross et al., 2015; Downie and Cottrell, 2001; Malone et al., 2006). Flicker et al. (2007) take this a step further and argue that IRBs using procedures that are not appropriate for CBPR may put communities at greater risk, waste time and resources, and further marginalize vulnerable communities. Of course, ethical obligations remain in the use of CBPR. Cross et al. (2015, p. 1014) offer a useful summary table on this issue.

Table 2. Ethical obligations of researchers, IRBs, and communities.

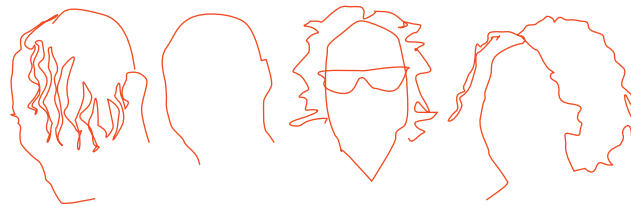
| Research Phase | Ethical Obligations | | | |
|------------------------------------|--|---|---|--|
| | Beneficence | Justice | Respect | Self-Improvement |
| Forming CBPR Group | Defining research question | Procedural justice - honoring community governance | Managing status inequality | R: expanding cultural competence C: expanding knowledge IRB: expanding ethical competency |
| Developing Research Design | Balancing risks and benefits to community and participants | Procedural justice - respect for community timeline - flexibility | Managing conflicting standards (community, academic) | All: expanding knowledge through consideration of competing standards of knowledge production |
| Implementing Research | Balancing risks and benefits to participants | Inclusion of participants | Culturally responsive protocols | R: transfer of knowledge and skills to community IRB: expanding knowledge of situational ethics |
| Reporting Results | Reports for community, scientific publication | Use of results for social change | Protecting community reputation, individual confidentiality | C, R: interpretation of data IRB: new protocols |
| Maintaining Long-Term Relationship | Addressing community needs; contributing to knowledge | Translating science for social and environmental justice | Including community in use and applications of research results | All: expanding skills for ethical negotiation and assessing conflicts of interest |

Note: R= researchers, C= community, IRB= any review board including RRB or REB, All refers to all parties listed previously.

- The review process can be very time consuming. It will be important to build in extra time for the completion of this task within your overall project timeline.
- Because of the ongoing collaborative process in CBPR, “emergent” research designs need to be explained for an IRB committee. Emergent designs simply refer to the iterative process that can occur in the CBPR process where realities that emerge in the implementation of a CBPR process requires modifications and adjustments to a study’s focus, approach, and methods. This could alleviate concerns and IRB procedural expectations regarding changes to an approved IRB, and decrease IRB questions regarding the adequacy of proposed research designs (Shore, 2007).

Final thoughts

CBPP is not only a commitment between a partner external to the community and a community; more so, CBPP is an internal commitment where researchers dedicate their skills to the service of the community, where researchers are committed to taking part in research that is dynamic, and researchers are committed to a long-term dialogue that may extent across various fields and social problems. For communities, CBPP is a commitment to be active in the processes of change, for community members. CBPP is a commitment to one's neighbor, so that together members of a community receive the benefits gained from such research and outcomes. For both, CBPP is a commitment to change in the processes of changing relations with the environment and above all, with other people.



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¹Community-Defined Evidence Practices are "A set of practices that communities have used and determined to yield positive results as determined by community consensus over time and which may or may not have been measured empirically but have reached a level of acceptance by the community."

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